The Ultimate Resource Guide

Resources for those diagnosed with or caring for someone with: Rare Disease, Undiagnosed Disease, Chronic Illness, Medical Complexities, and Disabilities

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HELPFUL INFORMATION TO USE THE GUIDE:

Hello! I am so glad that you are here. I hope this guide is able to provide you with some new resources for your specific situation.

Current Process: I am currently focusing on more general resources at the national level, and just starting my in depth research for each state. I am attempting to do the states in alphabetical order, so if there are few or no resources for your state, keep checking back! Even better, if you know of some, go ahead and email them to me to be added! I have temporarily stopped listing disease/gene specific groups, as there are SO many, and I figured most people with a diagnosis have found one already!

Helpful Tricks:

- If viewing in Microsoft Word, under the View Tab select Show Navigation Pane. This will enable the table of contents to always be visible and makes navigating to sections of interest super easy!
    - The Navigation Pane also has a search feature which makes searching for key words very easy!
- At the beginning of the US State Specific Resource section, I have listed resources that have pages dedicated to listing out state chapters/providers to cut down on some of the manual work of adding these for each state!

Have Resources? Please email me at sierra.phillips@ppd.com if there are any resources you would like added.

GENETICS RESOURCES:

Ambry Genetics: With over 20 years of scientific innovations and discoveries, Ambry is an industry leader enabling healthcare professionals to confidently make informed care decisions with their patients by providing them with advanced genetic testing solutions.

Baby's First Test | Newborn Screening: Baby's First Test is the nation's newborn screening education resource center for families and health professionals. Centered on real experiences navigating newborn screening, Baby's First Test provides up-to-date information, support, and services for families and education, materials, and resources about newborn screening at the local, state, and national levels. We are dedicated to educating and connecting parents, family members, health professionals, industry representatives, and other members of the public to the newborn screening system.

Congenica: We are a digital health company enabling genomic medicine with the world leading Clinical Decision Support platform for clinical use for the rapid analysis and interpretation of genomic data.

Decode Duchenne Program: PPMD's Decode Duchenne genetic testing program provides free genetic testing and counseling to people in the Duchenne and Becker muscular dystrophy community. Participants must be living in the United States or Canada. Genetic testing is performed at our designated laboratory, PerkinElmer Genomics. PPMD's certified genetic counselors specialize in Duchenne and Becker muscular dystrophy and are available to both healthcare providers and families at any point during the testing process.

Global Genetics and Genomics Community (G3C): Interactive Unfolding Case Studies (genomicscases.net): G3C (Global Genetics and Genomics Community) is a bilingual collection of unfolding case studies for use with students and practicing healthcare providers learning basic genetic/genomic concepts. When faced with a patient and their needs, there may be multiple ways to meet those needs. Yet, too often education requires learners to follow a linear path to form a solution - negating the multi-dimensional nature of human beings. An Unfolding Case Study (UCS) can address this deficiency by offering the student a self-guided learning experience which allows for nuanced experiential learning. For the instructor, a UCS offers a way to robustly cover a topic, bringing to light the subtleties in a more realistic practice-based skill environment.

EURORDIS: EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1000 rare disease patient organisations from 74 countries that work together to improve the lives of over 300 million people living with a rare disease globally.

Genetic Alliance: Genetic Alliance, a non-profit organization founded in 1986, is a leader in deploying high tech and high touch programs for individuals, families, and communities to transform health systems by being responsive to the real needs of people in their quest for health.

Genetic and Rare Diseases Information Center : The Genetic and Rare Diseases (GARD) Information Center is a public health resource aiming to support people living with a rare disease and their caregivers by providing access to easy-to-understand information that is free and reliable.

Genetic Disease Foundation: The Genetic Disease Foundation (GDF) is a non-profit 501c(3) organization established in 1997 by patients and families affected by genetic disorders. The Foundation's mission is to support research, education, and the prevention of genetic diseases.

Genetic Testing (rareiscommunity.com): From knowing what types of genetic testing exist, to understanding the role of a genetic counselor and how to talk to your family about testing, this #RAREis genetic testing resource is here to guide you to information and support to help you through your journey.

Global Genes: Global Genes provides hope for the more than 400 million people affected by rare disease around the globe. We fulfill our mission by helping patients find and build communities, gain access to information and resources, connect to researchers, clinicians, industry, government, and other stakeholders, share data and experiences, stand up, stand out, and become effective advocates on their own behalf.

Jewish Genetic Disease Consortium: The Jewish Genetic Disease Consortium (JGDC) increases awareness about Jewish genetic diseases and encourages timely and appropriate carrier screening for all persons who have any Jewish ancestry, as well as couples of mixed heritage. The JGDC is an alliance of non-profit organizations sharing the common goal of combating genetic diseases. While each JGDC member organization has its own individual mission, the JGDC unites these organizations to jointly strengthen public education and awareness about appropriate carrier screening.

Know Your Genes: Know Your Genes is a public service provided by the Genetic Disease Foundation, a 501(c)(3) nonprofit foundation supporting research, education, and the prevention of genetic diseases.

My Family Health Portrait: a free web-based tool, is helpful in organizing the information in your family health history. My Family Health Portrait allows you to share this information easily with your doctor and other family members.

My Faulty Gene – Genetic Testing Saves Lives: My Faulty Gene is a nonprofit organization which provides information and assistance to underserved, uninsured, and underinsured individuals whose family medical history suggests genetic testing might be helpful in identifying an increased risk of disease due to a genetic mutation. We believe that everyone in need of germline genetic testing should have access, including family members of individuals with a known mutation.

MyGene2 : MyGene2 is a portal through which families with rare genetic conditions who are interested in sharing their health and genetic information can connect with other families, clinicians, and researchers. The genetic cause of most rare conditions is unknown and as a result, most families who undergo exome sequencing or whole genome sequencing do not receive a diagnosis. By sharing information through MyGene2, a family can help and even participate in the discovery of new genetic conditions and the genes underlying these conditions.

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National Organization for Rare Disorders | NORD: NORD has been a national steward and a steadfast partner helping those who battle and care for rare disease feel seen, heard, supported, and connected. We are a full-service, mission-driven nonprofit reimagining a future where every person with a rare disease, and their families live their best lives.

New England Regional Genetics Network: The New England Regional Genetics Network advances the health and well-being of individuals with or at risk for genetic conditions by improving access to genetic services, educating professionals to strengthen systems of genetic care, and supporting families in New England.

OMIM: An Online Catalog of Human Genes and Genetic Disorders.

Orphanet: Orphanet is a unique resource, gathering and improving knowledge on rare diseases to improve the diagnosis, care and treatment of patients with rare diseases. Orphanet aims to provide high-quality information on rare diseases and ensure equal access to knowledge for all stakeholders. Orphanet also maintains the Orphanet rare disease nomenclature (ORPHAcode), essential in improving the visibility of rare diseases in health and research information systems.

Probably Genetic | Get answers for your symptoms: Genetic testing for 4,000+ diseases. See if you're eligible for free at-home genetic testing today.

Rare and Undiagnosed Network: RUN stands for Rare & Undiagnosed Network. We're a group of advocates, patients, families, researchers, healthcare providers who share the same mission and vision to bring genome sequencing into clinical practice to help undiagnosed patients and better understand these conditions as we all work together towards better lives for affected individuals and their families.

Rare Genomics Institute: RG is an international non-profit founded in 2011 to provide access to innovative genomic research, technologies, physicians, and scientists across the globe. By providing an expert network, RG helps families pursue personalized research projects for diseases not otherwise studied.

The Rare Diseases Registry Program: The Rare Diseases Registry Program (RaDaR) of the National Center for Advancing Translational Sciences (NCATS) provides guidance for setting up and maintaining high-quality registries that are based on best practices and data standards. The ultimate goal is to support the collection of patient data that can be used in developing treatments for rare diseases.

ThinkGenetic Foundation: The ThinkGenetic Foundation is an IRS registered Sec. 501(C) (3) organization and is governed by a Board of Directors specializing in genetic conditions. The foundation was founded by Dave Jacob and a team of nationally renowned genetics healthcare professionals he recruited to the board of directors. Dave hand-picked a board with a shared passion for directly helping patients and families living with or at risk of having genetic conditions get reliable information and access to important real-life resources, including genetic counselors and diagnostic testing.

Unique | Understanding Rare Chromosome and Gene Disorders: we aim to act as an international group, supporting, informing and networking with anyone affected by a rare chromosome disorder or an autosomal dominant single gene disorder and with any interested professionals.

VarSome: VarSome, a suite of bioinformatics tools for processing and annotation of NGS data.

Welcome to My46: My46 is an innovative web-based tool that enables individuals to manage their own genetic testing results.

Sponsored genetic testing | SMA Identified | Invitae: The SMA Identified program facilitates access to genetic testing to help in the diagnosis of SMA or carrier status identification of SMA. The SMA Identified program offers three different testing options to address the needs of your patients. Positive results from genetic testing are typically required to initiate treatment.1 Participation in the SMA Identified program does not guarantee access to treatment.

Gene & Cell Therapy Education | ASGCT - American Society of Gene & Cell Therapy |

Genome Medical: We are genomic and genetic experts who partner with healthcare organizations like yours to deliver best-in-class genetic services to more patients, bringing the promise of precision medicine to more lives.

GENETICS EDUCATION RESOURCES FOR PATIENTS AND FAMILIES:

Educational Resources (genome.gov)

Talking Glossary of Genetic Terms | NHGRI (genome.gov)

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For Patients and Families (genome.gov)

Genetic Disorders (genome.gov)

Glossary of Genetic Terms | ThinkGenetic

Genetic and Rare Diseases Information Center : The Genetic and Rare Diseases (GARD) Information Center is a public health resource aiming to support people living with a rare disease and their caregivers by providing access to easy-to-understand information that is free and reliable.

Help Me Understand Genetics | MedlinePlus : An introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.

Genetic Alliance: Genetic Alliance, a non-profit organization founded in 1986, is a leader in deploying high tech and high touch programs for individuals, families, and communities to transform health systems by being responsive to the real needs of people in their quest for health.

Genetic Education Materials for School Success: Genetic Education Materials for School Success (GEMSS) provides a family-friendly starting point to help family members learn more about genetic conditions and offers ideas to encourage inclusion and participation in the classroom. GEMSS shares condition-specific information and resources for multiple audiences, including families, professionals, healthcare providers, and schools. Contributors to GEMSS come from clinical, public health, advocacy, and academic settings. All content has been vetted by clinical and family experts.

Genetic Disease Foundation: The Genetic Disease Foundation (GDF) is a non-profit 501c(3) organization established in 1997 by patients and families affected by genetic disorders. The Foundation's mission is to support research, education, and the prevention of genetic diseases.

Know Your Genes: Know Your Genes is a public service provided by the Genetic Disease Foundation, a 501(c)(3) nonprofit foundation supporting research, education, and the prevention of genetic diseases.

My Family Health Portrait: a free web-based tool, is helpful in organizing the information in your family health history. My Family Health Portrait allows you to share this information easily with your doctor and other family members.

UNDIAGNOSED RESOURCES:

Amplify Hope — Rare Genomics Institute: The Amplify Hope Initiative is a new study to help families develop and launch crowdfunding campaigns to raise funds for sequencing while at the same time measure the impact of community engagement.

Center for Mendelian Genomics: The Center for Mendelian Genomics is a member of the GREGoR Consortium (Genomics Research to Elucidate the Genetics of Rare Disease) funded by the NHGRI (National Human Genome Research Institute), along with 5 other sites across the country. The Broad CMG provides research sequencing for families suspected to be affected by Mendelian diseases.

UW-CMG: The UW-CMG is one of several centers supported by the National Human Genome Research Institute and the National Heart, Lung, and Blood Institute of the National Institutes of Health with an overall goal of identifying the genetic basis of Mendelian conditions for which the underlying cause is unknown. The UW-CMG performs exome sequencing (ES), whole genome genome sequencing (WGS), and /or analysis of ES/WGS data at NO COST (i.e., FREE) for qualified investigators and Mendelian phenotypes. The UW-CMG also accepts ES/WGS data and clinical information from families with Mendelian conditions who have undergone clinical testing but no responsible gene has been identified.

Genetic Testing: From knowing what types of genetic testing exist, to understanding the role of a genetic counselor and how to talk to your family about testing, this #RAREis genetic testing resource is here to guide you to information and support to help you through your journey.

iHope: The iHope Program is a philanthropic initiative launched by Illumina to make clinical whole-genome sequencing (cWGS) accessible to underserved children facing rare and undiagnosed genetic diseases (RUGD). It operates through the Illumina Clinical Services Laboratory (ICSL) in San Diego, California.

iHope | Genetic Alliance: iHope™ Genetic Health is a program that diagnoses the undiagnosed across the globe. We address a desperate need to make genomic medicine available to all individuals regardless of their social status, income, or geographic location.

My Faulty Gene – Genetic Testing Saves Lives: My Faulty Gene is a nonprofit organization which provides information and assistance to underserved, uninsured, and underinsured individuals whose family medical history suggests genetic testing might be helpful in identifying an increased risk of disease due to a genetic mutation. We believe that everyone in need of germline genetic testing should have access, including family members of individuals with a known mutation.

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Odyssey Program (bioreference.com): Continuing with our commitment to improve patient care and to make genetic testing more accessible, we are very excited to announce our Odyssey Program on Rare Disease Day. Through this program, for each new disease-causing gene we publish this year, we will offer one exome sequencing at no cost to a patient who meets clinical criteria and may not be able to afford testing.

Rare and Undiagnosed Network | Genome SequencingRare & Undiagnosed Network (rareundiagnosed.org): RUN stands for Rare & Undiagnosed Network. We're a group of advocates, patients, families, researchers, healthcare providers who share the same mission and vision to bring genome sequencing into clinical practice to help undiagnosed patients and better understand these conditions as we all work together towards better lives for affected individuals and their families.

Rare Genomes Project: The Rare Genomes Project (RGP) at the Broad Institute of MIT and Harvard is a patient-driven research study led by genomics experts and clinicians who believe that the latest advances in genomic sequencing are changing medicine and should be accessible to families with rare and undiagnosed conditions.

U.R. Our Hope: U.R. Our Hope is a registered 501 (c)(3) non-profit organization that assists individuals and their families on their journey to diagnosis,or helps them navigate the healthcare system with a rare diagnosis. Our mission is to serve individuals with undiagnosed and rare disorders through education, advocacy, and support in order to bring hope through knowledge, empowerment, and healing. We assist families in the Austin area, and throughout Texas, the United States and beyond.

UDN | Undiagnosed Diseases Network: The Undiagnosed Diseases Network (UDN) is a research study backed by the National Institutes of Health Common Fund that seeks to provide answers for patients and families affected by these mysterious conditions.

Whole Genome Sequencing for Undiagnosed Disease (smithfamilyclinic.org): The Smith Family Clinic for Genomic Medicine, LLC., a wholly-owned subsidiary of HudsonAlpha Institute for Biotechnology, has been established to diagnose patients with undiagnosed and misdiagnosed diseases.

Wilhelm Foundation | The Undiagnosed: The Wilhelm Foundation works towards that children and adolescents who have an undiagnosed disease should receive a diagnoses. Doctors expect that there are several thousand different undiagnosed diseases, diseases that have not yet been discovered by medical science.

Yale Center for Mendelian Genomics < Yale Center for Genome Analysis (YCGA): The Centers for Mendelian Genomics will apply next-generation sequencing and computational approaches to discover the genes and variants that underlie Mendelian disorders. The discovery of new genes that cause Mendelian conditions will expand our understanding about their biology to facilitate their diagnosis, and potentially indicate new treatments. The Centers for Mendelian Genomics will provide free exome sequencing and analysis to collaborating investigators for qualified phenotypes.

UDNF | Until rarity is not a barrier: The UDNF aims to foster collaboration among patients, clinicians, and scientists to enhance the quality of life of undiagnosed and ultra-rare disease patients. We do this by mitigating barriers to equity and access in healthcare; setting standards for patient management; and bridging diagnosis and therapeutics as well as research and clinical care in undiagnosed patients and patients with ultra-rare diseases.

Undiagnosed Film: UNDIAGNOSED is a feature-length documentary film that brings forward remarkable cutting-edge science and compelling human drama to shine a light on a widespread but little-known issue devastating families across the world: undiagnosed illnesses.

Undiagnosed Diseases Program | UAB: The Undiagnosed Diseases Program (UDP) seeks to meet the needs of patients with severe chronic medical conditions in whom a diagnosis has not been made despite extensive efforts by the referring physician.

UW Undiagnosed Disease Program – Center for Human Genomics and Precision Medicine – UW–Madison (wisc.edu): The goal of the UW-Undiagnosed Disease Program (UW-UDP) is to improve the health and well-being of individuals with undiagnosed disorders. The program's objectives are to shorten the diagnostic odyssey for patients with rare diseases, discover new disease genes, develop novel diagnostic techniques, improve our understanding of the relationships between genomic variants and disease, and share our discoveries with the global genomic medicine community.

What You Should Know About Undiagnosed Rare Diseases | NORD: We offer help for dealing with an undiagnosed condition. We also share resources that may help you on your rare disease journey.

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RARE DISEASE FOUNDATIONS:

22q Family Foundation

Angelman Syndrome Foundation

ASXL Rare Research Endowment Foundation

Beckwith Wiedemann Children's Foundation Int'l

CDH International: The world's oldest, largest and leading Congenital Diaphragmatic Hernia charity. Created to help families of babies born with Congenital Diaphragmatic Hernia by providing support services, raising awareness and furthering research.

CDKL5

CdLS Foundation

CdLS Foundation

Coffin-Siris Syndrome Foundation

CTNNB1 Connect & Cure: Finding treatments and a cure for CTNNB1 to help children live their best lives possible while raising awareness and connecting families.

CTNNB1 Foundation: This foundation is driven by the parents, researchers and doctors. We are all joint together to help children with CTNNB1 Syndrome get a better tomorrow.

Cure Mito Foundation: Our primary focus is advancing research towards a cure for Leigh syndrome and eventually for mitochondrial disease as a whole. A successful outcome will mean not only hope for our own children, but also life-saving treatments for future generations impacted by this disease.

Hope for PDCD Foundation

International FOXG1 Foundation

International Rett Syndrome Foundation

Koolen-de Vries Syndrome Foundation | KDVS

List of Rare Diseases | A-Z Database | NORD: With more than 1,200 rare disorders, you can explore rare disease reports that include information on symptoms, causes, treatments, clinical trials, and sources of help such as patient advocacy organizations. Each report has a list of references, such as textbooks, articles, and government agency reports.

The Lilly and Blair Foundation: Founded by the Gregg and Lorek families, The Lilly and Blair Foundation is dedicated to improving the lives of our girls and others with de novo Hereditary Spastic Paraplegia SPG4 through collaboration with top scientists and funding of promising research

DeSanto Shinawi Syndrome

Directory of Genetic Disease Organizations: a list of different organizations organized by name. Provided by My Faulty Gene.

MLD Foundation: MLD Foundation is a 501(c)(3) non-profit US tax-exempt organization. We were formed in May 2001 to serve families throughout the world affected by metachromatic leukodystrophy (MLD), a terminal genetic disease.

Disease Education | LEMS Aware

Dravet Syndrome Foundation

Eastside EDS: Eastside EDS provides education, awareness, and advocacy to local Ehlers-Danlos Syndrome patients, providers, and families.

Finding a Rare Disease Patient Organization | NORD: Our Organizational Database (ODB) offers patients and families a listing of organizations and resources that can provide them with free information, support, and services. These organizations can be very important in helping navigate living with a rare disease.

FOXG1 Research Foundation

Hope for HIE - Hypoxic Ischemic Encephalopathy

Muscular Dystrophy Association (mda.org)

National MPS Society

National Tay-Sachs & Allied Diseases Association

Pompe Alliance

RARE List - Global Genes: Over 7,000 diseases have been classified as a rare disease, start your search here to learn more about your disease state.

Stickler Involved People: Stickler syndrome (hereditary progressive arthro-ophthalmopathy) is a connective tissue disorder, a genetic malfunction in the tissue that connects bones, eyes, and ears. This disorder is associated with problems to vision, hearing, bone and joint, facial and cleft palate.

Syngap1 Foundation

Team Joseph | Duchenne Family Assistance Program: Every child and young adult battling Duchenne deserves the resources, the equipment, access to approved treatments and the best care that they need. Every family deserves support and partnership so they don't have to navigate a complex medical system alone. The Duchenne Family Assistance Program is a collaboration between Team Joseph and Little Hercules Foundation, and provides personalized assistance to individuals and families affected by Duchenne Muscular Dystrophy.

The National Fragile X Foundation

United Cerebral Palsy

Vamp2

EVERYCURE ROADMAP PROJECT: IDENTIFYING RARE DISEASE GROUPS IN THE US

About the ROADMAP project | ROADMAP (everycure.github.io): The Repurposing Of All Drugs, Mapping All Paths (ROADMAP) project aims to identify the paths that can be taken to repurpose drugs, highlight the roles of various stakeholders, and centralize information on how to do this most effectively through an interactive "ROADMAP" tool. This project is supported by a grant from the Chan Zuckerberg Initiative (CZI).

IDENTIFYING ALL RARE DISEASE NONPROFIT ORGANIZATIONS IN THE US

- First, we set out to build a comprehensive list of all rare disease nonprofit organizations in the US.
- From here we hoped to gain an understanding of how many of them support research and drug repurposing in particular. Unfortunately, this list did not exist. We assembled a team of volunteers to combine several existing lists of organizations (i.e. NORD members, Global Genes members) and to perform additional searches to find more organizations.
- The final compiled list contained 982 organizations.

CHARACTERIZING RARE DISEASE NONPROFIT ORGANIZATIONS

Next a larger team of 70+ volunteers spent seven months (05/18/2021-12/16/2021) extracting data from the websites of these organizations, looking for:

- Whether the organization satisfied our inclusion criteria: US-based, registered 501(c)(3) nonprofit organization, focused on one or more rare diseases (one that affects less than 200,000 people in the US (2) and having an active website
- Basic organizational info: year of founding, name & contact information of founders
- Information on the organization's programs: conference, research agenda, biobank, registry, natural history study, etc.
- Whether the rare disease has treatment guidelines, or whether it is known that it is caused by a genetic mutation
- Any mention of drug repurposing, and if so - which drug(s) were pursued
- Any mention of partnerships or collaborations with other organizations

As a result of this exercise, 711 organizations were confirmed as rare disease nonprofit organizations in the US with active websites as of 12/2021. This dataset has been made available open-source here and basic information is listed below.

Organization Name	Website	General Email
11q Research and Resource Group	https://www.11qusa.org/home	11qusa@gmail.com
17q12 Foundation	http://www.chromo17q12.org/	chromosome17q12@gmail.com
1p36 Deletion	http://www.1p36dsa.org/	info@1p36dsa.org

Support & Awareness		
4p- Support Group	https://4p-supportgroup.org/	amanda@4p-supportgroup.org
5p- Society	https://fivepminus.org/	director@fivepminus.org
A Breath Of Hope Foundation For NMO - Neuromyelitis Optica	https://abreathofhopefornmo.org/	heather@abreathofhopefornmo.org
A Cure for Ellie	https://acureforellie.org/	ACureforEllie@gmail.com
A Cure in Sight	https://acureinsight.org/?v=7516fd43adaa	contact@acureinsight.org
A Foundation Building Strength for Nemaline Myopathy	https://buildingstrength.org/	info@buildingstrength.org
A Nonprofit Group Enriching Lives (ANGEL AID)	https://www.angelaidcares.org/	info@anglaidcares.org
A Twist of Fate-ATS	http://www.atwistoffate-ats.org/	contact form
Aaronâ€™s Ohtahara	https://sites.google.com/a/ohtahara.org/ohtahara2/	https://sites.google.com/a/ohtahara.org/ohtahara2/contact-us
ACDY5.org	https://www.adcy5.org/	info@ADCY5.org
Achalasia Awareness Organization	https://achalasiaawareness.org/	info@achalasiaawareness.org
Acid Maltase	https://amda-pompe.org/	info@amda-pompe.org

Deficiency Association (AMDA)		
Acoustic Neuroma Association	https://www.anausa.org/	info@anausa.org
Acromegaly Community, Inc.	http://www.acromegalycommunity.org	acromegalyinspiration@gmail.com
Adenoid Cystic Carcinoma Foundation	https://www.accrf.org/	info@accrf.org
ADNP-Kids Research Foundation	https://www.adnpfoundation.org/	ADMIN@adnpfoundation.org
Adrenal Alternatives Foundation	https://adrenalalternatives.com/	adrenalalternatives@gmail.com
Adrenal Insufficiency United (AIU)	https://aiunited.org/	contact@aiunited.org
Adult Polyglucosan Body Disease Research Foundation (APBDRF)	https://www.apbdrf.org/	info@APBDRF.org
Advancing Sickle Cell Advocacy Project, Inc.	https://www.advancingsicklecelladvocacyproject.org/	info@asapbeinformed.org
Advocacy & Awareness for	https://www.godoaaida.org/	info@godoaaida.org

Immune Disorders Association (AAIDA)		
AKU Society North America	http://akusocietyna.org/	info@akusocietyna.org
Alagille Syndrome Alliance	http://alagille.org/	alagille@alagille.org
ALD Alliance	https://www.aldalliance.org/	https://www.aldalliance.org/contact.html
ALD Connect	https://aldconnect.org/	info@aldconnect.org
All Things Kabuki	https://www.allthingskabuki.org/	https://www.allthingskabuki.org/contact
Alliance for Cryoglobulinemia	http://allianceforcryo.org/	http://allianceforcryo.org/about-us/contact-us/
Alliance for Safety Awareness for Patients	http://www.patientsafetyasap.org/	N/A
Alpha-1 Foundation	https://www.alpha1.org/	info@alpha1.org
Alport Syndrome Foundation	https://www.alportsyndrome.org/	info@alportsyndrome.org
ALS Association	https://www.als.org/	Care Services: alsinfo@alsa-national.org Media Relations: mediarelations@alsa-national.org
ALS Recovery Fund	https://www.alsrecovery.org/	info@alsrecovery.org
ALS Ride For Life	https://alsrideforlife.org/	rfldirector@aol.com
AlstrÃ¶m Angels	http://www.alstromangels.com/index.html	info@alstromangels.org
AlstrÃ¶m Syndrome	https://www.alstrom.org/	info@alstrom.org

International		
Alternating Hemiplegia of Childhood Foundation (AHCF)	http://ahckids.org/	ahcfoundation@ahckids.org
AMENSupport	https://amensupport.org/	Info@amensupport.org
American BehÃ§etâ€™s Disease Association	https://www.behcets.com/	info@behcets.com
American Multiple Endocrine Neoplasia Support	https://amensupport.org/	Info@amensupport.org
American Porphyria Foundation	https://porphyriafoundation.org/	info@porphyriafoundation.org
American Society of Cell and Gene Therapy	https://asgct.org/	https://asgct.org/contact
Amniotic Fluid Embolism Foundation (AFE Foundation)	https://www.afesupport.org/	info@afesupport.org
Amyloidosis Foundation	https://amyloidosis.org/	info@amyloidosis.org
Amyloidosis Research Consortium, Inc.	https://arci.org/	arc@arci.org

Amyloidosis Support Groups, Inc.	https://www.amyloidosissupport.org/	info@amyloidosissupport.org
AnCan(formerly Answer Cancer Foundation)	https://ancan.org/	info@ancan.org
Angelman Syndrome Foundation, Inc.	https://www.angelman.org/	info@angelman.org
Angels for Eosinophilic Research Alliance	https://web.archive.org/web/20161002015116/http://www.angelsforeos.org/	angelsforeos@sbcglobal.net
Angels with Missing Pieces	http://www.amp22q.org/	contact@amp22q.org - they gave this email for volunteers, but it is the only general contact us email on the website. No contact us page to link.
Angioma Alliance	https://www.angioma.org/	info@angioma.org
Aplastic Anemia & MDS International Foundation, Inc.	https://www.aamds.org/	help@aamds.org
Appendix Cancer/Pseudomyxoma Peritonei Research Foundation (ACPMP)	https://acpmp.org	info@acpmp.org
APS Type 1 Foundation	https://apstype1.org/	https://apstype1.org/about-us/contact-us/

Ara Parseghian Medical Research Foundation	http://parseghian.org/	promano@parseghian.org
ARPKD/CHF Alliance	https://www.arpkdchf.org/	info@arpkdchf.org
Association for Frontotemporal Degeneration (AFTD)	https://www.theaftd.org/	info@theaftd.org
Association for Glycogen Storage Disease	https://www.agsdus.org/index.php	info@agsdus.org
Association of Gastrointestinal Motility Disorders, Inc. (AGMD)	https://agmdhope.org/	info@agmdhope.org
ASXL Rare Research Endowment (ARRE) Foundation	https://www.arrefoundation.org/	info@arrefoundation.org
AT Childrenâ€™s Project	https://www.atcp.org/	https://www.atcp.org/about-us/contact-us/
Atlanta S.C.A.R., Inc	http://atlantascar.com/	info@atlantascar.com
Atypical HUS Foundation	https://www.ahus.org/	donna@ahus.org
Autoimmune Encephali	https://aealliance.org/	info@aealliance.org

tis Alliance		
Autoinflammatory Alliance	https://autoinflammatory.org/	N/A
Averyâ€™s Angels Gastroschisis Foundation	https://averysangels.org/	info@averysangels.org
Averyâ€™s Hope	https://www.averys-hope.org/	averyshopepa@gmail.com
Aware of Angels	http://awareofangels.org/	seasonatwater@gmail.com
AXYS	https://genetic.org/	info@genetic.org
Bardet Biedl Families	https://www.bardetbiedl.org/	timothy.ogden@bardetbiedl.org
Barth Syndrome Foundation	https://www.barthsyndrome.org/	bsfinfo@barthsyndrome.org
Batten Disease Support and Research Association	https://www.bdsra.org/	info@bdsra.org
BCM Families Foundation	https://www.blueconemonochromacy.org/	info@BCMFamilies.org
Beautiful You MRKH Foundation	https://www.beautifulyoumrkh.org/	bymrkh@gmail.com
Beckwith-Wiedemann Children's Foundation International	https://www.beckwithwiedemann.org/	bwcfikristen@gmail.com
Benâ€™s Friends	https://www.bensfriends.org/	info@bensfriends.org

Beyond Batten Disease Foundation	https://beyondbatten.org	info@beyondbatten.org
Beyond Blindness	https://www.beyondblindness.org & https://www.blindchildrenscenter.org	info@blindchildrenscenter.org
Bili Project Foundation	https://thebiliproject.org	info@thebiliproject.org
Bleeding Disorders Alliance Illinois - Inherited Bleeding Disorders	https://www.bdai.org	Info@bdai.org
Bohring-Opitz Syndrome Foundation, Inc.	http://bos-foundation.org	info@bos-foundation.org
Bold Lips For Sickle Cell â€“ Sickle Cell Disease	https://www.facebook.com/NowWeAreBoldplus/	boldlipsforsicklecell@gmail.com
Boomer Esiason Foundation	https://www.esiason.org	info@esiason.org
BORN A HERO, Pfeifferâ€™s Health and Social Issues Awareness	https://www.bornahero.org	info@bornahero.org
BPAN Warriors	https://www.bpanwarriors.org	info@bpanwarriors.org
Brandon's Battle Foundation For SKS Kids -	https://www.bbfskskids.org	brandonsbattlesks@gmail.com

Smith Kingsmore Syndrome		
Brave Minds Project - Brain and Brainstem Conditions	https://bravemindsproject.org	info@bravemindsproject.org
Bridge the Gap â€“ SYNGAP Education and Research Foundation	https://www.bridgesyngap.org	bridge.syngap@yahoo.com
CACNA1A Foundation	https://www.cacna1a.org/	info@cacna1a.org, also a contact form: https://www.cacna1a.org/contact
CADASIL Together We Have Hope	https://www.cadasilfoundation.org/	info@cadasilfoundation.org
California Action Link for Rare Diseases Inc. (CAL RARE)	https://www.calrare.org/	https://www.calrare.org/contact
Cardio-Facio-Cutaneous International (CFC)	https://www.cfcsyndrome.org/	info@cfcsyndrome.org
Care Beyond Diagnosis	https://carebeyonddiagnosis.org/	INFO@CAREBEYONDDIAGNOSIS.ORG
CARES Foundation	https://caresfoundation.org/	contact@caresfoundation.org

Carion Fenn Foundation	https://carionfenn.org/	smcm@carionfenn.org
Castleman Disease Collaborative Network	https://cdcn.org/	info@castlemannetwork.org
Cauda Equina Foundation, Inc.	https://www.ceslife.org/	info@CaudaequinaFoundation.org
CCHS Family Network (Congenital Central Hypoventilation Syndrome)	https://www.cchsnetwork.org/	mycchsnetwork@gmail.com
CDG Association of America	http://cgdassociation.org/	alan-hurley@socal.rr.com
CDG Care	https://cdgcare.org/	info@cdgcare.com
CDH International	https://cdhi.org/	info@cdhi.org
Center for Chronic Illness	https://www.thecenterforchronicillness.org/	info@thecenterforchronicillness.org
Central California Hemophilia Foundation	https://cchfsac.org	handi@hemophilia.org
CFC International	https://www.cfcsyndrome.org/	info@cfcsyndrome.org
CHAMP1 Research Foundation	https://champ1foundation.org/	email N/A, but phone is 813-600-7950
Champions Action Network	http://www.wecan.org/	Contact form is "coming soon" http://www.wecan.org/contact-us.html

Charcot-Marie-Tooth Association	https://www.cmtausa.org/	info@cmtausa.org
Charley's Fund	https://charleysfund.org/	info@charleysfund.org
Charlotte & Gwenyth Gray Foundation to Cure Batten Disease	https://www.curebatten.org/	info@curebatten.org
Chelseaâ€™s Hope Lafora Children Fund	https://chelseashope.org/	https://chelseashope.org/contact/#top
Cheyannaâ€™s Champions 4 Children (CC4C)	https://www.cc4c.org/	info@cc4c.org
chILD Foundation	https://child-foundation.org	info@child-foundation.org
Child Neurology Foundation	https://www.childneurologyfoundation.org/	info@childneurologyfoundation.org
Childrenâ€™s Alopecia Project	https://www.childrensalopeciaproject.org/	N/A
Childrenâ€™s Cardiomyopathy Foundation	https://www.childrenscardiomyopathy.org/pages/childrens-cardiomyopathy-foundation/	info@childrenscardiomyopathy.org
Childrenâ€™s Craniofacial Association	https://ccakids.org	contactCCA@ccakids.com

Childrenâ€™s Gaucher Research Foundation	www.childrensgaucher.org	research@childrensgaucher.org
Childrenâ€™s PKU Network	https://www.pkunetwork.org/	pkunetwork@aol.com
Childrenâ€™s Tumor Foundation	https://www.ctf.org/	info@ctf.org
Chion Foundation	https://www.chionfoundation.org/	info@chionfoundation.org
Chive Charities	chivecharities.org	volunteer@chivecharities.org
Chloeâ€™s Fight Rare Disease Foundation	https://www.chloesfight.org	info@chloesfight.org
Cholangiocarcinoma Foundation	https://cholangiocarcinoma.org	info@cholangiocarcinoma.org
Chordoma Foundation	https://www.chordomafoundation.org/	https://www.chordomafoundation.org/contact-us/ support@chordoma.org
Choroideremia Research Foundation	https://www.curechm.org/	info@curechm.org
Christy's Courage	http://christyscourage.org/	http://christyscourage.org/contact-us.html
Chromosome 18 Registry & Research Society	https://www.chromosome18.org/	office@chromosome18.org
Chromosome Disorder	https://chromodisorder.org/	https://chromodisorder.org/contact/ info@chromodisorder.org

Outreach, Inc.		
Chronic Granulomatous Disease Foundation	http://cgdassociation.org/	N/A
Chronic Intractable Pain And You Sites, Inc.	https://www.chronicintractablepainandyou.org/	drpattyverdugo@cipay.org.
Chronic Pain Partners	https://www.chronicpainpartners.com	info@edsawareness.com
Chronic Recurrent Multifocal Osteomyelitis Foundation	https://crmofoundation.org/	Contact-Us@crmofoundation.org
Cicatricial Alopecia Research Foundation (CARF)	http://www.carfintl.org/	info@carfintl.org
Cincinnati Comprehensive Sickle Cell Center at Cincinnati Childrenâ€™s Hospital	https://www.cincinnatichildrens.org/service/s/sickle-cell	Contact form link: https://www.cincinnatichildrens.org/service/s/sickle-cell/contact/form
Citizens United for Research in Epilepsy	https://www.cureepilepsy.org/	info@CUREepilepsy.org
CLOVES Syndrome Community	https://clovessyndrome.org/	info@clovessyndrome.org

Cluster Headache Support Group, Inc.	https://chsg.org/	channah@chsg.org
Clusterbusters, Inc.	https://clusterbusters.org/	info@clusterbusters.org
CMT Research Foundation (CMTRF)	https://cmtrf.org/	info@cmtrf.org and contact form https://cmtrf.org/contact/
CMTC Alliance	https://www.cmtcalliance.org/	N/A, but the "live chat" link on their website links to Facebook Messenger.
Coalition Duchenne	http://www.coalitionduchenne.org/	catherine@coalitionduchenne.org
Coalition to Cure Calpain 3	https://www.curecalpain3.org/	info@curecalpain3.org
COL4A1 Foundation	https://gouldsyndromefoundation.org/	info@col4a1foundation.org
Cold Agglutinin Disease Foundation	https://coldagglutinindisease.org/	info@cadfadvocacy.org
COMBINEDBrain	https://combinedbrain.org/	info@combinedbrain.org and contact page https://combinedbrain.org/contact/
Congenital Hyperinsulinism International	https://congenitalhi.org/	N/A
Connecting Families Urea Cycle Disorders Foundation	https://ucdfamily.org/	https://ucdfamily.org/contact-us/ possible email: zebrastreams@gmail.com (not sure how active this might be, though)
Connor B. Judge Foundation	https://www.connorbjudgefoundation.org/	chelsey@connorbjudgefoundation.org

Conquer MG	https://www.myastheniagravis.org/	info@myastheniagravis.org
Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders	https://www.combinedbrain.org/	info@combinedbrain.org
Consortium of Multiple Sclerosis Centers	https://www.mscare.org/general/?type=contact_cmsc	info@mscare.org
Cooley's Anemia	https://www.thalassemia.org/	info@thalassemia.org
COPA Syndrome Foundation	https://www.copasyndrome.com/	info@copasyndrome.com
Coriell Institute for Medical Research	https://www.coriell.org/	customerservice@coriell.org
Cornelia de Lange Syndrome Foundation, Inc.	https://www.cdlsusa.org/	info@cdlsusa.org
Cortical Foundation	https://cortfoundation.org/	info@cortfoundation.org
Costello Syndrome Family Network	https://costellosyndromeusa.org/	Info@CostelloSyndromeUSA.org
Courageous Faces Foundation	https://courageousfacesfoundation.org/	info@courageousfacesfoundation.com
CPRS Forum	https://crpsforum.com/	N/A

CRMO Foundation	https://crmofoundation.org/	contactus@crmofoundation.org
CSNK2A1 Foundation	https://www.csnk2a1foundation.org/	info@csnk2a1foundation.org
CTNNB1 Syndrome Awareness Worldwide	https://www.ctnnb1.org/	N/A
Cure AHC	https://www.cureahc.org/	info@cureahc.org
Cure CMT4J/ Talia Duff Foundation	http://www.curecmt4j.org/	info@curecmt4j.org
Cure Duchenne	https://www.cureduchenne.org/	info@cureduchenne.org
Cure Dystonia Now	https://www.curedystonianow.org/index	info@curedystonianow.org
Cure GM1 Foundation	https://curegm1.org/	info@curegm1.org
Cure HHT Foundation	https://curehht.org/	hhtinfo@curehht.org
Cure JM Foundation	https://www.curejm.org/	info@curejm.org
Cure Mito	https://www.curemito.org/	info@curemito.org
Cure RTD Foundation	http://curertd.org/	info@cureRTD.org
Cure Sanfilippo Foundation	https://curesanfilippofoundation.org/	Contact@CureSanfilippoFoundation.org
Cure SMA	https://www.curesma.org/	info@curesma.org
Cure TBM	https://www.curetbm.org/	info@curetbm.org
Cure VCP Disease, Inc.	https://www.curevcp.org	curevcpdisease@gmail.com
cureCADASIL	https://curecadasil.org	info@curecadasil.org

CureGRIN Foundation	https://curegrin.org/	info@curegrin.org
CureLGMD2J Foundation	https://curelgmd2i.com/	kbrazzo@curelgmd2i.org
CurePSP, Inc.	https://www.psp.org/	info@curepsp.org
Cures Within Reach	https://www.cureswithinreach.org/	info@cureswithinreach.org
CureSHANK	https://www.cureshank.org/	connect@cureshank.org
Curing Retinal Blindness Foundation	https://crb1.org/	info@crb1.org
Cushingâ€™s Support and Research Foundation, Inc.	https://csrf.net/	cushinfo@csrf.net
Cutaneous Lymphoma Foundation	https://www.clfoundation.org/	info@clfoundation.org
Cyclic Vomiting Syndrome Association	https://www.cvsaonline.org/	cvsa@cvsaonline.org
Cystic Fibrosis Foundation	https://www.cff.org/	info@cff.org
Cystic Fibrosis Relief Fund	https://www.cfrelieffund.org/	cfrelieffundorg@gmail.com
Cystic Fibrosis Research, Inc.	www.cfri.org	cfri@cfri.org

Cystinosis Foundation	www.cystinosisfoundation.org	Email@cystinosis.com
Cystinosis Research Foundation	https://www.cystinosisresearch.org	info@cystinosisresearch.org
DADA2 Foundation	https://dada2.org/	INFO@DADA2.ORG
Danaâ€™s Angels Research Trust	https://danasangels.org/	info@danasangels.org
Dannyâ€™s Dose Alliance	https://dannysdose.com/	dannysdose.darlene@yahoo.com
DDX3X Foundation	https://ddx3x.org/	Contact Form: https://ddx3x.org/contact/
debra of America	https://www.debra.org/	staff@debra.org
Defeat MSA	https://defeatmsa.org/	Info@defeatmsa.org
DeSanto-Shinawi Syndrome Corp	https://www.dessh.org/	cureDESSH.org@gmail.com
Desmoid Tumor Research Foundation	https://dtrf.org	lynne@dtrf.org
Determinence, Inc.	https://determinence.com/	info@determinence.com
DHPS Foundation	www.dhpsfoundation.org	Info@curedhps.org
Don't Forget Morgan	https://www.dontforgetmorgan.org/	bpan@dontforgetmorgan.org
Dravet Syndrome Foundation, Inc.	https://www.dravetfoundation.org/	info@dravetfoundation.org
Dreamsickle Kids Foundation	https://dreamsicklekids.org/	info@dreamsicklekids.org

Dup 15q Alliance	https://dup15q.org/	info@dup15q.org
DYRK1A Syndrome US	http://www.dyrk1a.org/	admin@dyrk1a.org
Dyskeratosis Congenita Outreach	https://teamtelomere.org/	info@teamtelomere.org
Dystonia Medical Research Foundation	https://dystonia-foundation.org/	dystonia@dystonia-foundation.org
EB Research Partnership	https://www.ebresearch.org/	info@ebresearch.org
EBF3 HADDS Foundation	https://www.hadds.org/	info@hadds.org
ECD Global Alliance	https://erdheim-chester.org/	support@erdheim-chester.org
EDMD International, Inc.	https://edmdfoundation.org/	larissa@edmdinternational.org
EDSers United	https://www.edsers.com/	edsersunited@edsers.org
EHE Foundation	https://fightehe.org/	info@fightehe.org
Ehlers-Danlos Society	https://www.ehlers-danlos.com/	info@ehlers-danlos.com
Emerie Lee Foundation	emesarmy.org	emesarmy@gmail.com
Emilyâ€™s Entourage	https://www.emilysentourage.org/	admin@emilysentourage.org
Endosalpingiosis Foundation Inc	https://www.endosalfoundation.org/	endosalpingiosisfoundation@gmail.com

Eosinophilic Family Coalition	https://eoscoalition.org/	contact@eoscoalition.org and they also have a contact form: https://eoscoalition.org/contact-us/ .
Epidermoid Brain Tumor Society	http://epidermoidbraintumorsociety.org/	epidermoidbraintumorsociety@gmail.com
Epilepsy Alliance America	https://www.epilepsyallianceamerica.org/	admin@epilepsyallianceamerica.org
Erdheim-Chester Disease Global Alliance	https://erdheim-chester.org/	https://erdheim-chester.org/contact-us/
Ethan Lindberg Foundation	https://www.ethanlindberg.com/	hello@ethanlindberg.com
Ethanâ€™s Reason	https://ethansreason.org/	ethansreason@gmail.com
EveryLife Foundation	https://everylifefoundation.org/	info@everylifefoundation.org
Fabry Disease Foundation	https://www.fabrydisease.org/	info@fabrydisease.org
Fabry Support and Information Group	https://fabry.org/	info@fabry.org
Facial Pain Association	https://www.facepain.org/	info@tna-support.org
Familial Dysautonomia Foundation	https://familialdysautonomia.org/	info@famdys.org
FamilieSCN2A Foundation	https://www.scn2a.org/	https://www.scn2a.org/contact.html

Family Caregiver Alliance	https://www.caregiver.org/	info@caregiver.org
Fanconi Anemia Research Fund, Inc.	https://www.fanconi.org/	info@fanconi.org
Fat Disorders Research Society, Inc.	https://www.fatdisorders.org/	info@fatdisorders.org
FCS Foundation	https://fcsf.org/	Foundation@FLCancer.com
Feeding Tube Awareness Foundation	https://www.feedingtubeawareness.org/	info@feedingtubeawareness.org
FH Foundation	https://thefhfoundation.org/	info@thefhfoundation.org
Fibrolamellar Cancer Foundation (FCP)	https://fibrofoundation.org/	info@fibrofoundation.org
Fibromuscular Dysplasia Society of America	https://www.fmdsa.org/	N/A
Fibrous Dysplasia Foundation	https://fdmasalliance.org/	info@fibrousdysplasia.org
Fighting for Kaiden Foundation, Inc. - Spinal Muscular Atrophy	https://www.fightingforkaiden.org/index.html	info@fightingforkaiden.org
Fighting H.A.R.D. Foundation	https://www.fightinghardfoundation.org/	info@fightinghardfoundation.org

FIRST: Foundation for Ichthyosis & Related Skin Types	https://www.firstskinfoundation.org/	info@firstskinfoundation.org
FMD Chat	http://fmdchat.blogspot.com/	N/A
Food Allergy & Anaphylaxis Connection Team	https://www.foodallergyawareness.org/	info@FoodAllergyAwareness.org and they also have a contact form: https://www.foodallergyawareness.org/contact/ .
Food Allergy Research and Education	https://www.foodallergy.org/about-us	contactfare@foodallergy.org
ForeBatten Foundation	https://www.forebatten.org/	admin@forebatten.org
Foundation Fighting Blindness	https://www.fightingblindness.org/	Users are referred state chapters. Each "state" page shows the email (chapters@fightingblindness.org) and may (or may not) display name and contact information for the chapter engagement manager in that area.
Foundation for Angelman Syndrome Therapeutics (FAST)	https://cureangelman.org/	info@cureangelman.org
Foundation for Batten Hope	https://battenhope.org/	gina@rarevillage.org
Foundation for Prader-	https://www.fpwr.org/	info@fpwr.org

Willi Research		
Foundation for Sarcoidosis Research	https://www.stopsarcoidosis.org/	info@stopsarcoidosis.org
Foundation for USP-7 Related Diseases	https://www.usp7.org/	admin@usp7.org
Foundation to Fight H-abc	https://www.h-abc.org/	contact@h-abc.org
FPIES Foundation	https://fpiesfoundation.org/	contact@thefpiesfoundation.org
Friedreichâ€™s Ataxia Research Alliance	https://www.curefa.org/mission	info@curefa.org
GACI Global - Generalized Arterial Calcification of Infancy	https://gaciglobal.org/	info@gaciglobal.org
Galactosemia Foundation	http://www.galactosemia.org/	outreach@galactosemia.org
Gaucher Community Alliance	https://www.gauchercommunity.org/	info@gauchercommunity.org
GBS/CIDP Foundation International	https://www.gbs-cidp.org/	info@gbs-cidp.org
Gene Giraffe Project	http://www.genegiraffe.org/	passow13@gmail.com
Genesic Nonprofit Organizat	https://www.genesicnonprofit.org/	info@genesicnonprofit.org

ion, Incorporated - Sickle Cell		
Genetic Alliance	http://www.geneticalliance.org/	info@geneticalliance.org
Global Foundation for Peroxisomal Disorders	https://www.thegfpd.org/?gclid=CjwKCAiAqIKNBhAIEiwAu_ZLDurzSI17ETqriJ1_qUBW7MMPVffExz3syjzxNnvFp0M68NDvTjgIGBoCA_IQAvD_BwE	contactus@thegfpd.org
Global Hydranencephaly Foundation	https://www.hydranencephalyfoundation.org/	President@ghf.life
Global Liver Institute - Liver Diseases	https://www.globalliver.org/	info@globalliver.org
Glut1 Deficiency Foundation	https://www.g1dfoundation.org/	info@G1DFoundation.org
Gorlin Syndrome Alliance	https://gorlinsyndrome.org/	info@gorlinsyndrome.org
Gould Syndrome Foundation (COL4a1/ COL4A2)	https://gouldsyndromefoundation.org/	info@col4a1foundation.org
GRIN2B Foundation	https://curegrin.org/	info@curegrin.org
Gut Check Foundation	https://www.gutcheckfoundation.org/	info@gutcheckfoundation.org
Guthy-Jackson Charitable Foundation	https://guthyjacksonfoundation.org/	info@guthyjacksonfoundation.org

Gwendolyn Strong Foundation	https://nevergiveup.org/	info@nevergiveup.org
Hadley Hope Fund	https://hadleyhope.com/	info@hadleyhope.com
Hairy Cell Leukemia Foundation - Hairy Cell Leukemia	https://www.hairycellleukemia.org/	info@hairycellleukemia.org
Halpin Foundation	http://www.halpinfoundation.org/	info@halpin.org
Hannahâ€™s Hope Fund	http://www.hannahshopefund.org/	N/A
Harmony 4 Hope	https://harmony4hope.org/	info@harmony4hope.org
Haystack Project - Multiple Rare Diseases	https://haystackproject.org/	https://haystackproject.org/contact
HCU Network America	https://hcunetworkamerica.org/	info@hcunetworkamerica.org
HD-Care â€“ Huntingtonâ€™s Disease	http://hdcare.org/	info@hdcare.org
Health Advocacy Summitâ€“ Chronic Disease	https://www.healthadvocacysummit.org/	sneha@healthadvocacysummit.org
Help 4 HD International	https://www.help4hd.org/	katie@help4hd.org
Helping Hands for GAND, Inc.	https://www.gatad2b.org/	info@GATAD2B.org
Hemophilia Federatio	https://www.hemophiliafed.org/	info@hemophiliafed.org

n of America		
Hemophilia Foundation of Southern California â€“ Genetic Bleeding Disorders	https://hemosocal.org/	https://hemosocal.org/contact-us/
Hereditary Angioedema Association	https://www.haea.org/	N/A
Hereditary Hemorrhagic Telangiectasia Foundation International â€“ Hereditary Hemorrhagic Telangiectasia	https://curehht.org/	hhtinfo@curehht.org (https://curehht.org/who-we-are/contact-us-2/)
Hereditary Neuropathy Foundation, Inc.	https://www.hnf-cure.org/	info@hnf-cure.org
Hermansky-Pudlak Syndrome Network, Inc.	https://www.hpsnetwork.org/	info@hpsnetwork.org
Heterotaxy Connection	https://www.heterotaxyconnection.org/	connect@heterotaxyconnection.org

Hide and Seek Foundation for LDN Research	https://hideandseek.org/	info@hideandseek.org
Highway of Hope	https://hwofhope.org/	info@hwofhope.com
Histiocytosis Association	https://histio.org/	info@histio.org
Hope for Hypothalamic Hamartomas	https://www.hopeforhh.org/	info@hopeforhh.org
Hope for Javier	https://www.hopeforjavier.org/	info@hopeforjavier.org
Hope for Trisomy 13 & 18	https://www.hopefortrisomy13and18.org/	info@hopefortrisomy.org
Hope4tylerandluke - Med 23 gene defect	http://www.hope4tylerandluke.com/	hope4tylerandluke@comcast.net
HPS Network	https://www.hpsnetwork.org/	info@hpsnetwork.org
HSAN1E Society	https://hsan1esociety.org/	info@hsan1esociety.org
HudsonAlpha Institute for Biotechnology	https://www.hudsonalpha.org/	foundation@hudsonalpha.org
Humans with Knobloch Syndrome - Knobloch Syndrome	https://www.humanswithknoblochsyndrome.org/	https://www.humanswithknoblochsyndrome.org/
Huntingtonâ€™s Disease Society of America, Inc.	https://hdsa.org/	HDSAinfo@HDSA.org

Huntingtonâ€™s Disease Youth Organization (HDYO)	https://en.hdyo.org/	info@hdyo.org
Hydrocephalus Association	https://www.hydroassoc.org/	info@hydroassoc.org
Hyper IgM Foundation, Inc.	https://hyperigm.org/	info@hyperigm.org
Hypersomnia Foundation	https://www.hypersomniafoundation.org/	info@hypersomniafoundation.org
Hypoparathyroidism Association	https://hypopara.org/	https://hypopara.org/who-we-are/contact.html
iCAN Research - Multiple Rare Diseases	https://www.icanresearch.org/	info@icanresearch.org
iDefine - Kleefstra Syndrome	https://www.idefine.org/	unlock@idefine.org
IFAA International Foundation for Autoimmune and Autoinflammatory Arthritis	https://www.aiarthritis.org/	info@AiArthritis.org
Illinois Spina Bifida Association - Spina Bifida	https://i-sba.org/	info@i-sba.org
Immune Deficiency	https://primaryimmune.org/	info@primaryimmune.org

Foundation		
INADcure Foundation	https://www.inadcure.org/	info@inadcure.com
IndoUSrare - General Support Organization	https://www.indousrare.org/	admin@indousrare.org
Intermountain PKU and Allied Disorders Association â€“ Phenylketonuria and allied disorders	https://ipadutah.org/	https://ipadutah.org/contact-us/
International Advocate For Glycoprotein Storage Diseases	https://www.ismrd.org/	info@ismrd.org
International Autoimmune Encephalitis Society	https://autoimmune-encephalitis.org/	IAES@AUTOIMMUNE-ENCEPHALITIS.ORG
International Cystinuria Foundation	https://cystinuria.org/	info@cystinuria.com
International Essential Tremor Foundation	https://essentialtremor.org/	info@essentialtremor.org

International Firefighter Cancer Foundation, Inc. â€“ Multiple Rare Cancers	https://firefightercancersupport.org/	info@fcsn.net
International FOP Association	https://www.ifopa.org/	together@ifopa.org https://ifopa.formstack.com/forms/email_signup
International Foundation for Autoimmune and Autoinflammatory Arthritis	https://www.aiarthritis.org/	info@AiArthritis.org
International Foundation for CDKL5 Research	https://www.cdkl5.com/	info@cdkl5.com
International FOXG1 Foundation	https://foxg1.org/	info@foxg1.org
International FPIES Association	https://www.fpies.org/	contact@fpies.org
International Neuroendocrine Cancer Alliance	https://incalliance.org/	post@incalliance.org
International Pemphigus & Pemphigoid	https://www.pemphigus.org/	info@pemphigus.org

Foundation		
International Rett Syndrome Foundation	https://www.rettsyndrome.org	admin@rettsyndrome.org
International Sacral Agenesis/ Caudal Regression Association (iSACRA)	https://isacra.org/	contact@isacra.org E-mail: contact@isacra.org (general questions/inquiries regarding the organization) E-mail: phyllis.rogers@isacra.org (questions/inquiries regarding the website)
International WAGR Syndrome Association	https://wagr.org	reachingout@wagr.org
International Waldenstromâ€™s Macroglobulinemia Foundation	https://iwmf.com/	office@iwmf.com
IRF2BPL Foundation - IRF2BPL Disorder	https://irf2bpl.zohosites.com/	irf2bpl@gmail.com
ISMRD	https://www.ismrd.org/	info@ismrd.org
Jack McGovern Coats Disease Foundation	https://coatsdiseasefoundation.org/	contact@curecoats.org

Jain Foundation - Limb Girdle Muscular Dystrophy type 2B/R2/Mioyshi Myopathy/Dysferlinopathy	https://www.jain-foundation.org/	admin/scientific: admin@jain-foundation.org; clinician/patient: patients@jain-foundation.org
Jamalâ€™s Helping Hands - Multiple Chronic Illnesses	https://www.jamalshelpinghands.org/	N/A, Facebook:https://www.facebook.com/JamalsHelpingHandsInc/about/
Jamieâ€™s Dream Team	https://www.jamiesdreamteam.org/	info@jamiesdreamteam.org
Jansen de Vries Syndrome Foundation - Jansen de Vries Syndrome Foundation	https://jansen-devries.org/	jdvsyndromefoundation@gmail.com
Jeffrey Modell Foundation	http://www.info4pi.org/	info@jmfworld.org
Jett Foundation	https://www.jettfoundation.org/	info@jettfoundation.org
Jonahâ€™s Just Begun â€“ Sanfilippo Syndrome, Mucopolysaccharidoses (MPSIII)	http://jonahsjustbegun.org/	jill@jonahsjustbegun.org

Jordan's Guardian Angels - Jordan's Syndrome; Genetic misspelling of the genes PPP2R5D, PPP2R1A, PPP2R5C	https://jordansguardianangels.org/	info@jordansguardianangels.org
Joshua Frase Foundation	https://www.joshuafrase.org/	info@joshuafrase.org
Joubert Syndrome & Related Disorders Foundation	https://jsrdf.org/	info@jsrdf.org
Judsonâ€™s Legacy â€“ Krabbeâ€™s Disease	https://judsonslegacy.org/	info@judsonslegacy.org
Juliaâ€™s Wings Foundation, Inc.	https://www.juliaswings.org/	info@juliaswings.org
K-T Support Group	https://k-t.org/	support@k-t.org
Kabuki Syndrome USA â€“Kabuki syndrome	https://www.kabukisyndromefoundation.org/	info@kabukisyndromefoundation.org
KAT6A Foundation	https://kat6a.org/	support@kat6a.org
KCNQ2 Cure	https://www.kcnq2cure.org/	info@kcnq2cure.org

Kennedyâ€™s Disease Association, Inc.	https://www.kennedysdisease.org/	ipad@go-ipad.org
Kids with Food Allergies	https://www.kidswithfoodallergies.org/	info@aafa.org
KIF1A.ORG	https://www.kif1a.org/	impact@kif1a.org
KIF4A Foundation - KIF4A Associated Neurodevelopmental Syndrome (KANS)	https://kif4a.org/	Info@KIF4A.org
Kindness for Kimberlee	https://www.kindnessforkimberlee.org/	kindnessforkimberlee@gmail.com
Klippel-Trenaunay Support Group	https://k-t.org/	support@k-t.org
Kneading Hope â€“ Multiple Rare Diseases	https://kneadinghope.org/	info@kneadinghope.org
Koolen-de Vries Syndrome Foundation - Koolen-de Vries Syndrome	https://kdvsfoundation.org/	ashley@kdvsfoundation.org
KrabbeConnect	https://krabbeconnect.org/	info@krabbeconnect.org
Kruzn for a Kure Foundation - Shimke Immuno	https://kruznforakurefoundation.org	stacy@kruznforakure.org

Osseous Dysplasia		
LAL Solace, Inc.	https://laldaware.org/	Unknown
Legg Calve Perthes Foundation	https://www.guidestar.org/profile/9700620	Email contact available with a Pro subscription, on subscription and payment contact info is given.
Leiomyosarcoma Direct Research Foundation â€“ Leiomyosarcoma	https://www.lmsdr.org/	info@LMSDR.org
LEMS Patients â€“ Lambert-Eaton Myasthenic Syndrome	https://www.mda.org/disease/lambert-eaton-myasthenic-syndrome	ResourceCenter@mdausa.org
LetsTalkPPCM	https://letstalkppcm.org/home-1	N/A
LGS Foundation	https://www.lgsfoundation.org/	info@lgsfoundation.org
Li-Fraumeni Syndrome Association	https://www.lfsassociation.org/	info@lfsassociation.org
Life Raft Group	https://liferaftgroup.org/	info@liferaftgroup.org
Lightning and Love Foundation - Advocacy and research into THAP12 mutation	http://www.lightningandlove.org	info@coloradononprofits.org

related disease		
Lilyâ€™s List - Pediatric patients with a need for hospital-to-home health nursing	https://www.lilyslist.org/	taylor@lilyslist.org OR joey@lilyslist.org
Lipodystrophy United	www.facebook.com/LipodystrophyUnited/ NOTE: This is the Facebook page. I could not find a website for them.	N/A - The website (lipodystrophyunited.org) is non-functional - there is only a Facebook page. The Contact link on the Facebook page goes to the (non-existent) website.
Little Hercules Foundation	https://littleherculesfoundation.org/	kelly@littleherculesfoundation.org
Little Miss Hannah Foundation	https://littlemisshannah.org/	info@littlemisshannah.org
Little Zebra Fund - Undiagnosed & General Support Organization	https://littlezebrafund.org/	littlezebrafund@gmail.com
Littlest Tumor Foundation - Neurofibromatosis	https://littlesttumor.org/	info@littlesttumor.org
Liv4TheCure	https://www.liv4thecure.org/	liv4thecure@gmail.com
Living LFS â€“ Li-Fraumeni	https://livinglfs.org/	hello@livingLFS.org

Syndrome		
Lowe Syndrome Association, Inc.	https://lowesyndrome.org/	info@lowesyndrome.org
Luka the Lion Foundation â€“ Multiple Pediatric Rare Diseases	https://www.lukathelionfoundation.org/	N/A - email julia@lukathelionfoundation.org
Lymphangiomatosis & Gorhamâ€™s Disease Alliance, Inc. (LGDA)	https://www.lgdalliance.org	support@lgdalliance.org
Lynch Syndrome International	https://lynchcancers.com/	info@lynchcancers.com
M-CM Network	https://www.m-cm.net/	hello@m-cm.net
Mackenzieâ€™s Mission - Amyloidosis	https://mm713.org/mission/	asb.mm713@gmail.com
MAGIC Foundation	https://www.magicfoundation.org/	contactus@magicfoundation.org
Malan Syndrome Foundation	https://www.malansyndrome.org/	info@malansyndrome.org
Marfan Foundation	https://www.marfan.org/	publicity@marfan.org
Martin Mueller IV Achalasia	https://www.achalasiainfo.com/	mmivaaf@gmail.com

Awareness Foundation, Inc.		
Mason Shaffer Foundation	http://masonshafferfoundation.org/	http://masonshafferfoundation.org/?page_id=30
Massachusetts Biotechnology Council â€“ Multiple Rare Diseases	https://www.massbio.org/	https://www.massbio.org/contact/
Mast Cell Hope, Inc. - Mast Cell Disease	https://www.mastcellhope.org/	info@mastcellhope.org
MDS Foundation, Inc.	https://www.mds-foundation.org/	patientliason@mds.org
MEBO Research, Inc.	https://www.meboresearch.org/	info@meboresearch.org
MECP2 Duplication Foundation	https://mecp2d.org/	info@mecp2d.org
Melanoma Research Foundation	https://melanoma.org/	info@melanoma.org
Melorheostosis Association	http://www.melorheostosis.com/	kathleen@melorheostosis.org
Meningitis Foundation of America	http://www.musa.org/	info@musa.org
MEPAN.org â€“ MEPAN	https://www.mepan.org/	info@mepan.org

Syndrome		
Metaplastic Breast Cancer Global Alliance	https://www.mpbcalliance.org/	admin@mpbcalliance.org
MHE Coalition	https://www.mhecoalition.org/	Contact form: https://www.mhecoalition.org/contact.html
Mickieâ€™s Miracles - Infantile Spasms, Pediatric Epilepsy	https://mickiesmiracles.org/	https://mickiesmiracles.org/contact/
Minutes Matter â€“ Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)	https://minutesmatter-mcadd.org/	https://minutesmatter-mcadd.org/?page_id=45
Miracle Flights	https://miracleflights.org/	info@miracleflights.org
Miracle For Madison & Friends	http://www.miracleformadison.org/	miracleformadison1@mac.com
Mission Massimo Foundation â€“ Leukodystrophy	https://missionmassimo.com/	info@missionmassimo.org
Mission: Cure	https://mission-cure.org/	info@mission-cure.org
Mississippi Metabolics Foundation - Rare Genetic Metabolic	https://www.msmetabolics.org/	https://www.msmetabolics.org/contact

Disorders / IEMs		
Mitchell Thorp Foundation	https://www.mitchellthorp.org/	info@mitchellthorp.org
MitoAction	https://www.mitoaction.org/	info@mitoaction.org
MLD Foundation	MLD Foundation	MLDinfo@mldfoundation.org
Mo Songs for Kerryâ€" Li Fraumeni Syndrome	http://www.mosongsforkerry.org/	mosongs4kerry@gmail.com.
Moebius Syndrome Foundation	https://moebiussyndrome.org/	info@moebiussyndrome.org
Morgan Leary Vaughan Fund, Inc.	https://morgansfund.org/	NECregistry@morgansfund.org
Mowat-Wilson Syndrome Foundation	https://mowat-wilson.org/	https://mowat-wilson.org/about/contact/
Moyamoya Foundation Co - Moyamoya Disease	https://moyamoya-foundation.org/	execboard@moyamoya-foundation.org
MPN Research Foundation	https://www.mpnresearchfoundation.org/	RNunez@mpnresearchfoundation.org
MSA NJ	http://www.msanj.org/	contact@msanj.org
MSUD Family Support	https://msud-support.org/donations-2/	https://msud-support.org/contacts/
MTM-CNM	http://www.mtm-cnm.org/	info@mtm-cnm.org

Family Connection, Inc.		
Mucolipidosis Type IV Foundation, Inc. (ML4Fdn)	http://ml4.org/	info@ml4.org
Muscular Dystrophy Association	https://www.mda.org/	resourcecenter@mdausa.org
Muscular Dystrophy Family Foundation Muscular Dystrophy, Neuromuscular Diseases	https://www.mdff.org/	info@mdff.org
My PKU Awareness Foundation - PKU	https://www.mypkuaf.org/	mypkuawareness@gmail.com
Myasthenia Gravis Foundation of America, Inc.	https://myasthenia.org/	mgfa@myasthenia.org
Myasthenia Gravis Hope Foundation	https://mghope.org/	support@mghope.org
Myhre Syndrome Foundation	https://www.myhresyndrome.org/	info@myhresyndrome.org
Myocarditis Foundation	https://www.myocarditisfoundation.org/	info@myocarditisfoundation.org

Myositis Association	https://www.myositis.org/	TMA@myositis.org
Myositis Support and Understanding Association - Idiopathic Inflammatory Myopathies,	https://understandingmyositis.org/myositis/myositis/	Info@UnderstandingMyositis.org
Myotonic Dystrophy Foundation	https://www.myotonic.org/	info@myotonic.org
Narcolepsy Network â€“ Narcolepsy	https://narcolepsynetwork.org/	info@narcolepsynetwork.org
Nathan's Battle Foundation	https://nathansbattle.com/	N/A
National Adrenal Diseases Foundation	https://www.nadf.us/	nadfsupport@nadf.us
National Ataxia Foundation	https://www.ataxia.org/	naf@ataxia.org
National Brain Tumor Society	https://braintumor.org/	development@braintumor.org
National CMV Foundation	https://www.nationalcmv.org/	info@nationalcmv.org
National Eosinophilia Myalgia	https://www.nemsn.org/	nemsntalk@aol.com

Syndrome Network		
National Foundation for Ectodermal Dysplasias	https://www.nfed.org/	info@nfed.org
National Fragile X Foundation	https://fragilex.org/	contact@fragilex.org
National Health Council	https://nationalhealthcouncil.org/	info@nhcouncil.org
National Hemophilia Foundation	hemophilia org	handi@hemophilia.org
National LeioMyoSarcoma Foundation	https://nlmsf.org/	annie@nlmsf.org
National Lymphedema Network	https://lymphnet.org/	nln@lymphnet.org
National Median Arcuate Ligament Syndrome Foundation, Inc.	https://www.malsfoundation.org/	BoardofTrustees@malsfoundation.org
National MPS Society, Inc.	https://mpssociety.org/	https://mpssociety.org/contact/
National Neutropenia Network	https://neutropenianet.org/	https://neutropenianet.org/contact-nnn/
National Niemann-Pick Disease	https://nnpdf.org/	nnpdf@nnpdf.org

Foundation, Inc.		
National Organization for Albinism and Hypopigmentation (NOAH)	https://www.albinism.org/	info@albinism.org
National Organization of Disorders of the Corpus Callosum (NODCC) - Disorders of the Corpus Callosum	https://nodcc.org/	info@nodcc.org
National PKU Alliance	https://www.npkua.org/	The only direct e-mail I could find was Director of Development at tracy.fossum@npkua.org.
National PKU News	https://pkunews.org/	info@pkunews.org
National Spasmodic Dysphonia Association	https://dysphonia.org/	nsda@dysphonia.org
National Stem Cell Foundation	https://nationalstemcellfoundation.org	info@nationalstemcellfoundation.org
National Tay-Sachs and Allied Diseases Association, Inc.	https://www.ntsad.org/	info@ntsad.org
National Urea Cycle	http://www.nucdf.org/index.htm	info@nucdf.org

Disorders Foundation		
NBIA Disorders Association	https://www.nbiadisorders.org/about-us/financials	info@NBIAdisorders.org Contact Form: https://www.nbiadisorders.org/component/mailto/?tmpl=component&template=rt_ricochet&link=d73d8ac9cb50475e7fdad80007fdc9b7f9517c4f
NEC Society	https://necsociety.org/	jennifer@NECsociety.org
NEHI Research Foundation	https://www.nehiresearch.org/	info@nehiresearch.org
NephCure Kidney International Foundation	https://nephcure.org/	info@nephcure.org
Neuroendocrine Tumor Research Foundation	https://netrf.org/	info@netrf.org
Neurofibromatosis Midwest - Neurofibromatosis and Schwannomatosis	https://www.nfmidwest.org/	info@nfmidwest.org
Neurofibromatosis Network	https://www.nfnetwork.org/	admin@nfnetwork.org
Neurofibromatosis Northeast	https://nfnortheast.org/	https://nfnortheast.org/contact-us/
Neuromuscular Disease Foundation	https://curegnem.org/	https://curegnem.org/contact/

Nevus Outreach , Inc.	https://www.nevus.org/	adminom@nevus.org
New Hope Research Foundation	http://newhoperesearch.org/	contact@NewHopeResearch.org
Newborn Coalition Foundationâ€“ Newborn Screening	http://www.newbornfoundation.org/	info@newbornfoundation.org
Next Step Fund	https://www.nextstepnet.org/	info@nextstepnet.org
NF2BioSolutions	https://nf2biosolutions.org/	info@nf2biosolutions.org
NGLY1.org	https://www.ngly1.org/	N/A
NICER Foundation	https://nicer.ngo/	Contact form: https://nicer.ngo/contact-us/
Niemann Pick Research Foundation â€“ Neimann Pick Disease	https://nnpdf.org/	nnpdf@nnpdf.org https://nnpdf.org/contact/
No Baby Blisters	https://nobabyblisters.org/	911@nobabyblisters.org
Noahâ€™s Hope- Hope 4 Bridget Foundation â€“ Batten Disease	https://hope4bridget.com/	no general email - only founder emails are listed (sjkennicott@comcast.net, davidkennicott@comcast.net, tracy@noahshope.com, jennifer@noahshope.com)
Nontuberculous Mycobacteria Info & Research â€“ Pulmonary Nontuber	https://www.aboutntm.com/what-is-NTM/	N/A

culous Mycobacterial		
Noonan Syndrome Foundation â€“ Noonan Syndrome	https://www.teamnoonan.org/	info@teamnoonan.org
NORDâ€™sâ„¢ Rare Cancer Coalition (RCC)	https://rarediseases.org/	https://rarediseases.org/contact-us/
NR2F1 Foundation - Bosch Boonstra Schaaf optic atrophy syndrome	https://nr2f1.org/	info@nr2f1.org
NTM Info & Research, Inc.	https://connect.ntminfo.org/home	ntmmail@ntminfo.org
NUBPL Foundation	http://www.nubpl.org/	nubpl.org@gmail.com
Ocular Melanoma Foundation	http://www.ocularmelanoma.org/	info@ocularmelanoma.org
Oley Foundation	https://www.inclusivechildcare.org/resource-library/website/oley-foundation#:~:text=Oley%20Foundation%20is%20a%20national,education%2C%20advocacy%2C%20and%20networking.	oleyfoundation@gmail.com

OMSLife Foundation	https://omslifefoundation.org/	info@omslifefoundation.org
One Rare - Serving young adults with rare and chronic conditions	https://onerare.org/	Info@OneRare.org
Organic Acidemia Association	https://www.oaanews.org/	same contact email as the executive director email: mkstagni@gmail.com
Orphan Disease Center	https://www.orphandiseasecenter.med.upenn.edu/	https://www.orphandiseasecenter.med.upenn.edu/contact-us
Osteogenesis Imperfecta Foundation	https://oif.org/	bonelink@oif.org
Osteopetrosis Society	http://www.osteopetrosis.org/	osteopetrosispatient@gmail.com
Ostomy 2-1-1 Inc. - Ostomy, Short Gut, Short Bowel	https://www.ostomy211.org/	ostomy211@gmail.com
Our Odyssey	https://ourodyssey.org/	info@ourodyssey.org
Oxalosis and Hyperoxaluria Foundation	https://www.ohf.org/ohf-home	info@ohf.org
Pachyonychia Congenita Project	https://www.pachyonychia.org/	info@pachyonychia.org
Pancreatic Cancer Action Network	https://www.pancan.org/	info@pancan.org

PANDAS Network.org	https://pandasnetwork.org/	pandasnetwork@gmail.com
Parent Project Muscular Dystrophy	https://www.parentprojectmd.org/	info@parentprojectmd.org
Parents of Infants and Children with Kernicterus (PICK)	https://pic-k.org/	pickorg@gmail.com
Pathways for Rare and Orphan Studies (PROS)	https://prosfoundation.org/	https://prosfoundation.org/#
Patient Advocate Foundation - General Support Organization	https://www.patientadvocate.org/	help@patientadvocate.org
Patient AirLift Services (PALS)	https://palservices.org/	info@palservices.org
PBCers Organization	https://pbcers.org/	pbcers@pbcers.org
PCD Foundation	https://pcdfoundation.org/	info@pcdfoundation.org
PCDH19 Alliance	https://www.pcdh19info.org/	On the contact form https://www.pcdh19info.org/contact they offer julie@pcdh19info.org (Julie Walters | President & Co-Founder)
Pediatric Brain Foundation	https://pediatricbrainfoundation.org/	info@pediatricbrainfoundation.org
Pediatric Hydrocep	http://www.hydrocephaluskids.org/wordpress/	mike@hydrocephaluskids.org

halus Foundation		
Pericarditis Alliance - Pericarditis Alliance	https://pericarditisalliance.org/	info@pericarditisalliance.org
Peripheral Nerve Society	https://www.pnsociety.com/i4a/pages/index.cfm?pageid=1	info@PNSociety.com
Perthes Kids Foundation	http://www.pertheskids.org/	http://www.pertheskids.org/contact
PHACE Syndrome Community	https://www.phacesyndromecommunity.org/	info@phacesyndromecommunity.org
Phelan-McDermid Syndrome Foundation	https://pmsf.org/	info@pmsf.org
Pheo Para Project â€“ Pheochromocytoma & Paraganglioma	https://pheopara.org/	info@pheopara.org
Pitt Hopkins Research Foundation	https://pitthopkins.org/	information@pitthopkins.org
Pituitary Network Association	https://pituitary.org/	info@pituitary.org
PKD Foundation	https://pkdcure.org/	pkdcure@pkdcure.org
PKS Kids	https://www.pkskids.net/	info@pkskids.com

Plan for Rare Foundation	http://plan4rare.org/	info@plan4rare.org
Platelet Disorder Support Association	https://www.pdsa.org/	pdsa@pdsa.org
PMG Awareness Organization, Inc.	https://pmgawareness.org/	information@pmgawareness.org
PMP Pals Network - Pseudomyxoma Peritonei	https://pmppals.net/	info@pmppals.net
Pompe Alliance - Pompe Disease	https://www.pompealliance.com/	pompealliance@gmail.com
Pompe Warrior Foundation - Pompe Disease	https://www.pompewarriorfoundation.com/	info@pompewarriorfoundation.com
Potocki-Lupski Syndrome Outreach Foundation, Inc	https://ptlsfoundation.org/	info@PTLSFoundation.org
Prader-Willi California Foundation â€“ Prader-Willi Syndrome	https://pwcf.org/	info@pwcf.org
Prader-Willi Syndrome Association (USA)	https://www.pwsausa.org/	info@pwsausa.org

PRISMS (Parents & Researchers Interested in Smith-Magenis Syndrome)	https://www.prisms.org/	info@prisms.org
Progeria Research Foundation	https://www.progeriaresearch.org/	info@progeriaresearch.org
Progressive Familial Intrahepatic Cholestasis Advocacy and Resource Network, Inc.	https://www.pfic.org/	emily@pfic.org
Project Alive - Hunter Syndrome or Mucopolysaccharidosis/MPS II	https://projectalive.org/	give@projectalive.org
PRP Alliance â€“ Pityriasis Rubra Pilaris	https://prpalliance.com/	https://prpalliance.com/contact/
PSC Partners Seeking a Cure	https://pscpartners.org/	contactus@pscpartners.org
PTEN Hamartoma Tumor Syndrome	https://ptenfoundation.org/	ptensyndromefoundation@gmail.com

Foundation		
PTen World â€“ Cowdenâ€™s Syndrome	https://www.ptenworld.com/	https://www.ptenworld.com/contactus.htm (link to contact form)
Pulmonary Alveolar Proteinosis Foundation, Inc.	https://www.papfoundation.org/	info@papfoundation.org
Pulmonary Fibrosis Foundation	https://www.pulmonaryfibrosis.org/	info@pulmonaryfibrosis.org
Pulmonary Hypertension Association	https://phassociation.org/	PHA@PHAssociation.org
PURA Syndrome Foundation	https://www.purasyndrome.org/	families@pura-syndrome.org appears to be the most generic e-mail listed.
Putting Rare Diseases Patients First! - All Rare Diseases	https://www.puttingrarediseasespatientsfirst.org/	lspeid@prdpf.org
Rare & Undiagnosed Network	https://rareundiagnosed.org/	https://rareundiagnosed.org/contact-us/
Rare Cancer Research Foundation	https://rarecancer.org/	requests@rcrf.org
Rare disease Innovations Institute -	https://rdii.org/	N/A

Multiple Rare Diseases		
Rare Genomics Institute	https://www.raregenomics.org/	contact@raregenomics.org
Rare Kids Network	https://www.rarekidsnetwork.org/	info@rarekidsnetwork.org.
Rare New England	https://www.rarenewengland.org/	Info@rarenewengland.org
Rare Science	https://www.rarescience.org/	info@rarescience.org
Rare Village Foundation - General Support Organization for several rare disorders	https://rarevillage.org/	info@rarevillage.org
Rare-X - General Support Organization	https://rare-x.org/	https://rare-x.org/connect/
RareKC	https://rarekc.org/	info@rarekc.org
RASopathies Network USA	https://rasopathiesnet.org/	info@rasopathiesnet.org
Raymond A. Wood Foundation - Hypothalamic-Pituitary Brain Tumor Survivors	https://www.rawoodfoundation.org/contact	info@rawoodfoundation.org
Recurrent Meningitis Association	https://recurrentmeningitis.org/	contact@recurrentmeningitis.org
Recurrent	https://rrpf.org/	bills@rrpf.org

Respiratory Papillomatosis Foundation		
Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)	https://rsds.org/	info@rsds.org
Relapsing Polychondritis Awareness and Support Foundation	https://polychondritis.org/	admin@polychondritis.org
Remember The Girls	https://www.rememberthegirls.org/	info@rememberthegirls.org
Rett Syndrome Research Trust	https://reverserett.org/	They have Contact forms for joining or donating. Here is the link to the Join site: https://reverserett.org/join/
Rhode Island Ehlers Danlos Syndrome Awareness and Support Group	https://www.ehlers-danlos.com/	N/A
Ring 14 USA	https://ring14usa.com/	info@ring14usa.org
Rothmund-Thomson Syndrome Foundation	Rothmund-Thomson Syndrome Foundationhttps://www.rtsplace.org	support@rtsplace.org

RUNX1 Research Program - RUNX1-Familial Platelet Disorder	https://www.runx1-fpd.org/	info@runx1-fpd.org
Ryan Wersten MIOP Foundation	https://www.curemiop.org/	miopfoundation@gmail.com
RYR-1 Foundation	https://www.ryr1.org/	lindsay@ryr1.org
Salla Treatment and Research Foundation	https://www.sallaresearch.org/	info@sallaresearch.org
Sam Day Foundation	https://samdayfoundation.org/	info@samdayfoundation.org
Sanford Research	https://research.sanfordhealth.org	no mailing address given but contact form i available to submit on the web
Saraâ€™s Cure	https://sarascure.org/	info@sarascure.org
Sarcoma Foundation of America	https://www.curesarcoma.org/	info@curesarcoma.org
SATB2 Gene Foundation	https://satb2gene.org/	https://satb2gene.org/contact/
Save Sight Now - Usher Syndrome Type 1B	https://www.savesightnow.org/our-mission	N/A
SCAD Alliance	https://scadalliance.org/	info@SCADalliance.org
Scleroderma Foundation	scleroderma.org	sfinfo@scleroderma.org
Scleroderma	https://srfcure.org/	info@srfcure.org

Research Foundation		
SETBP1 Society	https://www.setbp1.org/	info@setbp1.org
Severe Combined Immune Deficiency (SCID) Angels for Life Foundation	http://www.scidangelsforlife.com/	heather@scidangelsforlife.com
Shwachman-Diamond Syndrome Alliance - Shwachman-Diamond Syndrome	https://www.sdsalliance.org/adult-sds-patients	connect@SDSAlliance.org
Shwachman-Diamond Syndrome Foundation	https://shwachman-diamond.org/	info@shwachman-diamond.org
Sick Cells	https://sickcells.org/	info@sickcells.org
Sickle Cell 101	https://www.sc101.org/	hello@sc101.org
Sickle Cell Association of Houston, Inc.	https://www.sicklecellhouston.org	care@sicklecellhouston.org sicklecellhouston@gmail.com
Sickle Cell Association of Texas Marc Thomas Foundation	https://www.sicklecelltx.org/	info@sicklecelltx.org

Sickle Cell Consortium	https://sicklecellconsortium.org/	info@sicklecellconsortium.org
Sickle Cell Disease Association of America, Inc.	https://www.sicklecelldisease.org/	info@sicklecelldisease.org, scdaa@sicklecelldisease.org
Siegel Rare Neuroimmune Association	https://wearesrna.org/	info@wearesrna.org
Sing Me a Story - General Support	https://singmeastory.org/	https://singmeastory.org/contact
Sisters' Hope Foundation - Adult Onset Leukoencephalopathy with Axonal Spheroids and Pigmented Glia	https://sistershopefoundation.com/	sistershopefoundation@outlook.com
SjÃ¶gren's Foundation	https://www.sjogrens.org/	info@sjogrens.org
SLC6A1 Connect	https://slc6a1connect.org/	afreed@SLC6A1Connect.org
SMC1A Foundation - SMC1A Loss-of-function Epilepsy	https://smc1a-epilepsy.org/	info@smc1a-epilepsy.org
Smith-Kingsmore Syndrome	https://smithkingsmore.org/	contact@smithkingsmore.org.

Foundation		
Smith-Lemli-Opitz/Rsh Foundation	https://www.smithlemliopitz.org/	noahfamily@outlook.com
SMS Research Foundation	https://www.smsresearchfoundation.org/contact-us/	info@smsresearchfoundation.org
Snyder-Robinson Foundation	https://snyder-robinson.org/	info@snyder-robinson.org
Sofia Sees Hope	https://sofiasees.org/	info@sofiaseeshope.org
Soft Bones, Inc.: The US Hypophosphatasia Foundation	https://softbones.org/	info@softbones.org
Sophies Hope Foundation Inc - Glycogen Storage Disease Type 1b	https://sophieshopefoundation.org/	jamas.sophieshopefoundation@gmail.com
Spastic Paraplegia Foundation	https://sp-foundation.org/	information@sp-foundation.org
SPG15 Research Foundation - SPG15	https://www.spg15researchfoundation.org/	spg15researchfoundation@gmail.com
Spina Bifida Association	https://www.spinabifidaassociation.org/	sbaa@sbaa.org
Spinal CSF Leak	https://spinalcsfleak.org/	staff@spinalcsfleak.org

Foundation		
SSADH Association (Succinic Semialdehyde Dehydrogenase Deficiency)	https://www.ssadh.net/	ssadh@ssadh.net
St. Josephâ€™s Childrenâ€™s Hospital, New Jersey - Multiple Rare Diseases	https://stjosephshealth.org	contact form given in web
Stone Soup Group - All Rare Diseases	https://www.stonesoupgroup.org/resources/family-resource-guide/disability-specific/rare-disease-resources/	info@stonesoupgroup.org
Stop ALD Foundation	http://www.stopald.org/	info@stopald.org
Stronger Than Sarcoidosis - Sarcoidosis	https://www.strongerthansarcoidosis.org/	Info@strongerthansarcoidosis.org
STXBP1 Foundation	https://www.stxbp1disorders.org/	info@stxbp1disorders.org
Sudden Unexplained Death In Childhood (SUDC) Foundation	https://sudc.org/	info@sudc.org
Super Kids:	https://www.superkidsmissionzero.org/	contact@superkidsmissionzero.org

Mission Zero Inc.		
Super Tâ€™s Mast Cell Foundation	https://supertmastcell.org/	supertsmcfoundation@gmail.com
Superficial Siderosis Research Alliance, Inc.	https://ssra.livingwithss.com	info@ssra.livingwithss.com
Support Organization for Trisomy 18, 13 & Related Diseases	https://trisomy.org/new-here/	Contact form: https://trisomy.org/contact/
Supporters of Families with Sickle Cell Disease, Inc.	Supporters of Families with Sickle Cell Diseasehttps://sicklecelloklahoma.org	swithsicklecell@att.net
Supporting Families with Koolen-deVries Syndrome	https://kdvsfoundation.org/	ashley@kdvsfoundation.org
Sweet Nectar Society	https://sweetnectarsociety.org/	info@sweetnectarsociety.org
SynGap Research Fund - SynGap	https://www.syngapresearchfund.org/	Info@SyngapResearchFund.org
Systemic JIA Foundation	https://www.systemicjia.org/	info@systemicjia.org
TANGO2 Research Foundation	https://tango2research.org/	info@tango2research.org
TargetCancer	https://www.targetcancerfoundation.org/	info@targetcancerfoundation.org

Foundation		
Tarlov Cyst Disease Foundation	https://www.tarlovcystfoundation.org	retahoneyhiers@tarlovcystfoundation.org
Tatton Brown Rahman Syndrome Community	https://tbrsyndrome.org	tbrsyndrome@gmail.com
Taylorâ€™s Tale	https://taylorstale.org	laura@taylorstale.org
Team Impact	https://www.teamimpact.org/	info@teamimpact.org
Team Joseph - Duchenne	https://www.teamjoseph.org/	info@teamjoseph.org
Team Telomere, Inc.	https://teamtelomere.org/	info@teamtelomere.org
Team Titin	https://titinmyopathy.com/	curemyopathy@gmail.com
Tess Research Foundation	https://www.tessresearch.org/	https://www.tessresearch.org/contact-us/. There is a contact form.
The 22q Family Foundation â€“ 22q11.2 deletion, DiGeorge Syndrome, VCFS	https://22qfamilyfoundation.org	info@22qfamilyfoundation.org
The Akari Foundation - Duchenne Muscular Dystrophy	https://theakarifoundation.org/home/	Info@TheAkarifoundation.org
The APS Type 1	https://apstype1.org/	https://apstype1.org/about-us/contact-us/

Foundation		
The ARM Foundation - The ARM Foundation	https://www.thearmfoundation.org/	https://www.thearmfoundation.org/contact This is the link to the contact form. They also have this email: info@thearmfoundation.org
The Avalon Foundation	https://kidscaringforkids.org/how-to-help/	team@kidscaringforkids.org
The Bonnell Foundation: Living with Cystic Fibrosis	https://thebonnellfoundation.org/	thebonnellfoundation@gmail.com
The Boston International Turner Syndrome Summit - Turner Syndrome	http://bitssummit.org/pages/contact.html	info@bitssummit.org; â€Žinfo@bitssummit.org; â€Ž
The Bow Foundation	https://gnao1.org/	can contact by submitting a form
The Brain Recovery Project	https://www.brainrecoveryproject.org/	info@brainrecoveryproject.org
The Burning Limb Foundation	https://burninglimb.com/	philip@burninglimb.com
The Calliope Joy Foundation	https://www.thecalliopejoyfoundation.org/	info@thecalliopejoyfoundation.org
The Champ Foundation	https://www.thechampfoundation.org/	contact@thechampfoundation.org
The CHARGE	https://www.chargesyndrome.org/	info@chargesyndrome.org

Syndrome Foundation		
The Charles E. Holman Morgellons Disease Foundation	https://thecehf.org/	events@thecehf.org
The Chromosome 18 Registry & Research Society	https://www.chromosome18.org/	office@chromosome18.org
The Cilly Cell Project	https://www.totallyhealednetwork.org/	totallyhealed17@gmail.com
The Coalition Against Pediatric Pain	https://tcapp.org/	INFO@TCAPP.ORG or contact page https://tcapp.org/contact-us/
The Conley Cushingâ€™s Disease Fund	https://www.kickcushings.com/	info@kickcushings.com
The COPD Foundation	https://www.copdfoundation.org/	info@copdfoundation.org
The Cure Tay-Sachs Foundation	http://curetay-sachs.org	Only contact listed is for donation: Rick.Karl@curetay-sachs.org
The Dent Disease Foundation - Dent Disease	https://dentdisease.org	N/A
The DRESS Syndrome Foundati	https://www.dresssyndromefoundation.org/	Info@dresssyndromefoundation.org

on - Drug Reaction with Eosinophilia and Systemic Symptoms		
The E.WE Foundation	https://theewefoundation.org/	info@theewefoundation.org
The Ehlers-Danlos Society	https://www.ehlers-danlos.com/	info@ehlers-danlos.com or: https://www.ehlers-danlos.com/about-us/contact-us/
The FAVA Foundation	https://www.projectfava.org/	hello@projectfava.org and contact page https://www.projectfava.org/contact-us-1
The FD/MAS Alliance	https://fdmasalliance.org/	info@fibrousdysplasia.org
The Genesis Foundation for Children	https://thegenesisfoundation.org/	office@thegenfound.org
The Global Foundation for Peroxisomal Disorders	https://www.thegfpd.org/	contactus@thegfpd.org and operations@thegfpd.org
The Jansenâ€™s Foundation	https://www.thejansensfoundation.org/	info@thejansensfoundation.org
The LAM Foundation	https://www.thelamfoundation.org/	info@thelamfoundation.org
The Mast Cell Disease Society, Inc.	https://tmsforacure.org/	info@tmsforacure.org
The Menkes Foundation -	https://themenkesfoundation.org/	info@themenkesfoundation.org

General Support Organization		
The Multiple System Atrophy Coalition, Inc.	https://www.multiplesystematrophy.org/	info@multiplesystematrophy.org
The Network of Tyrosinemia Advocates	https://notacares.org/	https://notacares.org/contact/
The Rare Genomes Project at the Broad Institute of MIT and Harvard	https://raregenomes.org/	raregenomes@broadinstitute.org
The Ryan Foundation	http://ryanfoundation.org/home	markdant@outlook.com
The Sickle Cell Foundation of Tennessee - Sickle Cell	https://www.sicklecelltn.org/	officetn@sicklecelltn.org
The Snow Foundation	https://thesnowfoundation.org/	stephanie@thesnowfoundation.org
The Snyder-Robinson Foundation	https://snyder-robinson.org/	info@snyder-robinson.org membership@snyder-robinson.org
The Speak Foundation	https://thespeakfoundation.com/	jessica@thespeakfoundation.com
The Stiff Person Syndrome Research	https://stiffperson.org/	info@stiffperson.org

Foundation		
The Sturge-Weber Foundation	https://sturge-weber.org/	swf@sturge-weber.org
The Sumaira Foundation for NMO	https://www.sumairafoundation.org/	info@sumairafoundation.org
The TBCK Foundation	https://tbckfoundation.com/	tbckfoundation@gmail.com
The Vision of Children Foundation	https://www.visionofchildren.org/	info@visionofchildren.org
The WeHeal Foundation	https://weheal.org/	info@weheal.org
The Wiedemann-Steiner Syndrome Foundation	http://www.wssfoundation.org/	info@wssfoundation.org
The Yaya Foundation for 4H Leukodystrophy	https://yayafoundation4hl.org/	info@yayafoundation4hl.org
ThinkGenetic Foundation	https://thinkgenetic.org/	info@thinkgenetic.org
Thisbe and Noah Scott Foundation	https://thisbeandnoah.org/	lballew@thisbeandnoah.org
TNA â€“ The Facial Pain Association	https://www.facepain.org/	info@tna-support.org

Translational Genomics Research Institute	https://www.tgen.org/	<https://www.tgen.org/contact-us/>
Translational Pulmonary and Immunology Research Center	https://www.tpirc.org/tpirc-pipeline	info@tpirc.org
Transplant Unwrapped	https://www.transplantunwrapped.org/	info@transplantunwrapped.org
Trisomy 18 Foundation	https://www.trisomy18.org/	No email, just Office location, phone number, and executive director email
TUBB3 Foundation	https://tubb3foundation.org/	TUBB3Foundation@hotmail.com
Turner Syndrome Global Alliance	http://tsgalliance.org/	TSGA@TSGAlliance.org
Turner Syndrome Society of the United States	https://www.turnersyndrome.org/	Info@turnersyndrome.org
Tylerâ€™s Hope for a Dystonia Cure	http://www.tylershope.org/	info@tylershope.org
Tyrosinemia Society, Inc.	https://www.tyrosinemia.org/	https://www.tyrosinemia.org/contact-us
U.R. Our Hope	https://urourhope.org/	mary@urourhope.org
United Leukodystrophy Foundation	https://ulf.org/	office@ulf.org

United Mitochondrial Disease Foundation	https://www.umdf.org/	info@umdf.org
United MSD Foundation	https://curemsd.org/	info@curemsd.org
Uplifting Athletes - Umbrella Organization	https://www.upliftingathletes.org/	info@upliftingathletes.org
Usher 1F Collaborative, Inc	https://www.usher1f.org/	info@usher1f.org
Usher Syndrome Coalition	https://www.usher-syndrome.org/	info@usher-syndrome.org
USP7 Families	https://www.usp7.org/	admin@usp7.org
Utah Food Allergy Network	https://utahfoodallergy.org/	support@utahfoodallergy.org
Utah Rare	https://rareaction.org/resources-for-advocates/state-profiles/utah/	justine.case@rareaction.org
Vasculitis Foundation	https://www.vasculitisfoundation.org/	vf@vasculitisfoundation.org
Vestibular Disorders Association (VEDA)	https://vestibular.org/	info@vestibular.org
VHL Alliance	https://www.vhl.org/	info@vhl.org
Vincent Gaynor & Sophiaâ€™s Cure Foundation	http://sophiascure.org, https://www.linkedin.com/company/the-sophia's-cure-foundation/about/	https://www.linkedin.com/in/vincent-gaynor-55347214/#
Wake Up Narcolepsy	https://www.wakeupnarcolepsy.org/	info@wakeupnarcolepsy.org

White Sutton Syndrome Foundation	https://whitesutton.org/	contact@whitesutton.org
William E Proudford Sickle Cell Fund	https://wepsicklecell.org/	info@wepsicklecell.org
Williams Syndrome Association	https://williams-syndrome.org/	info@williams-syndrome.org
Wilson Disease Association	https://www.wilsonsdisease.org/	info@wilsonsdisease.org
Wiskott Aldrich Foundation	http://www.wiskott.org/	info@wiskott.org and they also have a contact form: http://www.wiskott.org/stay-connected/contact-us
Wobbly Feet Foundation	http://wobblyfeet0.us/	info@wobblyfeet.org and they also have a contact form: http://wobblyfeet0.us/contact-us/
Worldwide Syringomyelia & Chiari Task Force, Inc.	https://www.wstfcure.org/	wstfcure@wstfcure.org
Wylder Nation	https://wyldernation.org/	info@wyldernation.org
Xia-Gibbs Society	https://xia-gibbs.org/	gwilkinson@xgsociety.org
XLH Network Inc.	https://xlhnetwork.org	info@xlhnetwork.org
XP Family Support Group	https://xpfamilysupport.org	contact@xpfamilysupport.org
Yellow Brick Road Project	https://yellowbrickroadproject.org/	projectybr@gmail.com

Zoeâ€™s Story	https://zoestory.org/	info@zoestory.org

RARE DISEASE COMMUNITY RESOURCES:

1 of 20 Podcast • A podcast on Spotify for Podcasters: Jonathan Cappiello was diagnosed with a rare genetic disorder that only 20 people in the world have. The condition is called 3 hydroxyacyl coa synthase deficiency, which in short compromises his immune system and his body cannot process fats. Each week, he will discuss his lifestyle, his diet, and how he adapted to his condition. Additionally, he has a variety of guests to talk about their conditions. If you're interested in genetics, rare disorders, medicine, and healthy living-- this is the podcast for you!

24 Hours of Rare: 24 Hours of Rare is the only virtual event that celebrates the global rare disease community with content programmed by the rare disease community.

Adira Foundation: With a collaborative network of cross-disciplinary care and resources, we can finally help ease the burdens faced by people living with these complex health conditions. By working together, we can make it easier for people to navigate systems, grow our understanding of neurodegenerative disease and make real change.

Alliance for Genetic Etiologies in Neurodevelopmental | AGENDA: The mission of AGENDA is to improve outcomes for individuals with all forms of autism by fostering a genetics-first approach to autism and neurodevelopmental disorders research, and by strengthening collaborations among organizations representing genetically-defined disorders associated with neurodevelopmental disorders and autism.

Aware of Angels: Aware Of Angels advocates for children who have genetic, rare or undiagnosed disorders. An accurate and conclusive diagnosis for these children will not only give direction for proper treatments and improve their quality of life, but in some cases it may save their life. By sharing their stories and images, we are advocates for families to the medical and research fields, as well as connect families in similar situations.

BEING RARE PODCAST: conversations platform. We have intimate and sometimes difficult conversations about living with rare diseases, disability, medical complexities, and special health needs. Popular for our 1 minute episodes, Being Rare offers insight, perspective, and positive reinforcement. Join the conversation by following Being Rare wherever you listen to your podcasts!

Bens Friends: Ben's Friends is a network of safe and supportive patient communities for anyone affected by a rare disease or chronic condition. Recognized as a 501(c)(3) non-profit, Ben's Friends is a grassroots organization run by patients for patients. It is not a top-down, "expert advice" experience but a community offering peer to peer support. The value of this approach is evidenced by our hundred volunteer moderators, who are either patients themselves or relatives of patients, who believe in the mission and are willing to invest their time and share the knowledge and insights they have gained with members arriving daily in need of help.

Beyond The Diagnosis: The Beyond the Diagnosis art exhibit's focus is the rare disease patient. Artists have donated their time and talents to paint rare disease patients for this groundbreaking exhibit. Each portrait represents a single orphan disease. Our goal is to put a face to all 7,000 rare diseases. This beautiful exhibit is traveling to medical schools, research institutes and hospitals around the globe encouraging the medical community to look "beyond the diagnosis" to the patient.

CheckRare: learning platform for health care professionals and patients. Our platform allows users to gain insight and learn about rare diseases, current and emerging therapies, clinical trials, and the BioPharma companies behind them. There is no fee to register on CheckRare and all content is free of charge.

Child Neurology Foundation: To serve as a collaborative center of education, resources, and support for children and their families living with neurologic conditions and facilitate connection with medical professionals who care for them.

Complicated — Open Eye Pictures: COMPLICATED takes the viewer into the hidden world of children coping and trying to live their lives with rare, complex, and invisible illnesses, parents facing impossible choices to help them, and providers who dismiss them as "too complicated" or risk it all to save them.

CURE: The CURE brings together a community of extraordinary parents of children with undiagnosed, rare and complex medical conditions, to learn, share and support each other amidst their long journey.

Created by: Sierra Phillips @mrs.phillijt

CureUp: We first started CureUp because we saw there was a distinct lack of line support groups for certain health conditions. Since our start, we've created hundreds of online social communities dedicated towards providing those with medical conditions a place they can ask questions, get advice, and share their stories with others. Our health pages and support groups have enabled millions to learn more about their condition and provide a safe place for them to seek support from others living with the same condition. We partner with multiple non-profit organizations to provide them with resources such as our assistance cards, children's books, and more.

DEE-P Connections - DEE-P Information Resource Center: Bringing together families and advocacy partners to help children with DEEs live their best lives.

Disease InfoSearch: Disease InfoSearch is a consumer-facing directory of more than 10,000 diseases, with up-to-date information about current opportunities for research and support curated by advocacy organizations. InfoSearch also provides opportunities for you to connect with advocacy organizations, data registries, research opportunities, and clinical trials, and is a great place to learn more information about a specific disease or condition.

Easterseals Community and Disability Services: Easterseals is leading the way to full equity, inclusion, and access through life-changing disability and community services.

Family Support Program - Child Neurology Foundation: Your situation is unique, but it doesn't need to be isolating. Our Family Support Program was designed to offer you emotional and practical support from somebody who has lived through a similar experience.

Labeled and Loved: is to embrace and strengthen families with disabilities by providing connective experiences and educational resources igniting personal growth and systemic change within the community.

Little Hercules Foundation: Little Hercules Foundation works to improve the lives of those diagnosed with – and families facing – Duchenne Muscular Dystrophy through Advocacy, Awareness, Family Assistance and Funding Research.

Loving Luca Foundation, Inc.: To promote equality and inclusion for children with genetic disorders by providing support for families, inspiring change and funding research. We aim to provide love, hope and understanding for all unique children.

MDA & DMD Family Guide: This Family Guide will provide you with basic information to allow you to participate

Friendship Circle International: The Friendship Circle exists to bring happiness and companionship to children and young adults with special needs by celebrating their individuality, as well as bringing energy, support, and peace of mind to their families.

Global Network for Rare Diseases: The Global Network for Rare Disease (GNRD) is an initiative engaging and supporting the rare disease community to develop a person-centred global network of care and expertise for all Persons Living with a Rare Disease (PLWRD) worldwide.

Harmony 4 Hope : Welcome to Harmony 4 Hope! We are using music to fuel scientific discoveries in rare disease, educating medical students and uniting Rare Disease warriors!

Hope Knows No Boundaries: Hope Knows No Boundaries is a non-profit 501(c) dedicated to Educating patients to advocate for their medical needs, use their voice in their treatment, and create a team environment between the medical specialists, the patients, and the insurance companies.

Jeans for Genes: The Jeans for Genes campaign raises awareness of the daily challenges faced by those living with a genetic condition and raises money to fund projects that make a tangible difference to the lives of those affected.

Jordan's Guardian Angels: To conduct research seeking answers to rare genetic mutations affecting children and adults, and assist and improve the quality of life for children and families.

Know Rare: We want to empower you to know more about rare disease. Read the journeys of people who live every day with a rare disease, and learn about the new research and researchers working to create a better future.

effectively in the process of obtaining comprehensive care. Your NMS must be aware of all potential issues in Duchenne and must have access to the interventions that are the foundations for appropriate care and input from essential subspecialties

Megan Card Curator: Not everyone sees that someone has a rare condition. I believe it's genuinely about peeling back the layers like an onion. It comes to not only accepting the diagnosis and advocating, but especially when it comes to newborn screening. 1 in 7 people with 2q37 Deletion Syndrome like myself, is born with heart deformities, and must undergo heart surgery when they're born. I wasn't properly diagnosed until I was a teenager. This is also about breaking the stigma of "rare disease" and the stereotypes associated with disabilities. Not everyone knows about this reality, I am only one of about 1100 worldwide diagnosed with this condition. This leads me to use the support of faith, family, and friends to connect more with others in spreading awareness with The Onion Community. I am passionate about knocking down these "doors" that are barriers for 1 in 10 individuals living with rare diseases in the USA, and in communities worldwide.

Members & Partners | REN: The Rare Epilepsy Network is comprised of MEMBERS and PARTNERS. Use this page to find groups and organizations that support rare epilepsy.

Myles' Message: Myles' Message is a registered 501(c)3 nonprofit organization that empowers parents by providing accurate resources and a supportive community so that their child with Down syndrome may reach their fullest potential while celebrating each child's worth so they may thrive in a world without limits.

New England Regional Genetics Network: The New England Regional Genetics Network advances the health and well-being of individuals with or at risk for genetic conditions by improving access to genetic services, educating professionals to strengthen systems of genetic care, and supporting families in New England.

NIH Clinical Center: Search the Studies: The National Institutes of Health (NIH) Clinical Center Search the Studies site is a registry of publicly supported clinical studies conducted mostly in Bethesda, MD.

Love That Surpasses Ministries: A 501(c)3 partnering with the Lord to rebuild, restore hope, and bring healing to the disability community.

Once Upon A Gene- Rare Disease Podcast : mission is to learn, lift voices of the community, connect people to resources and to leave this world better than she found it for others in the rare disease world.

One Rare Adventure | One Rare: In 2023, One Rare has decided to pursue a long-weekend, adaptive camp. One Rare Adventure, which is intended to provide more outdoor recreation opportunities for this community. Programming for One Rare Adventure will focus on community, adaptive sports and physical recreation. Supportive programming will also be mixed in with a motivational keynote speaker and most importantly, time for peer-to peer networking and bonding through this shared experience.

Orphan Disease Center : Research and funding for orphan diseases is grossly unmet. ODC provides technological and educational resources, identifies funding opportunities, and fosters therapeutic development and innovative research.

Orphanet: Orphanet is a unique resource, gathering and improving knowledge on rare diseases to improve the diagnosis, care and treatment of patients with rare diseases. Orphanet aims to provide high-quality information on rare diseases and ensure equal access to knowledge for all stakeholders. Orphanet also maintains the Orphanet rare disease nomenclature (ORPHAcode), essential in improving the visibility of rare diseases in health and research information systems.

Our Odyssey: Our Odyssey's Mission: Connecting young adults impacted by a rare or chronic condition with social and emotional support in the hope of improving their quality of life.

Pathways To Trust Rare Disease: Pathways To Trust focuses on the needs of patients facing high hurdles to care. We know these biases can be eliminated once these patients' voices are part of the conversation. To make this happen, we provide disease-specific educational programs for medical students, healthcare providers and patients. Our content is developed by patients and patient advocates themselves, and incorporates the perspectives and contributions of multiple stakeholders so all members of the rare disease community can work together to deliver truly patient-centered care.

Patient Helpline Navigator: Patient Helpline Navigator program is an online and phone support service that is provided by a professional patient navigator that helps connect patients to the services they need.

Pediatric Rare Disease | Kids Rare Disease | Royal Oak - Defying Rare: To enrich the lives of children who have a rare disease or other pediatric disorder through our Golden Gifts program and by helping expand access to therapy and service animals for the patients we serve.

Peer Medical Foundation: A volunteer youth-led international not-for-profit organization advancing health equity, diversity, inclusivity & racial justice in medicine.

Project Sebastian: Our Mission statement is straightforward. Project Sebastian is a hub of information, education, and compassion. We will devote the time and energy necessary to educate, advocate, and provide support to fight all rare diseases. We also feel very strongly about connecting those in need that are suffering from all rare diseases. We will provide support groups for those wanting to discuss, share and connect with others going through the rare disease journey.

Rare And Black | Facebook: Our mission is to empower and amplify voices of Black people living with rare diseases.

Created by: Sierra Phillips @mrs.phillijt

Rare Collective: The Rare Collective partners with industry, patient organizations, and researchers to manage the development, commercialization, and adoption of innovative therapies and devices for rare disease communities.

Rare Disease Day: Raising awareness and generating change for the 300 million people worldwide living with a rare disease, their families and carers.

Rare Disease Male Support Group | Facebook

IndoUSrare: Our vision is to educate, empower and advocate for diverse patients with rare diseases in the US, India, and globally by building collaborative bridges between the western and eastern geographic silos for stakeholders of rare diseases to maximize diversity, equity, and inclusion in research and development for accelerating the development of diagnostics and therapies.

Rare Diseases Community Resources | National Center for Advancing Translational Sciences: NCATS offers free materials and resources to help patients, caregivers, patient support organizations, health care providers and scientists learn about rare diseases and help advance research on them. You can use the resources below on social media, on web pages, or at meetings, clinics and other places to raise awareness and to connect with the rare diseases community.

Rare Diseases International: RDI brings together national and regional rare disease patient organizations as well as international federations for specific diseases and multi-stakeholder groups.

Rare Epilepsy Network : The mission of Rare Epilepsy Network (REN) is to work with urgency to collaboratively improve outcomes of rare epilepsy patients and families by fostering patient-focused research and advocacy.

Rare In Common: The 2017 Emmy-nominated Rare in Common documentary gave people from the rare disease community an opportunity to tell their stories. Today, the storytelling has expanded to the world of audio with the Rare in Common podcast. Whether you watch or listen, prepare to be moved and inspired by those touched by rare disease.

Rare Life | Travere: Living with rare disease requires courage, strength, resilience, community—and, sometimes, even a little bit of humor. These are some of the people who inspire us to be In Rare for Life.

Rare New England: We are Rare New England, a nonprofit organization serving the rare disease community. Our mission is to bring together New England patients, families and providers touched by rare and complex disorders.

Patient Worthy: Patient Worthy® is an online publication that provides relevant information to rare disease patients, caregivers and advocates alike.

Rare Revolution Magazine: Rare Revolution is published by NRG Collective Ltd, a not-for-profit media company specializing in rare disease content.

RARE Youth Revolution: The RARE Youth Revolution is a dedicated news platform for young people to access relevant content centred around rare diseases.

RareAction Network: The RareAction Network®, powered by the National Organization for Rare Disorders (NORD), serves to connect and empower a unified network of individuals and organizations with tools, training and resources to become effective advocates for rare diseases through national and state-based initiatives across the United States. We stand for equitable access to timely diagnosis, treatment and care for every person impacted by a rare disease.

RareConnect: A safe, easy to use platform where rare disease patients, families and patient organizations can develop online communities and conversations across continents and languages. RareConnect partners with the world's leading rare disease patient groups to offer global online communities allowing people to connect around issues which affect them while living with a rare disease.

RAREisCommunity.com: #RAREisTM began as a social media campaign launched by Horizon Therapeutics to elevate the voices, faces and experiences of the rare disease community. It has since grown into a global program that provides individuals and families around the world with access to resources that connect, inform and educate as they navigate their daily lives.

RareWear: The RareWear program connects rare disease patients to medical device providers to offer free devices to help patients better monitor and manage their condition. RareWear is an ongoing program and patients are welcome to apply throughout the year.

Really Crappy Seizures Club (RCSC) - Google Groups: Informal list-serve for leaders of organizations to share resources and advice.

Relevant Resources - ConnectMed International: One of our most pressing goals is to help support and bring together the communities of patients with congenital and acquired differences and their families. To that end, we have compiled the following resources which may be relevant to this community.

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Remember The Girls: Remember The Girls aims to break the stigma facing females impacted by X-linked conditions by providing them with tools to seek support, engage with research, and access family planning options, as well as by advocating for increased attention of medical professionals to the physical, emotional, and reproductive needs of this community.

Rise For Rare: The Black Women's Health Imperative launched the Rare Disease Diversity Coalition to address the extraordinary challenges faced by rare disease patients of color. The Coalition brings together rare disease experts, health, and diversity advocates, and industry leaders to identify and advocate for evidenced-based solutions to alleviate the disproportionate burden of rare diseases on communities of color.

Seizing Life Podcast – CURE Epilepsy: Seizing Life® is a CURE Epilepsy podcast and videocast aiming to inspire empathy, offer helpful stories, and give hope as we search for a cure for epilepsy. Listen as guests share stories and insights on living with and battling epilepsy.

SHER | Sociedad Hispana de Enfermedades Raras en USA: Ayudar a las organizaciones de pacientes a tener una comunicación asertiva con su comunidad de pacientes hispanohablantes. Promover la inclusión, equidad y conocimiento para las familias hispanas que padecen enfermedades raras a través de un portal de recursos en español.

SOFT - Support Organization For Trisomy: SOFT is a network of families and professionals dedicated to providing support and understanding to families involved in the issues and decisions surrounding the diagnosis and care in Trisomy 18, 13 and other related chromosomal disorders. Support can be provided during parental diagnosis, the child's life and after the child's passing. SOFT is committed to respect a family's personal decision and to the notion of parent-professional relationships.

some1likeyou: Our mission for S1LY is to privately connect people across symptoms and diagnoses to empower the individuals facing these complex challenges.

Strong & Rare Parenting • A podcast: Hi, Welcome to the Strong and Rare parenting podcast. My name is Victoria, and I am a special needs momma of two fun loving boys. In this podcast, we will speak about all things Autism, ADHD, and Rare Diseases. This podcast will bring awareness, acceptance, and knowledge on all things we want to learn as parents raising children with special and medical needs. When you join me, I hope that you will walk away with hope and be empowered to be a driver of change for our community.

Strong and Rare Parenting: On a mission to support the inclusion of neurodiversity and rare diseases worldwide.

The Community of Practice for Support Families of Individuals with Intellectual & Developmental Disabilities: The Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities exists to enhance and drive policy, practice, and system transformation to support people with intellectual/developmental disabilities within the context of their families and communities. Nineteen member states are committed to developing systems of support for families throughout the lifespan of people with intellectual and developmental disabilities (I/DD) and their family, and receive technical assistance, products, opportunities for shared learning, and support from a National Team to integrate innovative practices into existing and ongoing state systems change efforts.

The Disorder Collection: Now the rarest stories in the world stream to your living room TV, for free! We've collected films about the rare disease patient experience—stories of hope in the face of the longest odds. Available on Roku and Firetv.

The Garner Foundation: We hope to help those in need in ways that myself and Garner needed. Rare diseases don't have to be fought alone when we can fight together. Support of familial and child resilience, fostering community connections, introduction and promotion of reputable clinical research, and mental health advocacy are the goals of our organization.

The Haystack Project: Haystack Project is a non-profit enabling rare and ultra-rare disease patient advocacy organizations to highlight and address systemic obstacles to patient access. Our core mission is to evolve health care payment and delivery systems to make innovative quality treatments accessible to the patients they were meant to reach.

The Mighty. Making health about people.: The Mighty is a growing community of people with lived experience sharing their honest stories. We help people connect with others around mental health, chronic illness, rare disease, disability, and more.

The More Than Project | Facebook: co-founded in 2021 by Kate Swenson and Amanda DeLuca. With both women being special needs mothers, they understood the stress, exhaustion, and struggle that comes with special needs caregiving and wanted to serve others with the support they wish they had years ago. As time went on, they recognized that supporting the caregiver was important but wanted to explore avenues to support the special needs family unit as a whole. This inspired the More Than Project as the overseeing

The Rare Fair: Launched in 2018 as a 100% virtual event, The Rare Fair was the original virtual event for the global rare disease community, seeking to connect rare disease patients, families, and other stakeholders across the globe.

ThinkGenetic Foundation: The ThinkGenetic Foundation is an IRS registered Sec. 501(C) (3) organization and is governed by a Board of Directors specializing in genetic conditions. The foundation was founded by Dave Jacob and a team of nationally renowned genetics healthcare professionals he recruited to the board of directors. Dave hand-picked a board with a shared passion for directly helping patients and families living with or at risk of having genetic conditions get reliable information and access to important real-life resources, including genetic counselors and diagnostic testing.

U.R. Our Hope: U.R. Our Hope is a registered 501 (c)(3) non-profit organization that assists individuals and their families on their journey to diagnosis,or helps them navigate the healthcare system with a rare diagnosis. Our mission is to serve individuals with undiagnosed and rare disorders through education, advocacy, and support in order to bring hope through knowledge, empowerment, and healing. We assist families in the Austin area, and throughout Texas, the United States and beyond.

UMDF | Mitochondrial Disease Education & Research: Promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.

UN Resolution on Persons Living with a Rare Disease: Recognizing the need to promote and protect the human rights of all persons, including the estimated 300 million Persons Living with a Rare Disease worldwide. The Resolution was adopted by all 193 UN Member States and is the first UN document to recognize the specific challenges of Persons Living with a Rare Disease (PLWRD) and their families.

Unique | Understanding Rare Chromosome and Gene Disorders: Unique supports and informs families affected by rare chromosome and gene disorders and the professionals working with them. It's free to join and become part of our supportive community.

Upopolis: Powered by TELUS, Upopolis is a free, fun, and secure online community that connects youth 10 to 18 with others like them who are going through medical experiences or stressful life events in North America. Upopolis reduces social isolation while educating and empowering youth to play an active role in managing and coping with their diagnosis, condition, or situation.

Verity's Village: Carrying a baby with a life-limiting diagnosis is not easy, and neither is raising a child with special needs. It truly does take a village to support families with a life-limiting diagnosis for their babies. If you or someone you love has received a prenatal diagnosis, we would love to be part of your village! Reach out and let us know how we can help you. We have a free welcome package so that you can have practical resources right at your fingertips.

WAWOS: WAWOS is committed to supporting and celebrating children with Cerebral Palsy and related neuromuscular delays through the application of design and technology. Through financial, clinical and social support for impacted children and their families, our organization strives to enable participation of all people, regardless of ability, in the community at large.

Young Adult Rare Representatives: Young Adult Rare Representatives (YARR) are highly motivated rare disease community members between 16 and 30 years old. The main purpose of YARR is to instill confidence in the next generation of rare disease advocates. We want to ensure that young adults have a growing, diverse impact on public policy in the rare space and offer skill-building opportunities to foster growth in each individual's advocacy journey.

CLINICAL TRIAL RESOURCES:

ASGCT | Clinical Trial Finder: Welcome to the ASGCT Clinical Trials Finder, a curated list of gene and cell therapy clinical trials. Clinical trial data is updated daily, and eligible trials are sourced from clinicaltrials.gov.

ASGCT | Clinical Trials Process: Clinical trials research the way a drug or treatment will interact with the human body. There are currently thousands of different gene and cell therapies being studied in clinical trials in hopes there could be a potential treatment for diseases that have little to no

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other treatment. Learn more about preclinical studies, the phases of a clinical trial, how to find a clinical trial, and FDA efforts to make the process faster.

ASGCT | Understanding a Clinical Trial Listing: The ASGCT Clinical Trials Finder is an excellent resource and is updated daily to be a user-friendly, searchable database to find all active and recruiting trials for gene and cell therapies internationally. However, if it is your first time navigating the database, you may want to know what specific information is provided and why it is relevant.

CenterWatch: CenterWatch delivers critical industry insights to 150,000 life science executives every week through its newsletters, conferences, webinars, books, in-depth market surveys, industry profiles and clinical databases.

CheckRare: learning platform for health care professionals and patients. Our platform allows users to gain insight and learn about rare diseases, current and emerging therapies, clinical trials, and the BioPharma companies behind them. Our peer-to-peer content is a trusted source for education and industry-related content. We are a trusted, strategic partner with all major organizations in the global network of rare disease advisors and advocates. There is no fee to register on CheckRare and all content is free of charge.

Children & Clinical Studies: supports the importance of children in clinical research.

Clinical Center Home Page: The National Institutes of Health Clinical Center, America's research hospital, is located on the NIH campus in Bethesda, Md. Through clinical research, clinician-investigators translate laboratory discoveries into better treatments, therapies and interventions to improve the nation's health.

Clinical Trials Information for Patients and Caregivers | NCI: Clinical trials are research studies that involve people. Any time you or a loved one need treatment for cancer, clinical trials are an option to think about. Learning all you can about clinical trials can help you talk with your doctor and decide what is right for you.

ClinicalTrials.gov | Glossary of Common Site Terms: This glossary will help you understand words and phrases frequently used on ClinicalTrials.gov. Many of these words are also used by clinical researchers and others in the same or a similar manner. But the definitions below are provided to explain content on ClinicalTrials.gov only.

ClinicalTrials.gov | How to Search: Learn how to use ClinicalTrials.gov search features to find studies.

ClinicalTrials.gov: ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world.

CPN | Evaluating the Clinical Trial Option: Visit the Clinical Trials Guided Pathway, created by the Courageous Parents Network, to continue learning more about the clinical trials process through this step-by-step curriculum for parents.

CPN | Understanding Clinical Trial Terms: Terms related to clinical trials are fairly standard across trials, but you should always discuss with medical providers or research coordinators how each term relates to the study you are considering for your child.

Cure Rare Disease: Through collaborations with world-renowned academics and clinicians, we are moving science forward to develop life-saving gene therapies for rare and ultra-rare disease patients overlooked and underserved by traditional drug development efforts.

FDA | Clinical Trials: The Patient Experience: The FDA's Center for Biologics Evaluation and Research (CBER) Office of Therapeutic Products (OTP) hosted a public virtual workshop on Thursday, April 13, from 11:00 a.m. – 3:00 p.m. ET. The workshop, Clinical Trials: The Patient Experience, featured a panel of rare disease patients, caregivers, and advocates who shared their experiences with gene therapy clinical trials. Through participation in clinical trials, patients can help advance the science of gene therapy and further the development of rare disease treatments.

Find NHLBI Clinical Trials | NHLBI, NIH: The NHLBI leads or sponsors studies for patients who have heart, lung, blood, or sleep related diseases or disorders. Find studies for diseases and conditions and see if you or a loved one is eligible.

Genome.gov | Current Clinical Studies: Researchers at the National Human Genome Research Institute (NHGRI) are working with patients and families to better understand of how genes can cause or influence diseases and develop new and more effective diagnostics and treatments.

If Not for Me; If Not for Me is an uplifting story built on the journeys of families involved in four different clinical studies as they share their experiences. The objective of the film is to get the word out about the important role clinical studies play in improving treatments of childhood illnesses. The film reveals the emotional challenges the families depicted in the film face as they tell their stories. It also shares the role of others in the medical community who are committed to clinical trials for children.

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Information on Clinical Trials & Research Studies | NORD

InformedDNA: InformedDNA optimizes clinical decisions through impactful solutions leveraging the most current genomics expertise. We are the nation's leading applied genomics company, with the largest independent team of genetics specialists representing the full breadth of specialties and sub-specialties, and backed by more than 14 years of clinical data and financial proof of effectiveness.

Invitae Patient Insights Network: Patient Insights Networks, or PINs, amplify the voice of patients to help researchers and drug developers find better treatments, faster. Since 2007, we have built more than 80 PINs and inspired thousands of patients to join the movement to collect and share data as broadly as possible. PINs benefit patients. We believe that advances are made when data are shared and collected in a standardized way, and when patients are at the center.

Leapcure: We connect patients with clinical trials to make research more equitable and efficient with patient advocacy at the forefront. Patients are the experts in their condition and advocacy groups provide a platform for patient voices. Working directly with these communities is the key to pushing research forward in an inclusive way.

myTomorrows: Across the world there are major advances happening in drug development. However, innovation is only meaningful when there are ways to access it. Patients and physicians may not know about drugs being developed for specific medical conditions. Sometimes they may also not know how to get through the potentially complex process of accessing these drugs in development. myTomorrows can help. We are dedicated to helping patients discover and access all possible treatment options. By building new pathways together, we want to give more patients more tomorrows.

myTomorrows | Clinical Trials: All You Need To Know YouTube

myTomorrows | Understanding a Clinical Trial Listing

NCATS | PaVe-GT: The NCATS-led Platform Vector Gene Therapy (PaVe-GT) pilot project seeks to increase the efficiency of clinical trial startup by using the same gene delivery system and manufacturing methods for multiple rare disease gene therapies. We will make program results and regulatory documents publicly available, with the intention of benefiting future gene therapy clinical trials for very rare diseases.

PatientsLikeMe: We believe in the power of community to improve the lived experience of patients managing complex health conditions. Our purpose is to create a trusted digital platform that empowers patients to navigate their health journeys together through peer support, personalized health insights, tailored digital health services and patient-friendly clinical education.

StudyKIK: We believe that all patients should have the power to access the most advanced healthcare available. But we understand that getting started on the journey can be daunting. We're not only here to help you start, we'll be with you every step of the way.

Varient : Varient is free, private, and objective. We will provide the proof to pharma companies, researchers, and all those with an interest in developing treatments for rare disease patients, that there are real people and real numbers that need better medicines – or cures. For those of you who might want to be part of those clinical trials, we will connect you. We will never sell your data to insurance companies, or anyone else whose interests do not serve you. Your trust is everything.

RESEARCH RESOURCES:

1000 Genomes: The 1000 Genomes Project created a catalogue of common human genetic variation, using openly consented samples from people who declared themselves to be healthy. The reference data resources generated by the project remain heavily used by the biomedical science community. The International Genome Sample Resource (IGSR) maintains and shares the human genetic variation resources built by the 1000 Genomes Project. We also update the resources to the current reference assembly, add new data sets generated from the 1000 Genomes Project samples and add data from projects working with other openly consented samples.

Every Cure: Together, with partners in medicine, pharma, tech, and philanthropy, we are building out a comprehensive, open-source database of drug-repurposing opportunities. We are deeply passionate about uncovering repurposed drugs for patients who are suffering while there is a drug sitting at their neighborhood pharmacy, and want to scale drug repurposing to help each and every patient who may benefit by using an already existing drug.

Every Cure | ROADMAP: The Repurposing of All Drugs, Mapping All Paths (ROADMAP) project was spearheaded by the Castleman Disease Collaborative Network (CDCN) to create a resource that would provide guidance for rare disease organizations seeking to pursue drug repurposing, based on real world experiences. It's aim was to identify all the paths that can be taken to repurpose drugs, highlight the roles of various stakeholders, and centralize information on how to do this most effectively.

Accelerating Medicines Partnership® Bespoke Gene Therapy Consortium: The Accelerating Medicines Partnership® (AMP®) Program Bespoke Gene Therapy Consortium (AMP BGTC) is the first AMP project to focus on a therapeutic platform. AMP BGTC brings together partners from the public, private, and non-profit sectors to foster development of gene therapies intended to treat rare genetic diseases, which affect populations too small for viable commercial development.

PaVe-GT (nih.gov): The NCATS-led Platform Vector Gene Therapy (PaVe-GT) pilot project seeks to increase the efficiency of clinical trial startup by using the same gene delivery system and manufacturing methods for multiple rare disease gene therapies. We will make program results and regulatory documents publicly available, with the intention of benefiting future gene therapy clinical trials for very rare diseases.

Impact through Insights |TREND Community: We're a digital health analytics company that turns the conversations of rare, chronic, and emerging disease communities into actionable insights. Our partnerships support community members, health care providers, researchers, pharmaceutical sponsors, and regulatory agencies as we advance our mission to facilitate understanding, strengthen advocacy, and spark scientific progress. Our proprietary technology listens to the online conversations happening within underserved rare, chronic, and emerging disease communities and derives actionable insights for community stakeholders, medical teams, researchers, scientists, biotechs, pharmaceutical companies, and regulatory agencies. We learn through listening, and we spark progress through insight.

CGT Science Series | Advocacy | ASGCT - American Society of Gene & Cell Therapy | ASGCT - American Society of Gene & Cell Therapy: The Cell and Gene Therapy (CGT) Science Series is a quarterly seminar series focused on scientific topics related to cell and gene therapy products. The CGT Science Series is intended to foster scientific exchange between the Biotechnology Innovation Organization (BIO), ASGCT, and Center for Biologics Evaluation and Research (CBER) review staff on a variety of topics that span the CGT product lifecycle. The seminars are planned as 60-minute virtual webinars featuring a speaker from one of the three organizations. The CGT Science Series will enable a deep dive into a specific technical and/or scientific area. Topics in the series may include, but are not limited to, nonclinical, CMC, clinical, or post-market phases of development related to CGT product lifecycle.

IASSIDD – International Association for the Scientific Study of Intellectual and Developmental Disabilities: The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) is the first and only world-wide group dedicated to the scientific study of intellectual disability. Founded in 1964 as the International Association for the Scientific Study of Mental Deficiency, IASSIDD is an international, interdisciplinary and scientific non-governmental organization which promotes worldwide research and exchange of information on intellectual disabilities.

Advancing Genomic Medicine Research | AGMR: The AGMR program stimulates innovation and advance understanding of when, where and how best to implement the use of genomic information and technologies in clinical care.

AllStripes: As the leading research platform dedicated to rare diseases, AllStripes makes it easy for patients to contribute to new treatment research from home. We do the work to collect and analyze de-identified medical records to help power faster, better drug development.

Beacon Network: A global search engine for genetic mutations.

Blu Genes Foundation: The BLU GENES Foundation is raising funds to advance gene therapy and find a cure for genetic disorders, beginning with Tay-Sachs disease. We believe in offering hope where currently there is none.

Born a Hero: Our mission is to accelerate innovation and research to improve the quality of life for patients with FGFR Syndromes, including Pfeiffer Syndrome.

Center for Mendelian Genomics: The Center for Mendelian Genomics is a member of the GREGoR Consortium (Genomics Research to Elucidate the Genetics of Rare Disease) funded by the NHGRI (National Human Genome Research Institute), along with 5 other sites across the country. The central goals of the GREGoR consortium are: to discover variants and genes underlying Mendelian diseases; to collaboratively facilitate gene discovery, validation and follow up; and to generate new methods for improving diagnosis across a wide spectrum of rare disorders.

Centers for Common Disease Genomics: The Centers for Common Disease Genomics (CCDG) are a collaborative large-scale genome sequencing effort to comprehensively identify rare risk and protective variants contributing to multiple common disease phenotypes.

Centers for Mendelian Genomics: The National Human Genome Research Institute funded the Centers for Mendelian Genomics (CMG) in 2011 with the charge to discover as many genes underlying human Mendelian disorders as possible. In doing so, the CMGs will define the state-of-the-art study designs and methods to find the variants and genes underlying Mendelian disorders.

Centers of Excellence in Genomic Science | CEGS: The CEGS program supports multi-investigator, interdisciplinary research teams working together to address biomedical problems through development of integrated, transformative genomic approaches.

CheckRare: learning platform for health care professionals and patients. Our platform allows users to gain insight and learn about rare diseases, current and emerging therapies, clinical trials, and the BioPharma companies behind them. We are a trusted, strategic partner with all major organizations in the global network of rare disease advisors and advocates. There is no fee to register on CheckRare and all content is free of charge.

Childrens Rare Disease Organization: the organization hopes to promote research of rare children's diseases and fund research labs and organizations, both in the United States and abroad, that focus on rare children's diseases. Priority will be those challenging diseases with no underlying cause identified. Research progress in these kinds of diseases is extremely behind in the scientific field because of their complexity and unknown causes.

Ciitizen: Ciitizen is a free service that helps patients get more out of their health records. Our platform enables patients to find better treatment options and allows them the opportunity to advance the research for cures.

ClinGen: ClinGen is a National Institutes of Health (NIH)-funded resource dedicated to building a central resource that defines the clinical relevance of genes and variants for use in precision medicine and research.

ClinVar: ClinVar aggregates information about genomic variation and its relationship to human health.

COMBINEDBrain: The Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders is devoted to speeding the path to clinical treatments for people with severe rare genetic non-verbal neurodevelopmental disorders by pooling efforts, studies and data. We are a non-profit consortium led by patient advocacy foundations, working with the clinicians, researchers and pharmaceutical firms that are developing treatments for the disorders they represent.

Congenica: We are a digital health company enabling genomic medicine with the world leading Clinical Decision Support platform for clinical use for the rapid analysis and interpretation of genomic data.

Critical Path Institute | c-PATH: Critical Path Institute (C-Path) is an independent nonprofit, public-private partnership with the U.S. Food and Drug Administration (FDA) created under the auspices of the FDA's Critical Path Initiative program in 2005. C-Path is dedicated to improving and streamlining the process of medical product development. We achieve tangible, actionable results by fostering collaboration between industry executives and scientists, academic researchers, regulators and patient groups. Since its founding, C-Path has been unique in its ability to develop actionable solutions through open, precompetitive collaboration.

CURE Epilepsy: Our mission is to find a cure for epilepsy, by promoting and funding patient-focused research.

Cure Rare Disease: Through collaborations with world-renowned academics and clinicians, we are moving science forward to develop life-saving gene therapies for rare and ultra-rare disease patients overlooked and underserved by traditional drug development efforts.

Current RDCRN Consortia: The RDCRN is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment and data sharing. Currently, the RDCRN consists of 20 individual clinical research consortia and a Data Management and Coordinating Center (DMCC). Each consortium focuses on at least three related rare diseases or conditions, participates in multisite studies and actively involves patient advocacy groups as research partners.

dbSNP: dbSNP contains human single nucleotide variations, microsatellites, and small-scale insertions and deletions along with publication, population frequency, molecular consequence, and genomic and RefSeq mapping information for both common variations and clinical mutations.

dbVar: dbVar is NCBI's database of human genomic Structural Variation — large variants >50 bp including insertions, deletions, duplications, inversions, mobile elements, translocations, and complex variants.

DECIPHER: DECIPHER is used by the clinical community to share and compare phenotypic and genotypic data. The

DECIPHER database contains data from 45,933 patients who have given consent for broad data-sharing; DECIPHER also supports more limited sharing via consortia.

ENCODE: ENCODE is a public research consortium aimed at identifying all functional elements in the human and mouse genomes.

Exomiser: The Exomiser is a Java program that finds potential disease-causing variants from whole-exome or whole-genome sequencing data.

FDNA: We use artificial intelligence to detect physiological patterns that reveal disease-causing genetic variations. With the world's largest network of clinicians, labs and researchers creating one of the fastest growing and most comprehensive genomic databases, FDNA is changing the game for precision medicine by detecting rare diseases early with the help of AI.

Gene.iobio: Gene.iobio: an interactive web tool for versatile, clinically-driven variant interrogation and prioritization.

GeneConvene Global Collaborative: The Gene Drive Research Forum brings together representatives from research, government, private sector, and not-for-profit organizations, as well as other parties with an interest in safe and ethical conduct of gene drive research for applications in public health, conservation, and agriculture. The Forum meets periodically to discuss the status and challenges of gene drive research and identify areas where collaboration, coordination, and cooperation among stakeholders will move the field forward in a positive manner. The Forum also coordinates panels with worldwide experts to discuss current issues related to gene drive.

GeneDx: GeneDx is focused on delivering personalized, actionable insights that improve health outcomes. We sit at the intersection of diagnostics and data science, pairing decades of genomic expertise with an unmatched ability to interpret clinical data at scale.

GeneMatcher: GeneMatcher is a freely accessible web site designed to enable connections between clinicians and researchers from around the world who share an interest in the same gene or genes.

Geno2MP: Geno2MP is a web-based query tool that searches a database of rare variants from exome sequencing data linked to phenotypic information from a wide variety of Mendelian gene discovery projects. Specifically, each rare genotype is linked to individual-level phenotypic profiles defined by human phenotype ontology (HPO) terms. Thus, it enables users to link "Genotypes to Mendelian Phenotypes" to facilitate new gene discovery efforts.

Genome Sequencing Program Analysis Centers: The NHGRI Genome Sequencing Program Analysis Centers (GSPAC) are a collaborative initiative that will undertake computational analyses of the data produced by the NHGRI Genome Sequencing Program to extract genomic and biological knowledge.

Genome Sequencing Program: The GSP aims to use genome sequencing to identify genes and genomic variants underlying human inherited disease across its full spectrum, including rare diseases likely to be due to rare variants with strong effects (Mendelian), and common, genetically complex diseases that are caused by many variants. The GSP will also develop methods, tools, and knowledge intended to enhance the ability of the community to pursue other human inherited diseases.

Genome TDCC – Stimulating an interactive culture among Genome Technology Development grantees that supports greater productivity through collaboration.

Genomic Variation Program: The Genomic Variation Program supports large-scale studies of human genetic variation as part of projects such as the International HapMap Project and the 1000 Genomes Project.

Get Support | UMDF: Promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.

gnomAD: The Genome Aggregation Database (gnomAD), originally launched in 2014 as the Exome Aggregation Consortium (ExAC), is a coalition of investigators seeking to aggregate and harmonize exome and genome sequencing data from a variety of large-scale sequencing projects, and to make summary data available for the wider scientific community.

GREGoR Consortium: The Consortium includes five Research Centers, a Data Coordinating Center, National Human Genome Research Institute (NHGRI) within the National Institutes of Health (NIH) program staff, and other collaborators and research groups studying the genomics of rare diseases who wish to become partner members. Collaboration is a primary theme and will be part of our work in many ways including data sharing within both the GREGoR Consortium and the broader community; Working Groups including members from each Research Center; and exploring innovative partnerships. Outreach, education and advocacy are critical as we learn new ways to solve Mendelian diseases and develop new tools and creative methods that we can share with the broader scientific community.

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HudsonAlpha Institute for Biotechnology: The HudsonAlpha Institute for Biotechnology has a three-fold mission of conducting genomics-based research to improve human health and wellbeing; sparking entrepreneurship and economic development; and providing educational outreach to nurture the next generation of biotech researchers and entrepreneurs, as well as to create a biotech literate public.

I Dream for A Cure: Our challenge is to find answers. Without our funding, the research will end here. We have made agreements with 2 world renowned children's hospitals to find answers fast! Both Texas Children's Hospital and Nationwide Children's hospitals are going through great efforts to find answers and a cure.

IAMRARE® Program: NORD's IAMRARE Program is an easy-to-use system that allows patients and organizations to inform and shape medical research and transnational science for rare diseases by launching high-quality, customized registries to collect the data needed to define the natural progression of their disease – ultimately advancing product development.

Impact of Genomic Variation on Function (IGVF) Consortium: The IGVF (Impact of Genomic Variation on Function) Consortium aims to understand how genomic variation affects genome function, which in turn impacts phenotype. The NHGRI is funding this collaborative program that brings together teams of investigators who will use state-of-the-art experimental and computational approaches to model, predict, characterize and map genome function, how genome function shapes phenotype, and how these processes are affected by genomic variation. These joint efforts will produce a catalog of the impact of genomic variants on genome function and phenotypes.

Impact through Insights |TREND Community: We're a digital health analytics company that turns the conversations of rare, chronic, and emerging disease communities into actionable insights. Our partnerships support community members, health care providers, researchers, pharmaceutical sponsors, and regulatory agencies as we advance our mission to facilitate understanding, strengthen advocacy, and spark scientific progress.

InformedDNA: InformedDNA optimizes clinical decisions through impactful solutions leveraging the most current genomics expertise. We are the nation's leading applied genomics company, with the largest independent team of genetics specialists representing the full breadth of specialties and sub-specialties, and backed by more than 14 years of clinical data and financial proof of effectiveness.

Jordan's Guardian Angels: To conduct research seeking answers to rare genetic mutations affecting children and adults, and assist and improve the quality of life for children and families.

JumpStart | Orphan Disease Center: The Orphan Disease Center's JumpStart program serves to establish and progress research agendas in emerging and neglected rare diseases. The JumpStart program works closely with patient groups and foundations, pharma and biotech, and the academic community to drive therapeutic development for rare diseases.

LPDx: Clinical Genetic Testing; The UW Laboratory for Precision Diagnostics (LPDx) is a state-of-the-art CLIA Certified and CAP Accredited clinical genetic testing program. At LPDx we work with clinicians, families and researchers to provide accurate results with a rapid turnaround time and superior customer service. In addition to clinical testing, we offer consultation to scientists on the application of these technologies that in turn translates into robust research opportunities and improved patient care.

MARRVEL: MARRVEL (Model organism Aggregated Resources for Rare Variant ExpLoration) aims to facilitate the use of public genetic resources to prioritize rare human gene variants for study in model organisms.

Matchmaker Exchange: The 'Matchmaker Exchange' project was launched in October 2013 to address this challenge and find genetic causes for patients with rare disease. This involves a large and growing number of teams and projects working towards a federated platform (Exchange) to facilitate the matching of cases with similar phenotypic and genotypic profiles (matchmaking) through standardized application programming interfaces (APIs) and procedural conventions.

Matrix: A shared platform to help care for and cure Rare Diseases.

ModelMatcher: A team of basic scientists, bioinformaticians and clinicians in the US and Canada are jointly developing ModelMatcher, a global matchmaking platform to facilitate collaborative research on rare and undiagnosed diseases.

Molecular Phenotypes of Null Alleles in Cells | MorPhiC: MorPhiC aims to develop a consistent catalog of molecular and cellular phenotypes for null alleles for every human gene by using in-vitro multicellular systems.

Monarch Initiative Explorer: The Monarch Initiative is an integrative data and analytic platform connecting phenotypes to genotypes across species, bridging basic and applied research with semantics-based analysis.

Created by: Sierra Phillips @mrs.phillijt

NASR: We are an international group of collaborating researchers – including the SUDEP executive board and the SUDEP advisory committee - dedicated to uncovering the risk factors, causes, and mechanisms of SUDEP so that we may improve future epilepsy treatment and SUDEP prevention.

NCATS Toolkit for Patient-Focused Therapy Development: Online resources for patient groups to advance medical research for rare diseases.

NETS | Genetic Alliance: NETS is a dynamic, interactive map that is intended to provide a realistic view of drug development. Unlike the overly simplistic and unrealistic linear pipeline model, the NETS map portrays drug development for what it actually is: a complex system of interconnected elements. Each of the components displayed on the map links to a 'toolkit' of resources helpful for understanding and executing that process.

Non-Coding Variants Program: The Non-Coding Variants Program (NoVa) supports the development of approaches to figure out which of the many variants in a region associated with a disease or trait functionally cause the higher risk for the disease or trait.

Orphan Disease Center: Our Center, the first of its kind, works closely with patient groups and foundations, pharma and biotech, and the academic community. We bring a unique set of programs to the table, enabling us to add value at any stage - from building the initial knowledge base to enabling therapeutic development. Through our grants, Programs of Excellence, JumpStart programs, and a number of new initiatives, the ODC seeks to drive therapeutic development for rare diseases. We help identify and fund the most promising therapeutics while also tackling obstacles present in rare disease drug development.

Pediatric Epilepsy Research Consortium: The Pediatric Epilepsy Research Consortium (PERC) is a national collaboration of more than 60 US pediatric epilepsy programs. Founded in 2010 by physicians and scientists determined to find better treatments for their patients, PERC has grown to become the leader in pediatric epilepsy research by providing a network and infrastructure to facilitate collegial, collaborative, practice-changing research. Through fourteen special interest groups, PERC works to improve the care of every child with epilepsy.

PhenomeCentral: PhenomeCentral is a repository for clinicians and scientists working in the rare disorder community. PhenomeCentral encourages global scientific collaboration while respecting the privacy of patients profiled in this centralized database. Once users enter their patients' data, they are connected to other patient profiles within PhenomeCentral that share similar phenotypes and genotypes.

RaDaR: Rare Diseases Registry Program; Online resources for patient groups on setting up and managing a successful registry.

Raiden Science Found: We are overcoming research barriers in order to advance treatment for UBA5, a debilitating and ultra-rare genetic disorder. In doing so, we are pushing forward medical breakthroughs like gene therapy with the goal of helping millions of kids all around the world who are suffering from rare diseases.

Rare Collective: The Rare Collective partners with industry, patient organizations, and researchers to manage the development, commercialization, and adoption of innovative therapies and devices for rare disease communities.

Rare Disease Registry | Sanford Research: Based at Sanford Research, a nonprofit research institution, CoRDS is a centralized international patient registry for all rare diseases.

Rare Diseases Clinical Research Network | RDCRN: The RDCRN program is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment and data sharing. Through the RDCRN consortia, physician scientists and their multidisciplinary teams work together with patient advocacy groups to study more than 200 rare diseases at sites across the nation.

Rare Science: RARE Science is a non- profit research organization that focuses on accelerating identification of more immediate therapeutic solutions for kids with rare disease potentially through repurposing currently approved drugs and other therapeutic approaches.

Rarebase: Rarebase is a public benefit precision medicine company that leverages cutting-edge technology and biology to discover and develop treatments for the millions of people worldwide living with a rare disease.

rareLife solutions: We forge the connections that engage, unify, and amplify the voices of patients, advocates, and caregivers to inform and accelerate the development and commercialization of emerging treatments.

RARe-SOURCE: Unlocking Novel Insights into Rare Disease Commonalities Through Multimodal Data Integration.

RARE-X: RARE-X is a collaborative platform for global data sharing and analysis to accelerate treatments for rare disease.

RePORTER: The RePORT Expenditures and Results (RePORTER) module allows users to search a repository of NIH-funded research projects and access publications and patents resulting from NIH funding.

Research Groups (rarediseasesnetwork.org): We are an NIH-funded research network of 20 active consortia or research groups. We foster collaborative research among scientists to better understand how particular rare diseases progress and to develop improved approaches for diagnosis and treatment.

ResearchMatch: ResearchMatch is a nonprofit program funded by the National Institutes of Health (NIH). It helps to connect people interested in research studies with researchers from top medical centers across the U.S.

Riaan Research Initiative: Riaan Research Initiative is dedicated to promoting and furthering translational scientific research to advance treatments for severe and life-limiting genetic disorders.

Rare Disease Cures Accelerator | RDCA-DAP: an integrated database and analytics hub that is designed to be used in building novel tools to accelerate drug development across rare diseases. It is being developed by the Critical Path Institute (C-Path) and NORD through a collaborative grant from the FDA. RDCA-DAP's goal is to use data to accelerate clinical development, lowering costs and encouraging even more companies and researchers to get involved in rare disease research and innovation. The platform will promote sharing patient-level data and encourage the standardization of new data collection, resulting in a fuller understanding of a rare disease. This tool can do a lot to drive innovation and aid those looking for novel treatments.

Rx4Good; Rx4good works with companies, government, academia and nonprofits, and view all our clients as partners engaged in a mutual effort to improve the lives of the patients we all serve.

Scripps Genomic Medicine: SGM, now part of STSI, was created to take advantage of the explosion of new knowledge and technologies from the government's investment in the Human Genome Project (HGP). With an 80-year history of medical research and clinical care, Scripps Health is dedicated to advancing patient care by tailoring prevention, diagnosis and treatment to an individual's unique genomic signature and educating and training current and future physicians about genomic medicine.

seqr: Dashboard: An open-source software platform for rare disease genomics.

Simons Searchlight: Simons Searchlight understands that in order to create scientific breakthroughs for rare genetic neurodevelopmental disorders, families and scientists must come together. Simons Searchlight is an international research program and its mission is to shed light on these disorders by collecting high-quality, standardized natural history data and building strong partnerships between researchers, industry and families. Families like yours are the key to making meaningful progress. Simons Searchlight collects medical history information over the phone and information on behavior, communication, motor skills, and more through surveys.

Steve and Cindy Rasmussen Institute for Genomic Medicine: The Steve and Cindy Rasmussen Institute for Genomic Medicine is a nationally recognized provider of expertise in multiple aspects of genomics data generation and analysis. It creates a unique environment where state-of-the-art testing by its clinical laboratory, advanced computational data analytics and translational research efforts come together to transform patient care and make genomic testing results accessible and meaningful for patients and families.

Take Part Foundation: Take Part Foundation is a 501(c)(3) that allows anyone to "take part" in fighting for possible. We identify existing medical research for rare pediatric conditions that likely will not be able to find funding elsewhere, and fund it until it reaches the point where the research team can apply for funding from larger organizations and foundations. Take Part is also committed to assisting and equipping families who have a little warrior with a rare medical condition by giving them a platform to share their story.

The Global Alliance for Genomics and Health: The Global Alliance for Genomics and Health (GA4GH) is a policy-framing and technical standards-setting organization, seeking to enable responsible genomic data sharing within a human rights framework.

The GREGoR Consortium: The GREGoR Consortium is aimed at significantly increasing the proportion of Mendelian disorders with an identified genetic cause through enhanced data sharing, collaboration and an increased focus on the application of new technologies, sequencing strategies and analytical approaches.

The National Patient-Centered Clinical Research Network: PCORnet is a national resource that offers the kind of research ecosystem that has long been pursued: a fully integrated network where vast, highly representative health data, research expertise, and patient insights are built-in and accessible from the very start. The infrastructure of PCORnet is well established, meaning that the community knows how to maximize the value of these connections to deliver fast, trustworthy answers that advance public health.

The Rare Disease Translational Center at The Jackson Laboratory: The Rare Disease Translational Center at the Jackson Laboratory leverages expertise in CRISPR/Cas9 precision genome engineering, embryonic stem cell mutagenesis technology and classical transgenesis to identify and import or generate novel mouse models that are potential preclinical models for Rare and Orphan Disease.

Therapeutics for Rare and Neglected Diseases | TRND: TRND program supports preclinical development of therapeutic candidates intended to treat rare or neglected disorders, with the goal of enabling an Investigational New Drug (IND) application.

Upequity: Upequity delivers patient-centered, evidence-based research, novel projects and incubates emerging entities to drive improved access to quality, affordable healthcare for underserved populations with rare and serious health conditions.

Utah Foundation For Biomedical Research: The Utah Foundation for Biomedical Research is dedicated to discovering the genetic underpinnings of chronic diseases and advancing the field of genomic medicine.

Varient: Varient is free, private, and objective. We will provide the proof to pharma companies, researchers, and all those with an interest in developing treatments for rare disease patients, that there are real people and real numbers that need better medicines – or cures. For those of you who might want to be part of those clinical trials, we will connect you. We will never sell your data to insurance companies, or anyone else whose interests do not serve you. Your trust is everything.

VarSome: VarSome, a suite of bioinformatics tools for processing and annotation of NGS data.

VIGOR Study: the VIGOR Study is an NIH-funded endeavor coordinated out of Boston Children's Hospital which collaborates with chosen NICUs that serve underserved populations. VIGOR has created partnership between these leading NICUs to develop and implement a novel virtual model for genomic care with the hopes of proving that a model of tele-genomic care is feasible and reproducible to any NICU.

DRUG DEVELOPMNET RESOURCES:

Cellular & Gene Therapy Guidances | FDA

Gene Therapy: Your Questions Answered - YouTube

A Guide to Gene Therapy | Global Genes

Gene Therapy Inside Out - YouTube

Rare Pediatric Disease (RPD) Designation Request Template (nih.gov)

Orphan Drug Designation (ODD) Request Template (nih.gov)

The Drug Development Process | FDA: The development processes for drugs and devices are similar—each involves five basic steps. However, the processes differ within those steps. Click on either Drug Development or Device Development in the graphic below to learn more.

PaVe-GT Resources (nih.gov): PaVe-GT is committed to sharing lessons learned on our journey. As this project progresses over several years, this page will be populated with project results and documents, including communications with the U.S. Food and Drug Administration, all four Investigational New Drug packages with NIH-submitted data, product profiles, clinical study documents, and more.

PaVe-GT (nih.gov): The NCATS-led Platform Vector Gene Therapy (PaVe-GT) pilot project seeks to increase the efficiency of clinical trial startup by using the same gene delivery system and manufacturing methods for multiple rare disease gene therapies. We will make program results and regulatory documents publicly available, with the intention of benefiting future gene therapy clinical trials for very rare diseases.

CGT Science Series | Advocacy | ASGCT - American Society of Gene & Cell Therapy | ASGCT - American Society of Gene & Cell Therapy: The Cell and Gene Therapy (CGT) Science Series is a quarterly seminar series focused on scientific topics related to cell and gene therapy products. The CGT Science Series is intended to foster scientific exchange between the Biotechnology Innovation Organization (BIO), ASGCT, and Center for Biologics Evaluation and Research (CBER) review staff on a variety of topics that span the CGT product lifecycle. The seminars are planned as 60-minute virtual webinars featuring a speaker from one of the three organizations. The CGT Science Series will enable a deep dive into a specific technical and/or scientific area. Topics in the series may include, but are not limited to, nonclinical, CMC, clinical, or post-market phases of development related to CGT product lifecycle.

Patient Access & Affordability: Making effective decisions in health care requires a thorough understanding of the patient perspective, as well as robust, precise measures of response to therapy. The Patient Access & Affordability Project evaluates the various frameworks used to assess and demonstrate the value of new treatments to ensure that the patient is kept at the center of health care decisions.

myTomorrows | Drug development process

Impact through Insights |TREND Community: We're a digital health analytics company that turns the conversations of rare, chronic, and emerging disease communities into actionable insights. Our partnerships support community members, health care providers, researchers, pharmaceutical sponsors, and regulatory agencies as we advance our mission to facilitate understanding, strengthen advocacy, and spark scientific progress. Our proprietary technology listens to the online conversations happening within underserved rare, chronic, and emerging disease communities and derives actionable insights for community stakeholders, medical teams, researchers, scientists, biotechs, pharmaceutical companies, and regulatory agencies. We learn through listening, and we spark progress through insight.

Successfully Navigating Food and Drug Administration Orphan Drug and Rare Pediatric Disease Designations for AAV9-hPCCA Gene Therapy: The National Institutes of Health Platform Vector Gene Therapy Experience | Human Gene Therapy (liebertpub.com)

Global Access to Gene Therapies

Gene Therapy 101 | (asgct.org)

Gene Therapy (utah.edu)

MEDICAL TRANSPORTATION + LODGING RESOURCES:

Air Charity Network Mercy Medical Angels: To the patients we serve, our volunteer pilots are "angels" providing non-emergency medical transportation to specialized medical care centers. Many patients cannot afford transportation costs to one-time or regular visits to long-distance healthcare. Angel Flight Mid-Atlantic fills the gap. Our network of experienced volunteer pilots generously donate their time and airplane to help patients to reach their destination. The only reward our pilots receive are large smiles and huge hugs from the patients they fly to life-saving care.

Air Charity Network: Air Charity Network is a charitable organization that provides access for people in need who are seeking free air transportation to specialized health care facilities or distant destinations due to family, community, or national crisis. Air Charity Network serves all 50 states, and its volunteer pilots utilize their own aircraft, fuel and time to provide free air transportation to medical facilities for citizens who are financially distressed or otherwise unable to travel on public transportation.

All Wheels Up: All Wheels Up's mission is to increase awareness for safer and more dignified accessible air travel through research and advocacy.

Angel Flight Central: Angel Flight Central (AFC) is a volunteer non-profit 501(c)(3) organization whose mission it is to "Serve people in need by arranging charitable flights for health care or other humanitarian purposes." Today, AFC volunteers and supporters throughout the Midwest have made possible over 32,000 flights "free of charge" covering over 11 million nautical miles. We are helping thousands of families access specialized health care, special needs camps, and other destinations for disaster response efforts and compassionate reasons. Angel Flight Central, in the heart of the mid-west, collaborating coast-to-coast as we give hope wings every day!

Children's Flight of Hope: Children's Flight of Hope believes that distance and the cost of travel should never be barriers to care. That is why we provide flights to specialized medical care that might otherwise financially be out of reach.

Disabilities and Medical Conditions | Transportation Security Administration

Discount for Passengers with Disabilities and Companions | Amtrak: information on discounts for people with disabilities and companion travelers on Amtrak.

Created by: Sierra Phillips @mrs.phillijt

Easterseals Project Action: Easterseals Project Action, a division of Easterseals, Inc., provides customized training solutions and technical expertise on the Americans with Disabilities Act and accessible transportation for transportation providers, human service agencies, states, regional agencies, tribal nations, and communities with the goal of working together to build accessible communities for all!

Endure to Cure: Our Travel for Treatment Assistance Program helps families with travel costs associated with their child's cancer treatment. Many families do not live near hospitals with the ability to treat children with cancer. In fact, nearly 60% of children diagnosed with cancer must travel over 50 miles to get to their nearest oncologist.

Medical Transportation for Needy Patients | Mercy Medical Angels: The compassionate team at Mercy Medical Angels is ready to help you and your caregiver with transportation to life changing, life-saving medical care across the U.S.

Medical Transportation Grant Program | Southwest Airlines:, Southwest provides complimentary round trip tickets to nonprofit hospitals and medical transportation organizations, lessening the financial burden on patients and their families requiring travel for specialized lifesaving or life-changing medical care.

Miracle Flights. A Cure For Distance: Our team provides commercial plane tickets to all U.S.-based medical treatment facilities at no cost to families. Thanks to the generous support of our donors, we're able to fly patients as many times as needed. We've been flying some for more than 18 years.

FOOTPRINTS in the SKY: FOOTPRINTS in the SKY is a Denver-based 501(c)(3) non-profit corporation dedicated to providing NO COST flights for patients to medical facilities throughout the United States, using mainly donated charter and corporate jets. Those who seek our help are typically in need of routine, critical or life-saving care and cannot use commercial airline service or other means of transportation because of financial constraints and medical issues.

Healthcare Hospitality Network: If you are a patient or caregiver traveling away from your community for medical care, check to see if there is an HHN member providing affordable lodging and support near your healthcare system provider.

Patient Airlift Services: We provide free medical flights to people who need to access medical care that may be too far to get to by car.

Patient Transportation | Patients Rising Concierge

Wings Flights of Hope: The mission of Wings Flights of Hope Inc. is to help people in need of free air transportation for medical and humanitarian purposes. Basically, helping anyone, anytime, anyplace. At Wings we do not want transportation to stand in the way of a patient receiving the best possible treatment available. With this purpose in mind our volunteer pilots enjoy giving the gift of hope to so many passengers, and we are honored to be able to give someone a lift when they are down. Wings Flights of Hope Inc. is a non for profit 501 (c) 3 organization.

MEDICAL AND DENTAL RESOURCES:

1in100.org: teach sonographers and parents about the importance of early detection of CHDs by telling her story and sharing her research to make lasting change.

A Simple Patch: We design and manufacture adhesives that help make life a little easier for those needing extra security for their medical devices or wanting to add colour and fun!

Afraid of the Doctor | Parents Guide to Medical Trauma: Afraid of the Doctor: Every Parent's Guide to Preventing and Managing Medical Trauma is the first book written for parents with the primary goal of equipping them with the knowledge and skills to support their children through medical challenges.

AfterPICU: Every family who has ever had a child admitted to the pediatric intensive care unit (PICU) knows how scary and stressful this time can be. Often, we overlook how transition from the PICU back to a normal routine can come with challenges for the children or adolescents who were ill, as well as for their parents and siblings.

AGENDA | Alliance for Genetic Etiologies in Neurodevelopmental: The mission of AGENDA is to improve outcomes for individuals with all forms of autism by fostering a genetics-first approach to autism and neurodevelopmental disorders research, and by strengthening collaborations among organizations representing genetically-defined disorders associated with neurodevelopmental disorders and autism.

Be Not Afraid: BNA is a private non-profit organization supporting parents carrying to term following a prenatal diagnosis. Our staff and volunteers strive to develop relationships of trust while providing for the emotional and tangible needs of parents at diagnosis, during pregnancy, at birth, and during the post postpartum period for up to one year.

Brain Recovery Project: To enhance the lives of children who need neurosurgery to treat medication-resistant epilepsy by empowering their families with research, support services, and impactful programs across the lifespan.

Brave Gowns: Our gowns are the perfect way to bring comfort and fun when patients have to get something scary done! We use our fun designs to give everyone a little hope and normalcy at a time they need it most. Available in both children and adult sizes.

Buzzy - Needle Fear & Pain Relief: Buzzy uses natural "gate control" pain relief by confusing the body's own nerves, thereby dulling or eliminating sharp pain. In the same way that rubbing a bumped elbow helps stop the hurt, Buzzy controls sharp pain. The premise is that when nerves receive non-painful signals such as vibration or cold, the brain closes the gate on pain signals.

Chronic Illness, Children, Health Education (cuny.edu): Welcome! This is a site about growing up with medical problems ...any ole type. Its goal is to help people understand what it's like, from the perspective of the children and teens who are doing just that. These kids have become experts at coping with problems that most of you have never heard of. They'd like you to know how they do it, and they hope that you'll be glad you came to visit. I've divided the contents into three ponds; one for kids, one for teens, and one for adults. Figure out which you are, and jump in!

Ciitizen: Ciitizen is a free service that helps patients get more out of their health records. Our platform enables patients to find better treatment options and allows them the opportunity to advance the research for cures.

Coping Space: At Case for Smiles, everything we do is designed to walk alongside families as they cope with the trauma of childhood illness or injury. We understand this is a difficult time, and CopingSpace provides a variety of resources to assist both children and their families in dealing with the stresses of this experience.

CureUp: We first started CureUp because we saw there was a distinct lack of line support groups for certain health conditions. Since our start, we've created hundreds of online social communities dedicated towards providing those with medical conditions a place they can ask questions, get advice, and share their stories with others. Our health pages and support groups have enabled millions to learn more about their condition and provide a safe place for them to seek support from others living with the same condition. We partner with multiple non-profit organizations to provide them with resources such as our assistance cards, children's books, and more. By purchasing from our shop, you continue to let us provide non-profits with amazing resources at no cost. Since our inception, we've given away over 25,000 assistance cards and hundreds of our children's books for free because of your support.

DAT: DAT is a web-based tool that will identify your child's risk for distress (DistrEstimate) and provide you with instructions based on your individual child. Predictions are based on data from over 1,000 children, 4-10 years of age, having a needle stick procedure. However, distraction does work for children outside of this age range and for other medical procedures. In those cases, adjust the plan relative to the intensity of the procedure compared to a needle stick (for example, removing tape may be less intense and a bone marrow aspirate may be more intense)

Dental Care Guidance for Caregivers of Patients with Down Syndrome: hen it comes to heading to the dentist, there can be feelings of stress and anxiety. For patients with Down syndrome, these feelings can be much more intense. Our dental experts, Dr. Greg Grillo, and Dr. Andrew Jordan, have spent many years working with patients and caregivers on preparing for their dental visits and providing them with tips and care for instilling good oral hygiene habits.

Disease InfoSearch: Disease InfoSearch is a consumer-facing directory of more than 10,000 diseases, with up-to-date information about current opportunities for research and support curated by advocacy organizations. Condition pages aggregates links to quality disease information across the Internet and pairs them with up-to-date, curated information on support groups and resources. Viewers can find information ranging from scientific articles to active clinical trials and everything in-between. Disease InfoSearch acts as an all-in-one resource for newly diagnosed individuals and their families, as well as the medical community. This resource aggregates information from partner sites around the internet, allowing you to access all of the information, resources, and support you might need. Disease InfoSearch also provides opportunities for you to connect with advocacy organizations, data registries, research opportunities, and clinical trials, and is a great place to learn more information about a specific disease or condition.

Grottoes of North America: Dental Care for Children with Special Needs Bringing Special Smiles to Special Kids.

Infantile Spasms Action Network:: the Infantile Spasms Action Network (ISAN), convened by CNF – has grown into a collaborative network of 32 national and international entities focused on raising awareness for infantile spasms. Do visit the websites of these wonderful organizations to see first-hand their commitment to the child neurology community.

Kids' Medical Dictionary: Symptoms, inhaler, tonsillectomy - what do all those medical words mean? Check out our virtual glossary for lots of easy-to-read definitions.

Lauren's Hope | Medical ID Bracelets and Alert Jewelry: Lauren's Hope reinvented medical alert jewelry in 2001. Over the last 20 years, we've perfected the art of conveying your personal medical info to first responders through stylish medical alert bracelets, medical ID necklaces and medical dog tags. Wearing your medical information is a great way to alert others with your details which can help prevent an event from turning into a life-threatening emergency.

Lily's List: Lily's List works with pediatric patients that have a need for home health nursing. No matter what the need, we work to ensure the hospital-to-home transition is as smooth as possible. Our demographic ranges from birth to 18.

Matrix: A shared platform to help care for and cure Rare Diseases.

MedicAlert® Assistance Program: NORD's MedicAlert Assistance Program provides MedicAlert products and services to eligible individuals in the rare disease community. If someone with a rare disease can't speak for themselves in an emergency, MedicAlert can be their voice in providing important and potentially life-saving information. The program provides eligible individuals with a MedicAlert product and 3-years of membership.

Medicine Assistance Tool: PhRMA's Medicine Assistance Tool (MAT) is a search engine designed to help patients, caregivers and health care providers learn more about the resources available through the various biopharmaceutical industry programs.

Meet mejo | Putting me back in medicine: a better way to simplify, organize and share your kid's most important medical & care information all in one web app.

My Family Health Portrait: a free web-based tool, is helpful in organizing the information in your family health history. My Family Health Portrait allows you to share this information easily with your doctor and other family members.

My Rare ID: At My Rare ID, we demonstrate our commitment to the rare disease community by not only investing in ongoing research and solutions but partnering with rare disease patients and organizations. That's why we not only created My Rare ID to support rare disease patients and save lives, but we also built it to create a sustainable fundraising mechanism for the rare disease organizations we partner with. Our Rare Partners program ensures that not only do rare patients have access to affordable digital IDs, but that the organizations supporting patients receive ongoing financial support as well.

NASPGHAN: The mission of NASPGHAN is to be a world leader in research, education, clinical practice and advocacy for Pediatric Gastroenterology, Hepatology and Nutrition in health and disease.

NASR (sudepregistry.org): We are an international group of collaborating researchers – including the SUDEP executive board and the SUDEP advisory committee - dedicated to uncovering the risk factors, causes, and mechanisms of SUDEP so that we may improve future epilepsy treatment and SUDEP prevention.

National Home Infusion Association | NHIA: The National Home Infusion Association (NHIA) is committed to meeting the needs of its growing and diverse membership—and to advocating on behalf of our members and the home-based infusion patient. Home and alternate site infusion providers coordinate care through highly skilled professionals in a team that will often include the infusion pharmacist, infusion nurses, physician, and dietitian to help ensure the patient is receiving the best care possible.

National Infusion Center Association: Infusion Therapy Advocacy: We help preserve, optimize, and advance the trade of furnishing provider-administered medications by being the nation's leading voice for non-hospital, community-based infusion providers.

NillyNoggin EEG Cap: The NillyNoggin EEG Cap reduces much of the "scary" associated with the test and brings some happy and fun to the whole experience. NillyNoggin EEG Caps are colorful and come in a wide assortment of patterns. Children get to choose their own NillyNoggin EEG cap –

giving them some control during the medical procedure. The caps are perfectly designed for kids or even adults to wear while they receive an ambulatory or prolonged EEG tests.

NORD Rare Disease Center of Excellence Database: Every person who has a rare disease deserves the best possible care and support. NORD Rare Disease Centers of Excellence are working together to make this vision a reality. Each Center offers world-class doctors in all major specialties and brings together medical teams experienced in diagnosing and treating a wide array of rare diseases. In addition, researchers at each Center are working with doctors and patients to find more treatments and cures for rare diseases. NORD is interconnecting this network of Centers to encourage collaboration and sharing of best practices and expertise.

Partners Against Mortality in Epilepsy: PAME's mission is to convene, educate and inspire all stakeholders – from the bereaved to those living with epilepsy, to health care professionals, advocates, clinical and basic scientists, and death investigators – to promote understanding and drive prevention of epilepsy-related mortality.

Patient Helpline: Welcome to the Patient Helpline, a free program that supports patients and caregivers by connecting you to free or reduced-cost services that are personalized to your needs.

Pediatric Complex Care Association: We create opportunities for organizations to promote excellence in the continuum of care for children with medical complexity and their families.

Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

Peer Medical Foundation: A volunteer youth-led international not-for-profit organization advancing health equity, diversity, inclusivity & racial justice in medicine.

PhoenX | All Your Health in One App: We use our unique Data Processing and AI Technology to compare your DNA information provided to the latest medical and scientific knowledge.

Rare STRIDES® – Connecting Care to Those with Rare: Rare STRIDES® mission is to empower patients and medical teams with innovative tools to successfully fight rare diseases, and we are committed to the delivery of exceptional clinical care for rare patients in every medical setting. We are passionate about giving back to fund patient programs and continued innovation for children and adults with rare diseases who deserve excellence in healthcare.

Seizure Tracker®: Seizure Tracker is dedicated to providing patients, doctors and researchers with free comprehensive tools to help understand relationships between seizure activity and anti-epileptic therapies.

SHADOW BUDDIES: The mission of the Shadow Buddies Foundation is to provide emotional support through education regarding illness, disability, or medical treatments. The foundation accomplishes this through unique programs designed to enhance the lives of children and adults. In pursuit of that mission, the foundation will continually raise funds, develop new programs and build relationships between organizations with complimentary goals.

Sleuth: Where parents share hard-fought lessons and specific data about kids' health.

STARS | Special Needs Tracking and Awareness Response System: SSM Health Cardinal Glennon Children's Hospital created the Special Needs Tracking and Awareness Response System (STARS) to provide focused, individualized training to area hospitals and first responders in more than 30 counties, to help them better care for children living in their districts who have challenging medical needs, such as heart defects, autism, severe neurological disorders and more. The ultimate goal of STARS is to have pertinent, up-to-date information about each STARS child in the hands of first responders before they arrive at the child's home and for community hospitals to be equipped with the knowledge to safely care for these special children. This ultimately helps decrease anxiety (for caregivers as well as the children) and potentially prevents unnecessary hospitalizations, reducing overall health care costs.

Sudden Unexplained Death in Childhood | SUDC Foundation: Promote awareness, advocate for research, and support those affected by sudden unexpected or unexplained death in childhood.

The Charlie Foundation for Ketogenic Therapies: The Charlie Foundation for Ketogenic Therapies was founded in 1994 to provide information about diet therapies for people with epilepsy, other neurological disorders and select cancers. Charlie Abrahams, pictured above, continues to be the inspiration for the foundation, working as a pre-school teacher, and proving that Epilepsy can be cured through Ketogenic Therapy.

The Global Tracheostomy Collaborative: We are a global Quality Improvement Collaborative (QIC) for tracheostomy patients consisting of a multidisciplinary team of physicians, nurses, allied health clinicians and patients/caregivers from a global community working together to disseminate best practices and improve outcomes. Dr. David Roberson, ENT specialist, from Harvard is the lead on the Collaborative.

The Phoenix Ostomy Magazine: Get answers to the challenges of living with a colostomy, ileostomy or urostomy by subscribing to The Phoenix magazine, the official publication of United Ostomy Associations of America. Medical professionals, clinicians and ostomy experts provide answers you won't find anywhere else.

The Rett Clinic | Children's Hospital Colorado: We provide up-to-date information on Rett syndrome and genetically related disorders to parents, physicians, therapists and care providers.

World Pediatric Project: World Pediatric Project partners with governments, health workers, and organizations to ensure that children in lower-resource settings have access to safe, timely surgical care. When children are healed, the social and emotional health of families is restored, and the economic productivity of communities is strengthened.

MEDICAL PROFESSIONAL RESOURCES:

1in100.org: teach sonographers and parents about the importance of early detection of CHDs by telling her story and sharing her research to make lasting change.

AGENDA | Alliance for Genetic Etiologies in Neurodevelopmental: The mission of AGENDA is to improve outcomes for individuals with all forms of autism by fostering a genetics-first approach to autism and neurodevelopmental disorders research, and by strengthening collaborations among organizations representing genetically-defined disorders associated with neurodevelopmental disorders and autism.

For Doctors | CCD Smiles: We want to help you, the medical community, have a better understanding of CCD, empowering you to better assist your patients with CCD. We're currently working on building out this section of the website to display, so please come back soon for more information.

Be Not Afraid: BNA is a private non-profit organization supporting parents carrying to term following a prenatal diagnosis. Our staff and volunteers strive to develop relationships of trust while providing for the emotional and tangible needs of parents at diagnosis, during pregnancy, at birth, and during the post postpartum period for up to one year.

2023 Healthcare Professionals' Genomics Education Week: Genomics is becoming an increasingly important part of patient care, but healthcare providers may not be aware of genomics education resources that are available. The National Human Genome Research Institute and its partners are organizing a social media campaign from June 5 to June 9, 2023, that focuses on healthcare provider genomics education. This initiative will include panel discussions, webinars, Twitter chats and Q&As.

Healthcare Provider Genomics Education Resources: Healthcare providers (HCPs) will increasingly use knowledge about genomics to meet the needs of their patients. This page provides resources targeted to HCPs and their educators.

InformedDNA: InformedDNA optimizes clinical decisions through impactful solutions leveraging the most current genomics expertise. We are the nation's leading applied genomics company, with the largest independent team of genetics specialists representing the full breadth of specialties and sub-specialties, and backed by more than 14 years of clinical data and financial proof of effectiveness.

Genomics Education Resource Center (GenomeEd): GenomeEd is a free repository of high-quality genomics educational resources for group instruction or self-directed learning by healthcare professionals and educators. This centralized web resource is built upon the foundation of the previous version, the Genetics/Genomics Competency Center (G2C2). The new site, incorporated into genome.gov, includes filters to help users quickly browse materials by topic and format, including the ability to find resources that qualify for continuing education credits.

Global Genetics and Genomics Community (G3C): Interactive Unfolding Case Studies: G3C (Global Genetics and Genomics Community) is a bilingual collection of unfolding case studies for use with students and practicing healthcare providers learning basic genetic/genomic concepts. When faced with a patient and their needs, there may be multiple ways to meet those needs. Yet, too often education requires learners to follow a linear path to form a solution - negating the multi-dimensional nature of human beings. An Unfolding

Case Study (UCS) can address this deficiency by offering the student a self-guided learning experience which allows for nuanced experiential learning. For the instructor, a UCS offers a way to robustly cover a topic, bringing to light the subtleties in a more realistic practice-based skill environment.

Pathways To Trust Rare Disease: Pathways To Trust focuses on the needs of patients facing high hurdles to care. We know these biases can be eliminated once these patients' voices are part of the conversation. To make this happen, we provide disease-specific educational programs for medical students, healthcare providers and patients. Our content is developed by patients and patient advocates themselves, and incorporates the perspectives and contributions of multiple stakeholders so all members of the rare disease community can work together to deliver truly patient-centered care.

FDrisk: Online Fabry Disease Screening Tool for Clincians: Welcome to the FDrisk, a risk assessment tool developed to predict the probability of someone having Fabry disease (FD). This tool was designed to be used by healthcare professionals seeking to learn more about their patients' risks of having FD.

Infantile Spasms Action Network:: the Infantile Spasms Action Network (ISAN), convened by CNF – has grown into a collaborative network of 32 national and international entities focused on raising awareness for infantile spasms. Do visit the websites of these wonderful organizations to see first-hand their commitment to the child neurology community.

Medics 4 Rare Diseases: driving an attitude change towards rare disease amongst medical professionals. M4RD provides education about the relevance of rare disease to everyday clinical medicine and equips doctors to manage their patients effectively. Our ultimate aim is to speed up the journey to diagnosis and improve the patient experience.

NASPGHAN: The mission of NASPGHAN is to be a world leader in research, education, clinical practice and advocacy for Pediatric Gastroenterology, Hepatology and Nutrition in health and disease.

Rare Diseases Working Group | Alliance for Patient Access: AfPA's Rare Diseases Working Group is a network of policy-minded health care providers who advocate for patient-centered care. By participating in advocacy initiatives and the development of educational resources, working group members ensure that the clinician's perspective informs policy discussions that impact health care for people living with a rare disease.

NASR (sudepregistry.org): We are an international group of collaborating researchers – including the SUDEP executive board and the SUDEP advisory committee - dedicated to uncovering the risk factors, causes, and mechanisms of SUDEP so that we may improve future epilepsy treatment and SUDEP prevention.

National Home Infusion Association | NHIA: The National Home Infusion Association (NHIA) is committed to meeting the needs of its growing and diverse membership—and to advocating on behalf of our members and the home-based infusion patient. Home and alternate site infusion providers coordinate care through highly skilled professionals in a team that will often include the infusion pharmacist, infusion nurses, physician, and dietitian to help ensure the patient is receiving the best care possible.

National Infusion Center Association: Infusion Therapy Advocacy: We help preserve, optimize, and advance the trade of furnishing provider-administered medications by being the nation's leading voice for non-hospital, community-based infusion providers.

Partners Against Mortality in Epilepsy: PAME's mission is to convene, educate and inspire all stakeholders – from the bereaved to those living with epilepsy, to health care professionals, advocates, clinical and basic scientists, and death investigators – to promote understanding and drive prevention of epilepsy-related mortality.

For Clinicians & Researchers | NORD: We support clinicians and researchers so they can advance research and treatment that will enable people living with rare diseases to live healthier and fuller lives

Pediatric Complex Care Association: We create opportunities for organizations to promote excellence in the continuum of care for children with medical complexity and their families.

Rare STRIDES®: Rare STRIDES® mission is to empower patients and medical teams with innovative tools to successfully fight rare diseases, and we are committed to the delivery of exceptional clinical care for rare patients in every medical setting. We are passionate about giving back to fund patient programs and continued innovation for children and adults with rare diseases who deserve excellence in healthcare.

Rising Kites: Our mission is to provide hospitals, birthing centers, and prenatal clinics with resources that can be immediately distributed to parents who have just learned that their child has a diagnosis of Down syndrome.

The Rett Clinic | Children's Hospital Colorado: We provide up-to-date information on Rett syndrome and genetically related disorders to parents, physicians, therapists and care providers. We also participate in groundbreaking clinical research trials and work as a team with your family, primary care providers and other specialists from your medical home.

Osmosis - Learning Medicine Made Simple: Our mission is to empower the world's clinicians and caregivers with the best learning experience possible.

The Global Tracheostomy Collaborative: We are a global Quality Improvement Collaborative (QIC) for tracheostomy patients consisting of a multidisciplinary team of physicians, nurses, allied health clinicians and patients/caregivers from a global community working together to disseminate best practices and improve outcomes. Dr. David Roberson, ENT specialist, from Harvard is the lead on the Collaborative.

PHARMACEUTICAL COMPANY RESOURCES:

Alnylam Assist™ Patient Support: Alnylam Assist™ is committed to providing support throughout treatment with Alnylam products.

Alnylam® Pharmaceuticals: Alnylam has led the translation of RNA interference (RNAi) from Nobel Prize-winning discovery into an entirely new class of medicines, which we believe has the potential to help people all over the world to live longer, healthier, and fuller lives. Through pioneering science, unwavering commitment to patients, and our approved therapies and deep pipeline of investigational RNAi therapeutics, we have cemented our reputation for innovation and leadership in RNAi.

Horizon Therapeutics: At Horizon, we believe science and compassion must work together to transform lives. Our mission to deliver medicines for rare, autoimmune and severe inflammatory diseases and provide compassionate support comes from our strong and simple philosophy to make a meaningful difference for patients and communities in need.

Rare Diseases | Takeda: Takeda aspires to transform the treatment of rare diseases in immunology, hematology, metabolic and lysosomal storage disorders. These rare genetic and metabolic diseases can have symptoms that vary widely and progress very differently from person to person, which means that people affected by these diseases are frequently misdiagnosed.

MyIgSource: Your Primary Immunodeficiency (PI) Support Community: We are a community committed to helping each other and our loved ones manage a life with primary immunodeficiency (PI). Here, you can find information on PI and connect with our Ig Community Support Team Advocates—people who live with or love someone with PI. MyIgSource is a trademark or registered trademark of Baxalta Incorporated, a Takeda company.

OnePath® Patient Portal Log In | Shire: OnePath® online accounts offer patients and caregivers enrolled in OnePath convenient access to OnePath as well as helpful tools and information

Travere Therapeutics | In Rare For Life: Travere Therapeutics is determined to bring life-changing treatments, support, and hope to people with rare disease – an area often overlooked. Together, we can create a better future for families affected by rare disease.

Ultragenyx—Treatment of Rare and Ultrarare Genetic Diseases: Ultragenyx was founded to advance innovative medicines for rare and ultrarare diseases that have never been treated before. We are delivering transformative therapies across multiple indications, and we have one of the most robust and diverse clinical pipelines in rare disease. Our focus is on doing the right things for patients both during development and commercialization to deliver on the promise of these therapies in a way that's meaningful for rare disease communities.

ONESOURCE: personalized support throughout your Alexion treatment.

INSURANCE RESOURCES:

Created by: Sierra Phillips @mrs.phillijt

ACA Disability Navigator Health Insurance Enrollment Resources: The mission of the National Disability Navigator Resource Collaborative (NDNRC) is to provide cross-disability information and support to Navigators and other enrollment specialists thereby ensuring people with disabilities receive accurate information when selecting and enrolling in insurance through the Affordable Care Act Marketplaces.

Hope Knows No Boundaries: Hope Knows No Boundaries is a non-profit 501(c) dedicated to Educating patients to advocate for their medical needs, use their voice in their treatment, and create a team environment between the medical specialists, the patients, and the insurance companies.

State Health Insurance Marketplace Types, 2023 | KFF: These states are considered to have a State-based Marketplace, and are responsible for performing all marketplace functions for the individual market, except that the state will rely on the federal Healthcare.gov website for eligibility and enrollment functions. Consumers in these states apply for and enroll in coverage through Healthcare.gov.

2023 statutory disability insurance matrix by state

Chartbook State Data (ciswh.org): The State Data Chartbook is designed to help visitors understand the multiple dimensions of care for Children and Youth with Special Health Care Needs (CYSHCN). It contains a selective list of health indicators for all 50 states as well as Puerto Rico and the District of Columbia. Drawing from a range of trusted sources and updated regularly, it provides data in areas that include demographics, economics, child health services, insurance availability, and factors impacting coverage for CYSHCN.

PRESCRIPTION RESOURCES:

Affordability (astrazeneca-us.com): Helps eligible uninsured and Medicare patients gain access to AstraZeneca medications.

America's Drug Card: National Benefit Builders, Inc. (NBBI) is a for-profit company, established in 1994, with the highest rating from the Better Business Bureau. NBBI developed an outreach program called America's Drug Card. The America's Drug Card program was established in response to the many requests that NBBI receives for assistance for the uninsured and underinsured with their prescription needs. Through our network of Reps, the America's Drug Card gives away free discount prescription cards to as many people who could benefit.

Good Days: Good Days is here to pay for treatments that can help return a degree of normalcy to your daily life. Red tape is the last thing you want to deal with at this time; our Care Navigators are expert in dealing with the healthcare and insurance industries and will also guide you to other resources that can provide support and any additional assistance you may need. Apply online and get an immediate result.

NeedyMeds: Find help with the cost of medicine.

Medicine Assistance Tool: PhRMA's Medicine Assistance Tool (MAT) is a search engine designed to help patients, caregivers and health care providers learn more about the resources available through the various biopharmaceutical industry programs. MAT is not its own patient assistance program, but rather a search engine for many of the patient assistance resources that the biopharmaceutical industry offers.

RxHope: RxHope is exactly what its name implies...a helping hand to people in need in obtaining critical medications that they would normally have trouble affording. We act as your advocate in making the patient assistance program journey easier and faster by supplying vital information and help.

The Assistance Fund | TAF: No one should go without treatment because of an inability to pay. That's why we work every day to ensure you can access the treatment you need. See if you are eligible for one of our more than 80 disease programs.

Medicare Access for Patients Rx | MAPRx: Medicare Access for Patients Rx (MAPRx) is a coalition of patient, family caregiver and health professional organizations committed to safeguarding the well-being of patients with chronic diseases and disabilities who rely on Medicare's prescription drug coverage, Medicare Part D.

Find out if your state has a State Pharmaceutical Assistance Program (medicare.gov): If your state offers a State Pharmaceutical Assistance Program, we'll show information about that program.

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Pfizer RxPathways: We're here to help clear the path for patients by serving as a single point of access to all of the programs that might be right for them. From insurance support and co-pay assistance* to medicines for free, Pfizer RxPathways connects patients to a range of programs and resources that can help them access the Pfizer medicines they need.

RARE CANCER RESOURCES:

ACCO - Comfort Kits: The ACCO "Comfort Kit" is a free resource designed to ease the transition for newly-diagnosed children and teens with cancer by helping them acclimate to their new surroundings and adapt to significant (and potentially traumatic) lifestyle changes.

Arms Wide Open Childhood Cancer Foundation: Arms Wide Open Childhood Cancer Foundation's mission is to fund less toxic therapies for children with cancer so they can have a better quality of life as they battle the disease and to give children battling cancer and their families hope during the most difficult days of their lives.

Face 2 Face Healing: To offer life-enhancing experiences for cancer patients and/or people with conditions causing disfigurement, their caregivers and their healthcare professionals, by providing effective individual counseling, case management, advocacy and education in the region.

Joes House: Joe's House is not an actual house, but a nonprofit organization that helps cancer patients and their families find a place to stay when traveling away from home for medical treatment.

Alex's Lemonade Stand Foundation: Alex's Lemonade Stand Foundation (ALSF) recognizes that childhood cancer affects the whole family, not only the child who receives the diagnosis. SuperSibs is dedicated to comforting, encouraging and empowering siblings of children with cancer, so they can face the future with courage and hope. Our Comfort and Care mailing program sends age-appropriate mailings over a two-year period that include coping skills and encouragement for siblings as their brother or sister fights cancer. This program can go a long way towards helping siblings find their footing in a new normal and thrive in the future.

Amanda Hope Rainbow Angels : Amanda Hope Rainbow Angels supports the here and now needs of families impacted by childhood cancer and other life-threatening illnesses through Comfort and Care counseling, Comfycozy's for Chemo adaptive apparel, Financial Assistance, and Major Distractions events.

Emily's Army - Arms Wide Open Childhood Cancer Foundation: Private funding for research is essential to finding a cure for DIPG and our family is committed to continuing Emily's legacy of giving by supporting brain cancer research and families currently in treatment. Facebook group is more active than the website: Facebook.

Believe In Tomorrow: The Believe In Tomorrow Children's Foundation provides exceptional hospital and respite housing services to critically ill children and their families.

Cents: In an effort to reach patients and caregivers beyond its research studies, CENTS launched the Financial Planning for Cancer program in mid-2018. Through this program, patients or caregivers are matched with a Certified Financial Planner (CFP) for free confidential one-on-one meetings to address the costs of cancer treatment. The patients or caregivers are also matched with a Patient Advocate Foundation (PAF) case manager to work on any health insurance or benefits-related issues. This program is funded by the Foundation for Financial Planning and is supported by the Financial Planning Association.

Children's Brain Tumor Foundation - Care Kits: We send CBTF Care Kits so families know that they don't have to face a brain tumor diagnosis alone. And when they are ready, CBTF is here to guide and support them throughout their journey. If you would like to refer a family to receive a CBTF care kit, please fill out the form below.

Children's Brain Tumor Foundation: The Children's Brain Tumor Foundation (CBTF) was founded in 1988 by a group of dedicated parents, physicians, and friends to improve the treatment, quality of life, and the long-term outlook for children with brain and spinal cord tumors through research support, education, and advocacy to families and survivors. In addition to providing funds to research a cure, the organization is the nation's leader in quality-of-life programs for families impacted by brain and spinal cord tumors. We support families from the day of diagnosis and throughout the brain tumor journey. Our mission is dedicated to improving the treatment, quality of life and the long-term outlook for children and families affected by a brain or spinal cord tumor.

Children's Leukemia Research Association: Since 2001, the CLRA Patient Aid Program has provided $1.4 million in co-pay reimbursements assistance to 600 patients with blood cancer. We've been able to do this through the generous contributions of our Donors. Assistance includes medical bills for oral chemotherapy, IVIG, immunosuppressants, tyrosine kinase inhibitors (TKI), preventative antibiotics, neutropenia, thrombocytopenia, pain and numbing, anti-nausea, anti-anxiety, antidepressants, blood thinners, and vitamins and minerals.

Coming up Rosies: Our mission is to restore confidence, happiness and pride to anyone struggling with low self-esteem during their medical journey, especially bald children. Our vision is a world where every child goes to sleep proud of their differences. We accomplish this by donating Smile Kits inclusive of paints, brushes and canvases to children's hospitals and charity organizations around the world. Children can paint and customize their very own head scarves, neck scarves and superhero capes.

Endure to Cure | Travel for Treatment Assistance Application: Our Travel for Treatment Assistance Program helps families with travel costs associated with their child's cancer treatment. Many families do not live near hospitals with the ability to treat children with cancer. In fact, nearly 60% of children diagnosed with cancer must travel over 50 miles to get to their nearest oncologist.

Join the Flock, Inc.: Join the Flock, Inc. is a certified 501(c)(3) nonprofit with a mission to provide joy and financial relief to families impacted by cancer through gifted mortgage payments. 100% of donations will go to a family in need through a community-led nomination process, achieving our goal of spreading a bit more joy in the world, one member of our flock at a time.

Kids & Art Foundation: Kids & Art uses the power of the arts and creativity to mitigate stress, anxiety, and trauma induced from diagnosis and treatment of pediatric cancer and other critical medical conditions.

Kylie Rowand Foundation: The Love Like Kylie Program is a care package program for Pediatric Cancer Patients that are currently in treatment. If your child is N.E.D. but still receiving treatment, they qualify for the program.

Lock In Hope: Lock Boxes of Love want the siblings of pediatric cancer patients to feel special, and feel the love and hope we send in each special box. Lock Boxes of Love are gift boxes that are tailored to the age and gender of each child and are filled with things such as books, blankets, toys and stuffed animals. We hope to make the siblings of pediatric cancer patient's, who often feel unnoticed, feel loved and special. We call these special sibling "sibling warriors."

Pinky Swear: Pinky Swear's mission is helping kids with cancer and their families with financial and emotional support.

Programs - American Children's Cancer Foundation: ACCF is committed to helping people with limited finances and special needs receive funds to assist in meeting their financial obligations. ACCF is also committed to help reduce the stress of this diagnosis on children, their parents and shine a light of hope and joy while managing the disease. Thanks to the generous support we receive from our community of donors, we are able to award a limited number of partial and full individual grants to qualified applicants.

Project Yechi: Helping those who have been confronted with cancer by making their lives easier and offering support during very trying times.

Special Spaces: Special Spaces is a not-for-profit 501(C)(3) organization creating dream bedrooms for children with cancer.

Survivorship - The NCCS: The NCCS recognizes that childhood cancer survivorship is a journey, and we remain committed every step of the way. Our Beyond the Cure program prepares survivors and their families for life after cancer.

The Hope Portal: The Hope Portal is a curated, community-driven directory of organizations in childhood cancer.

View Resources on RedTreehouse.org: Supporting the well-being of families and children with challenges, disabilities, and health care needs. Find tools, organizations, and events in your community to meet your need.

CONGENITAL HEART DEFECT RESOURCES:

Created by: Sierra Phillips @mrs.phillijt

Heart and Soul: Heart and Soul: Your Guide to Living With Congenital Heart Disease.

Conquering CHD: Originally founded as the Pediatric Congenital Heart Association in 2013, we quickly filled a niche as the voice of the congenital heart patient and family. We are changing both the national landscape and empowering patients and families in their local communities. In 2020, to better reflect our efforts in being more inclusive both culturally and across the lifespan, we changed our name to Conquering CHD. Visit the site to connect with your local chapter!

Lasting Imprint: Lasting Imprint is a non-profit corporation established by individuals committed to fighting congenital heart defects (CHD). Our inspiration comes from the big hearts of the children and adults that have fought and continue to fight CHD every day. Their hearts have touched ours and it is our hope that you join us in our efforts to leave a lasting imprint on the CHD community.

Ollie Hinkle Heart Foundation: Ollie Hinkle Heart Foundation (OHHF) is committed to addressing the unmet needs of heart families while transforming the future of pediatric heart care.

Kids With Heart: Kids With Heart National Association for Children's Heart Disorders is dedicated to providing support for families affected by congenital heart defects through surgical care packages, local support group meetings, and through an online listserv. Kids With Heart NACHD Inc. continues to raise awareness through local events across the U.S, displays at fairs, and numerous awareness projects such as car magnets. Kids With Heart NACHD Inc. also has an extensive library of congenital heart defect books. Hospitals throughout the U.S. have bought our books and have them displayed in parent libraries. These books are also available to parents to purchase at our low price.

Ollie's Branch - Ollie Hinkle Heart Foundation (theohhf.org): FREE MENTAL HEALTH SERVICES FOR HEART WARRIORS, THEIR FAMILIES, AND CAREGIVERS.

Tiny HeartsCan Foundation: Tiny HeartsCan Foundation is the only not-for-profit organization in North America working to improve prenatal detection of Congenital Heart Disease (CHD) through targeted sonographer training and public outreach.

DEAF AND HOH RESOURCES:

Sertoma, Inc.: Service to Mankind. It's more than just how we got our name; it's been our foundation for over 100 years. Sertomans across the country are unified with a single purpose: serve our communities and improve the lives of those who need help. Our mission and our passion is to improve the quality of life for those at risk or impacted by hearing loss through education and support.

All About Audiology Podcast: Dr. Saperstein loves sharing her passion for audiology. Her specialty is helping parents of children with hearing loss, explaining test results and providing information, support and guidance. Dr. Saperstein obtained her doctorate of audiology (AuD) at The CUNY Graduate Center in New York. She has experience working with patients of all ages and has worked as both a clincial audiologist and an educational audiologist. She is the producer and host of the All About Audiology Podcast.

Optimizing Outcomes for Students who are Deaf or Hard of Hearing | Educational Service Guidelines: This purpose of these guidelines is to supplement and update the information needed by teachers, leaders, families, school instructional support personnel and other stakeholders to have the knowledge, skills and vision to help children be successful. Persons using these guidelines must understand the guidelines supplement and update what they need to know and do in working on behalf of children and youth who are deaf or hard of hearing; the guidelines do not provide the totality of what they need. Fast emerging knowledge and technological advances make it imperative that continuous learning be an important goal.

National Center on Deaf-Blindness: NCDB is part of a network of projects for children and youth with deaf-blindness (birth through 21) that includes state deaf-blind projects in every state, as well as Puerto Rico, the District of Columbia, the Pacific Basin, and the Virgin Islands. We are funded by the U.S. Department of Education. Our primary mission is to support state deaf-blind projects as they assist educators, agencies, and organizations to acquire the knowledge and skills needed to help children with deaf-blindness learn, access the general education curriculum, and successfully transition to adult life.

Created by: Sierra Phillips @mrs.phillijt

EHDI-PALS: EHDI-PALS is a web-based searchable national directory. It helps families, healthcare professionals, and state public health organizations to find pediatric audiology expertise for children ages birth to five. The website provides information about childhood hearing to support families and professionals through the process of screening, diagnosis, and intervention.

Lions Camp Merrick: Lions Camp Merrick provides a fun and exciting, week-long residential camping experience for children ages 6-16 who are diagnosed diabetic type 1, and children that are hearing or visually impaired. The camp can also accommodate organizations and businesses seeking to coordinate off-site team-building sessions or retreats.

Home : OPTION Schools, Inc. (optionlsl.org): OPTION Schools, Inc. is an international, non-profit organization comprised of listening and spoken language programs and schools for children who are deaf or hard of hearing in Canada, South America, and the U.S. OPTION Schools, Inc. advances excellence in listening and spoken language education by providing information and support to programs and school leaders. Member schools and programs, both individually and collectively, educate the public, professionals and policy makers as to what is possible for children who are deaf and hard of hearing in the 21st century.

Current OPTION Regular Members : Our Members : OPTION Schools, Inc. (optionlsl.org): browse the list of option schools and programs near you.

Signs of Fun Camp: Signs of Fun offers enriching day camps in Virginia and Hawaii. Deaf, hard of hearing children, and their siblings, ages 3 to 18 years old, are welcome to join the fun! Campers will have the opportunity to go swimming, fishing, and many more fun experiences with old and new friends. They will also enjoy hands-on art, games, and sports. Our day camp is rich with experiences that encourage and promote communication. We hope you choose to come and play with us this summer!

Registry of Interpreters for the Deaf: The Registry of Interpreters for the Deaf, Inc. (RID), a national membership organization, plays a leading role in advocating for excellence in the delivery of interpretation and transliteration services between people who use sign language and people who use spoken language.

The HIKE Fund, Inc.: The purpose of the Fund is to provide hearing devices for children with hearing losses between the ages of newborn and twenty years whose parents are unable to meet this special need financially.

Cochlear Implant Awareness Foundation: non-profit organization based in Springfield, Illinois. The mission of CIAF is to raise awareness of how cochlear implants restore sound to the hearing impaired and to provide cochlear implant equipment to qualified applicants in need.

Signing Time - Teaching Sign Language to children of all abilities & ages.: Our vision of the world is one in which all children – regardless of their abilities – can express themselves, feel valued and understood, and be supported in achieving their full potential.

Who Will Sign With My Deaf Child? | Rachel Coleman

• ASL • American Sign Language (lifeprint.com): What you are learning here is important. Knowing sign language will enable you to meet and interact with a whole new group of people. It will also allow you to communicate with your baby many months earlier than the typical non-signing parent! Learning to sign even improves your brain! (Acquiring a second language is linked to neurological development and helps keep your mind alert and strong as you age.)

Communication Junction: At Communication Junction, we are a team of speech pathologists and early educators that teaches families how to communicate and connect with their children through sign language, so they can develop a lifelong love of learning.

Let Them Hear Foundation: The Let Them Hear Foundation helps hearing-impaired individuals to H.E.A.R., specifically those lacking adequate access to funding and healthcare resources. LTHF provides Hearing services for underprivileged American youth; Education for professional and public sectors per cochlear implant hearing healthcare issues and practices; Access development for under-served persons through insurance advocacy and overseas medical missionary efforts; and Research concerning treatment for ear disease and function. Founded by world leader in ear surgery Dr. Joseph Roberson, M.D., LTHF operates in conjunction with the California Ear Institute in Northern California.

SonicCloud Personalized Sound: SonicCloud's speech intelligibility algorithm brings out unprecedented clarity while maintaining a completely natural sound quality. Our proprietary signal processing and patented self-tuning capabilities deliver unrivaled, personalized speech understanding across the entire spectrum of hearing ability.

Hearing Industries Association: The Hearing Industries Association (HIA) was formed in 1955 and serves as a forum for hearing aid manufacturers, suppliers, distributors, and hearing health professionals. Our members are responsible for the majority of the over 4 million hearing aids that are purchased in the United States on an annual basis. Today, HIA remains the only association in America to represent hearing aid technology. The Association provides companies a unique platform to communicate on hearing health and technology issues.

Sign Language 101 - Learn Sign Language Online Free

Hearing Aid Project: For those who require assistive devices, economics shouldn't be a barrier to hearing health. Driven by the missions of organizations like Sertoma and Hearing Charities of America, and through the generosity of so many others, hearing aids are now available to those who might otherwise go without.

Pocket Sign: Learning sign language will have you connecting with many more people in your community. There are many advantages to learning asl such as making new friends, teaching a baby how to talk and if your family is deaf or hard of hearing, Pocket Sign offers hundreds of video sign language ASL lessons packed in small sized lessons. Learn sign language effectively with our interactive questions.

Hands & Voices: parent-led, professionally-collaborative organization infused with the life experiences of adults who are Deaf or Hard of Hearing, that is dedicated to serving families with children who are D/HH without a bias around communication modes or methodology.

American Society for Deaf Children: The American Society for Deaf Children (ASDC) is committed to empowering diverse families with Deaf/Hard-of-Hearing children and youth by embracing full access to language-rich environments through mentoring, advocacy, resources, and collaborative networks.

Friends Like Me | SignOn: SignOn Friends like Me is a new subscription service within the SignOn Platform that promotes social language and peer to peer companionship in small groups. Deaf and Hard of Hearing (DHH) children connect with 2-3 other DHH children under the guidance of one of our DHH Adult Mentors. Through a live, two-way video session, Friends Like Me provides fun social learning experiences for DHH children around the country. SignOn Friends like Me is for Deaf and Hard of Hearing (DHH) children who use American Sign Language (ASL), those who use Oral Communication (do not use ASL) and those who use Total Communication (a combination of both oral skills and ASL). This Is a great opportunity for DHH children to connect with someone who is DHH similar in communication style, improve on their social skills, and to make new friends.

SignOn Connect: SignOn was created out of a need to practice American Sign Language live online with a Deaf Language Model - true language immersion. While Ashlee was studying to become a sign language interpreter, she became homebound and struggled to meet the required interaction hours with the Deaf Community. She was unable to go to the scheduled Deaf events or Deaf Socials. Through these struggles, Ashlee created the idea for SignOn! She felt there had to be a better way for students and others like her that wanted to interact with the Deaf Community but were limited by their schedules or could not travel.

Starkey Hearing Foundation: Starkey Hearing Foundation focuses on the training, educating and capacity building of the next generation of hearing care professionals in the developing world, who then give the gift of hearing to people in need. We believe hearing is a vehicle to reflect caring and to improve the lives of individuals, their families, and communities.

The HIKE Fund, Inc.: It is our joy to provide hearing devices for children with hearing losses between the ages of newborn and twenty years whose parents are unable to meet this special need financially.

The Miracle-Ear Foundation: The Gift of Sound™: The Gift of Sound is more than just a pair of free hearing aids—it's an opportunity to reconnect with the world. Working with a Hearing Care Professional at their nearest Miracle-Ear location, recipients of the Gift of Sound are fitted with hearing devices that meet their specific needs.

EHDI Annual Conference: The goal of the annual EHDI Conference is to enhance the implementation of comprehensive state-based Early Hearing Detection and Intervention (EHDI) programs.

Deaf Camps, Inc.: A volunteer-run non-profit organization dedicated to providing fun, safe, communication-rich camps that promote the physical, spiritual, and social development of Deaf/hard of hearing children and children learning American Sign Language.

Deaf Counseling Center: Deaf Counseling Center is a Deaf-owned and operated therapy, counseling, coaching, assessments and psychiatric and consulting practice staffed by Deaf licensed professional therapists. It is always Deaf Counseling Center's goal to offer accessible Deaf therapy services nationwide.

National Deaf Therapy - ASL Therapy by Deaf Therapists - National Deaf Therapy: From initial contact to intensive ASL therapy sessions, our team is here to center mental health care in every part of the human experience by offering full-service support. We are here to partner with you on your healing journey. We take care of the hassles, so you can focus on yourself.

BLINDNESS AND VISION IMPAIRMENT:

Navigating Blindness: This blog contains information about our day-to-day wins and challenges as well as blindness awareness, Braille advocacy, mainstream education, and inclusivity.

Xavier Society for the Blind: avier Society provides religious, spiritual, and inspirational reading materials in braille and audio to blind and visually impaired individuals worldwide. We are able to provide these materials free of charge thanks to the generous support of our donors. We support this community of faithful in understanding, developing and practicing their Faith. Our service began in 1900 and we hope to serve many more people in new and innovative ways for many years to come.

Lighthouse Guild: Lighthouse Guild provides exceptional services that inspire people who are visually impaired to attain their goals.

Lighthouse Guild | Tele-Support Groups: Connect with someone who "gets it" through Lighthouse Guild's tele-support groups. Our National Tele-Support Network for Parents of Children with Visual Impairment encourages parents to share resources, experiences, strength, and hope. Our Youth Transition Program helps students who are blind or visually impaired prepare for life after high school, including the transition to college. We also have groups for adults and a book club. Join us!

National Center on Deaf-Blindness: NCDB is part of a network of projects for children and youth with deaf-blindness (birth through 21) that includes state deaf-blind projects in every state, as well as Puerto Rico, the District of Columbia, the Pacific Basin, and the Virgin Islands. We are funded by the U.S. Department of Education. Our primary mission is to support state deaf-blind projects as they assist educators, agencies, and organizations to acquire the knowledge and skills needed to help children with deaf-blindness learn, access the general education curriculum, and successfully transition to adult life.

American Council of the Blind: To increase the independence, security, equality of opportunity, and quality of life for all blind and visually impaired people.

Vision Nanny: Vision Nanny aims to ensure that every child with CVI has access to personalized intervention by equipping special educators and parents with a suite of CVI-specific, customizable and interactive, vision stimulation activities. They can be used in both clinical settings and at home. Also, they can be accessed from a variety of devices like tablets, laptops, and smart TVs.

Be My Eyes - See the world together: Be My Eyes connects people needing sighted support with volunteers and companies through live video around the world.

CSB CARE – Independence Through Technology: CSB CARE's mission is to give clients independence through assistive technology. CSB CARE specializes in electronic braille for the blind and eye tracking communication and computer access for ALS and other neurodegenerative disorders.

Keren Or: Keren Or Jerusalem Center for Blind Children with Multiple Disabilities is 501(c)(3) nonprofit dedicated to the education and care of children who are visually impaired and also cognitively, developmentally, and/or physically disabled. Our mission is to provide our students with comprehensive care, stimulating educational exercises, and rehabilitative therapies designed to help them reach their full potential and lead lives that are meaningful and productive.

OneSight EssilorLuxottica Foundation: The OneSight EssilorLuxottica Foundation aims to eliminate uncorrected poor vision in a generation by creating sustainable access through an innovative approach to impact philanthropy, partnerships and raising awareness.

Partners for Pediatric Vision: The mission of Partners for Pediatric Vision is to turn possibilities into achievements for children with visual impairment and their families.

American Foundation for the Blind: The mission of the American Foundation for the Blind is to create a world of no limits for people who are blind or visually impaired. We mobilize leaders, advance understanding, and champion impactful policies and practices using research and data.

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Computers for the Blind: Computers For the Blind is determined to bridge the digital divide for the community of the blind and visually impaired in the US by providing affordable, accessible refurbished computers and training. We don't have any age or ability restrictions. We are an ally for the community of the blind and visually impaired and some of us are members. Our solutions are ready and accessible. They facilitate the individual to lead an independent and connected life – opening life-long opportunities for employment and digital equity. We provide customer guidance from purchase and beyond.

Lions Camp Merrick: Lions Camp Merrick provides a fun and exciting, week-long residential camping experience for children ages 6-16 who are diagnosed diabetic type 1, and children that are hearing or visually impaired. The camp can also accommodate organizations and businesses seeking to coordinate off-site team-building sessions or retreats.

WonderBaby: WonderBaby.org is dedicated to helping parents of young children with visual impairments as well as children with multiple disabilities. Here you'll find a database of articles written by parents who want to share with others what they've learned about playing with and teaching a blind child, as well as links to meaningful resources and ways to connect with other families.

Thriving Blind Academy: If you or your child have received the diagnosis of "blind" or "progressive vision loss" you might feel like you have no idea how to survive, let alone thrive. We understand how overwhelming it can feel to realize your lack of knowledge of blindness, and succeeding without sight. Thriving Blind Academy is your road map. With our help you can navigate a world not built for blindness. We help families and individuals like you take the next right steps so that you can move from pain to purpose and thrive.

Foundation Fighting Blindness: The urgent mission of the Foundation Fighting Blindness is to drive the research that will provide preventions, treatments and cures for people affected by retinitis pigmentosa, macular degeneration, Usher syndrome and the entire spectrum of retinal degenerative diseases.

Lighthouse Guild: Lighthouse Guild provides exceptional services that inspire people who are visually impaired to attain their goals.

FamilyConnect: FamilyConnect is a service offered by the American Printing House for the Blind (APH) to give parents and other family members of children who are blind or low vision–and professionals who work with them–a supportive place for sharing and finding resources on raising their children from birth to adulthood.

the independent little bee: I write about concepts directly relating to the Expanded Core Curriculum (ECC) for children with vision impairments. The ECC is a disability specific curriculum and is a vital part to the education of children with vision impairments.

Strategy To See: Strategy To See's Mission is to provide strategies, suggestions and techniques to parents, caretakers, teachers and other action heroes, who hope to encourage more consistent and efficient use of vision in children with Cerebral/Cortical Visual Impairment.

American Printing House: At APH we've been innovating products and technology to help people with blindness and visual impairment live and learn more independently since 1854, and we're not stopping any time soon.

20 best toys for visually impaired babies - Smart Toys (smart-toys.info)

Resources - APH | American Printing House

Classes and Services for the Blind and Visually Impaired | Braille Institute: Braille Institute is a non-profit organization whose mission is to positively transform the lives of those with vision loss. We offer a broad range of free programs, classes and services serving thousands of students of all ages helping to demonstrate that vision rehabilitation is a beginning, not an end. We serve the community from seven centers, and hundreds of community outreach locations throughout Southern California, and lead popular national programs like Braille Challenge and Cane Quest. Our staff and volunteers understand losing your vision can be scary, but we believe it is not the end of independence, but a new way of living.

CABVI – Central Association for the Blind and Visually Impaired – Live Your Vision: CABVI is one of the most comprehensive agencies in the Nation for individuals who are blind or visually impaired, and their mission is to assist people who are blind or visually impaired achieve their highest level of independence. Each day, their goal is to transform the lives of the blind or visually impaired.

Camp Abilities – CABVI – Central Association for the Blind and Visually Impaired: Camp Abilities-CABVI is a youth development program for children and teens that are blind or visually impaired. We engage kids who have low vision, to remain physically active by: participating in leisure activities, engaging in physical education classes, using technology and developing independent living skills that will last a lifetime. Children and teens discover what they CAN do.

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Little Bear Sees - Helping children with cortical visual impairment (CVI) learn to see: The goal of the foundation is to provide families in need with the information, products and tools to help their children with cortical visual impairment (CVI) learn to see. We believe that the fact that many children are either misdiagnosed or not diagnosed at all is tragic and avoidable. We strive to provide as many people as possible with information and tools to improve the lives of children with CVI.

FACIAL DIFFERENCES AND CLEFT RESOURCES:

ACPA | Educational Materials: ACPA Family Resources offers information about cleft and craniofacial care. ACPA's educational materials are written for affected individuals and families by cleft and craniofacial experts.

ACPA | Financial Assistance

ACPA | Paying for Treatment

AmeriFace

AmeriFace | State Resource Guide

Angel Faces: Angel Faces provides intensive education, healing retreats and ongoing support for girls and young women with burn/trauma injuries. Our mission is to provide inspiration and empowerment, so that they can achieve the optimum potential and develop meaningful relationships for themselves, their families, and communities.

Born a Hero | Books

Born a Hero Research Foundation: Our mission is to accelerate innovation and research to improve the quality of life for patients with FGFR Syndromes, including Pfeiffer Syndrome.

Smile Strong | Podcast on Spotify: I'm Alyssa Messick, a wife and cleft mama x2. This podcast was created to help women who were made for more smile stronger every day.

Camp Reflections: Camp Reflections for kids with cleft/craniofacial differences and their siblings is one week long and serves youth ages 8 through 16. Our camp is in New Hampshire on our own beautiful 116-acre lakefront property, about 1 hour and 45 minutes from Boston and 4 hours from New York City.

CCA | CARE PACKAGE REQUEST: This form is intended for use by members of the craniofacial community, including parents, caregivers, patients and siblings. Please only request care packages for people who fall in these categories and are undergoing treatment for a craniofacial condition, or are a member of a family that includes a person with a craniofacial difference (ie, siblings). Thank you for understanding.

CCA | Children's Craniofacial Association: Children's Craniofacial Association is a national, 501(c)3 nonprofit organization, headquartered in Dallas, Texas. Nationally and internationally, CCA addresses the medical, financial, psychosocial, emotional, and educational concerns relating to craniofacial conditions.

CCA | Resources

CCA Annual Family Retreat & Educational Symposium: CCA's Annual Family Retreat & Educational Symposium is held each June to provide individuals affected by a facial difference, their siblings and parents an opportunity to interact with others who have endured similar experiences. The unique format of the Retreat allows families to share ideas, problems and solutions and make life-long friendships. The weekend kicks off on Thursday with an Educational Symposium and the rest of the weekend allows time and activities to build new relationships and bonds of understanding and caring, which will lend support through both difficult and good times in the future.

CCA Kids Blog

CCD Resources | CCD Smiles: One of our primary goals is to provide those with CCD with helpful information, including: CCD specialists in your area, working with health insurance to cover medical procedures, case studies, and more.

Cleft Advocate

Created by: Sierra Phillips @mrs.phillijt

Cleft Advocate | Resources: Find a team, get information on Early Intervention services in your area, learn more about medical financing options and MORE! The State Resource Guide is currently being updated. The new format is designed to serve all programs of AmeriFace. Revised state pages will be rolled out as they are completed, marked in BLUE to denote new format.

cleftAdvocate | Facebook

Cleftopedia | Cleft Teams: The mission for Cleftopedia is to help new cleft parents with all of the choices they must make by offering a place to evaluate all options in one easy to read location. Cleftopedia is here to educate new and existing parents, and in no way is it meant to sway anyone in any direction. Remember – you, the parent, are your child's best advocate, and only you know what is best for your child. We're just here to help along the way!

Cleftopedia | Resources: Here is a listing of some of our favorite cleft information, support, and charity sites. Be sure to check them all out!

Cleidocranial Dysplasia Resources & Connections | CCD Smiles

ConnectMed International

ConnectMed International | Camp Cosmos: Camp Cosmos programs provide positive, inclusive and community-building events and activities for children with craniofacial and other visible differences and their families. We are based in San Diego but offer virtual services for families across the USA and Mexico!

ConnectMed International | Relevant Resources: One of our most pressing goals is to help support and bring together the communities of patients with congenital and acquired differences and their families. To that end, we have compiled the following resources which may be relevant to this community.

Contact Information for Manufacturers of Cleft Nursers

Cranio Care Bears: Our mission is to spread awareness, support & compassion through loving care packages to families of children facing surgery for craniosynostosis. Our care packages include items for the child & family to relieve the stress accompanying this very serious surgery.

Cuddles for Clefts: Cuddles for Clefts was founded with that mission in mind. It's not about the material things that are received in the package but our hope is that a much deeper meaning is felt. We hope that we can help be a source of comfort and support as you or someone you love undergoes a cleft related operation. We hope that we can come along side you and remind you there are others walking the same journey. There are others who care and you are never alone.

FACES | SERVICES: FACES: The National Craniofacial Association is a non-profit organization serving children and adults throughout the United States with severe craniofacial differences resulting from birth defects, injuries, or disease. There is never a charge for any service provided by FACES. Our service goals address three distinct areas: Client Travel, Public Awareness and Understanding, and Information and Support.

FACES | The National Craniofacial Association: FACES assists children and adults with severe craniofacial anomalies in the United States.

FACES Camp: a camp for kids with a facial difference!

Face the Future Foundation: Face the Future Foundation is dedicated to raising funds and public awareness in support of the multi-disciplinary patient care at the University of Illinois Craniofacial Center, so that every child with craniofacial differences can live a confident, joyful and fulfilling life.

Foundation for the Faces of Children | Useful Websites: The information on this page is provided as a service to visitors of our website and does not represent an endorsement by the Foundation for Faces of Children or an assurance that the information on these sites is accurate and up-to-date. The most reliable source of information about craniofacial conditions is a team of specialists associated with a major hospital.

Foundation for the Faces of Children: The Foundation for Faces of Children (FFC) is a New England-based, not for profit, 501(c) 3 organization. We provide clear, accurate information and other educational resources to children born with craniofacial differences and their families.

Fresh Start Surgical Gifts: Fresh Start Surgical Gifts transforms the lives of disadvantaged infants, children, and teens with physical deformities caused by birth, accidents, abuse, or disease through the gift of reconstructive surgery and related healthcare services, at no cost whatsoever to patients.

My Name is Lentil: Lentil, the cleft palate puppy with one big mission...to raise awareness for those with craniofacial differences.

Mia Moo Fund | Application For Assistance: We are here to help children born with cleft lip and palate find a place, seek treatment, gain support and love, and aspire to become who they want to be. The Mia Moo Fund receives hundreds of applicants, and we are motivated, dedicated and obligated to assuring that each applicant receives a response and are equal with-in the consideration process of delegation of funds.

Mia Moo Fund: The Mia Moo Fund is a fund of the Worldwide Foundation which is the 501(c)3 charitable organization. Your donations to the fund are tax deductible. The Mia Moo Fund is dedicated to raising awareness and funds towards treatments of cleft lip & palate. We invite everyone countrywide to participate with us as we strive to support one another, lend a helping hand and bring a smile to each and every child.

myFace | Craniofacial Care Centers: A child born with a facial difference may experience several physical and emotional challenges that need special attention and care. This care usually requires the expertise of an interdisciplinary care team to ensure that all problems are addressed and that your child's care is coordinated. Such interdisciplinary care is often provided at a craniofacial center. This page features some common questions and answers related to craniofacial centers.

myFace | The Genetics of Craniofacial Conditions: A genetics evaluation is an important part of the care of a child with a facial difference because it will help you better understand the cause of your child's condition and help you learn more about the condition itself.

myFace: Supporting the Craniofacial Difference Community: myFace is a non-profit organization dedicated to changing the faces – and transforming the lives – of children and adults with facial differences.

National Institute of Dental and Craniofacial Research: The mission of the National Institute of Dental and Craniofacial Research (NIDCR) is to advance fundamental knowledge about dental, oral, and craniofacial (DOC) health and disease and translate these findings into prevention, early detection, and treatment strategies that improve overall health for all individuals and communities across the lifespan.

Smile Train | Resources

Smile Train: Smile Train is the world's largest cleft-focused organization, with a sustainable and local model of supporting surgery and other forms of essential care. Over the last 20+ years, we have supported safe and quality cleft care for 1.5+ million children and will continue to do so until every child in need with a cleft has access to the care they deserve.

The Pathfinder Outreach Network: The Pathfinder Outreach Network is a system of networking families and individuals whose lives are touched by congenital and acquired facial differences...and much more.

A Beautiful Child | Welcoming a Baby with a Cleft Lip and Palate

Wide Smiles: Wide Smiles was founded more than two decades ago with the aim of providing cleft repair surgery coupled with subsequent comprehensive cleft healthcare to thousands of children in California.

Vascular Birthmarks Foundation | Travel Assistance for KTS: In honor of Brian's life, a fund supported by Brian's family and friends will be administered through the Vascular Birthmarks Foundation to assist families affected by KTS for travel expenses related to the diagnosis and/or treatment of KTS. We aim to enable sufferers to actively seek out experts who can help with early diagnosis and better management of their particular condition, and guide them through to a productive and fulfilling life.

Vascular Birthmarks Foundation: The Vascular Birthmarks Foundation is an international charitable organization that networks families affected by vascular birthmarks, anomalies, and/or related syndromes (VBARS) to the appropriate medical professionals for evaluation and/or treatment, provides informational resources as well as sponsors physician education, mobilizes medical missions trips, and supports research and programs that promote acceptance for individuals with birthmarks.

LIMB DIFFERENCE RESOURCES:

Travel Assistance for KTS - Vascular Birthmarks Foundation: In honor of Brian's life, a fund supported by Brian's family and friends will be administered through the Vascular Birthmarks Foundation to assist families affected by KTS for travel expenses related to the diagnosis and/or treatment of KTS. We aim to enable sufferers to actively seek out experts who can help with early diagnosis and better management of their particular condition, and guide them through to a productive and fulfilling life.

AUTISM RESOURCES:

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Interdisciplinary Technical Assistance Center | ITAC: The purpose of the Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities at AUCD is to improve the health of autistic people and people with developmental disabilities. The Center accomplishes this by providing technical assistance to interdisciplinary training programs (i.e., the LENDs and Developmental-Behavioral Pediatrics (DBP) programs) to better train professionals to utilize valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for children with AS and other developmental disabilities.

Sleep and Autism | Sleepopolis

Autism and Sleep: Empowering Children with ASD for Better Sleep | Slumber Yard (myslumberyard.com)

Devereux Advanced Behavioral Health: Devereux operates a comprehensive national network of clinical, therapeutic, educational, and employment programs and services that positively impact the lives of tens of thousands of children, adults – and their families – every year. Focused on clinical advances emerging from a new understanding of the brain, its unique approach combines evidence-based interventions with compassionate family engagement.

Autism & Grief Project: Autism and grief are both highly individualized, making each person's life experience and grief journey unique. This website was designed to help visitors navigate and support the often rocky journey of grief and loss. Our intent is to provide reliable information and helpful suggestions that respect and acknowledge the grief experiences of adults with autism and fully involve them in the grief process. Accordingly, information is presented visually and through text to enhance accessibility for all users.

Ascent Autism | Online Peer Groups | Help Your Child Socialize: Ascent Autism provides social skills group therapy. We help individuals with autism develop their social skills and grow social and emotional bonds with peers. Our expert-designed program from UCSF and Stanford Medical School has fostered lasting social abilities and friendships for over a thousand participants. Ascent Autism's program curates groups of peers on the spectrum and creates a safe and conducive space for them to practice their social skills in order to unlock deeper social and emotional bonds with one-another - and it works. Made with ❤ in California, Serving families nationally.

Nancy Lurie Marks Family Foundation: The Nancy Lurie Marks Family Foundation is committed to understanding autism from a scientific perspective, increasing opportunities and services available to the autism community and educating the public about autism. In pursuit of its mission, the Foundation develops and provides grants to programs in research, clinical care, policy, advocacy and education.

Parallel: Parallel partners with individuals and stakeholders worldwide to build pipelines that create inclusive opportunities, architect support ecosystems, and develop sustainable strategies for communities and businesses where Neurodiversity thrives. Our philosophy is prepare, educate, inspire, change, and create. We build opportunity on the post-secondary pipeline by preparing pathways to inclusive settings, educating for inclusion, inspiring meaningful corporate change, and creating supportive ecosystems. Together, we can make the world a more inclusive place.

Floreo | Research-based Virtual Reality Therapy for the Neurodiverse: At Floreo, we believe in creating safe, supportive digital spaces for neurodiverse people to practice critical skills and thrive. Floreo's research-based simulations are developed by clinicians, therapists, engineers and neurodiverse people.

Nancy Lurie Marks Family Foundation | Grants: The NLM Family Foundation supports autism-related endeavors in a variety of fields. For more information about our specific areas of interest, please visit Grant Categories.

Social Thinking: The Social Thinking Methodology provides evidence-based strategies to help people ages four through adult develop their social competencies, flexible thinking & social problem solving.

Carrie Cariello

GRASP: GRASP, the Global and Regional Autism Spectrum Partnership, is an Autistic and Neurodivergent led 501(c)3 non-profit improving and enriching the lives of our Autistic peers.

Directory | Autism Speaks: Find the Autism Services and Support You Need.

Autism Resources For Parents – The Ultimate Help Guide For Families: We invite you to download the guide and share it with other families who may benefit from this valuable resource. We hope that this guide will help you and your family navigate the unique challenges of parenting an autistic child.

Pathfinders for Autism – Improving the lives of individuals with autism and the people who care for them: Pathfinders for Autism works to support and improve the lives of individuals with autism through expansive, customized programming, and by providing resources, training, information and activities free of charge.

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Find Your Act Early Ambassador | CDC: Act Early Ambassadors expand the reach of the "Learn the Signs. Act Early." program and support their respective state's work toward improving early identification of developmental delays and disabilities, including autism.

Spectrum | Autism Research News: Spectrum began in 2008 as the News & Opinion section of SFARI.org. In the summer of 2015, we spun off to create an independent online identity. As we evolved over the years, we experimented with various types of articles and added dozens of voices — but one thing that has never wavered is our commitment to provide accurate and objective coverage of autism research. We invite you to add your voice to that important conversation.

Autism Watch | Quackwatch: The purpose of Autism Watch is to provide a scientific perspective on the many aspects of autism. This Web site is for families of autistic children (including adult children), practitioners treating autistic patients, and anyone else with an interest in autism.

Madison House Autism Foundation: To promote, model and advocate for the full inclusion of adults with autism and their families in the life of our communities; and to expand choice and opportunity in housing, employment, and social participation.

Think Safety | A Resource for Autism Safety Awareness (thinkautismsafety.org): The forums on this website contain advice and tips from experienced family members to first-hand experts. Because the challenges for an individual with autism evolve throughout the lifespan, the forums are specialized for each age demographic, from childhood to adulthood. The forum's purpose is to not only to provide information to promote safety, but to also empower and strengthen the autism community one post at a time.

Autism and Developmental Disabilities Monitoring (ADDM) Network Sites | Autism | NCBDDD | CDC: The Autism and Developmental Disabilities Monitoring (ADDM) Network is the only collaborative network to track the number and characteristics of children with autism spectrum disorder (ASD) and other developmental disabilities in multiple communities throughout the United States. Beginning in 2000, the ADDM Network has been tracking the number and characteristics of 8-year-old children with ASD. The program is now in its sixth phase of funding, and the ADDM Network includes ten funded sites and one CDC-managed site in Georgia.

SPARK: Join a growing community of families, autistic adults, and researchers working to understand autism and improve lives.

ITAC: Search Resources: This central hub contains information and resources that are relevant to MCH training program management and administration. Topic areas, and the resources highlighted therein, reflect commonly raised technical assistance needs related to program administration.

Academic Autism Spectrum Partnership in Research and Education | AASPIRE: ASPIRE conducts action research focused on improving the lives of autistic adults. We use a Community Based Participatory Research (CBPR) approach where autistic and non-autistic scientists and community members work together in all phases of the research process.

Autism, My Sibling, and Me | OAR (researchautism.org): Autism, My Sibling, and Me is a fun and engaging workbook for children between the ages of 5 and 10. A host of colorful cartoon characters accompany these siblings as they learn about what autism means for their brother or sister – and handle potentially stressful issues. Through fun activities and supportive content, this resource also helps children work through many of the autism-related questions they may have.

Summer Camp for Kids with High-Functioning Autism & Social Challenges in Maine (campalsing.com)

Autism, My Sibling, and Me PDF

Brothers, Sisters, and Autism: A Parent's Guide | OAR (researchautism.org): Brothers, Sisters, and Autism: A Parent's Guide to Supporting Siblings outlines what parents can do to support children who do not have an autism diagnosis. The topics range from dealing with perceived discrepancies fairly to facilitating a positive relationship between siblings. The guide also includes testimonials from families with autism who deal with similar issues. It can be read from start to finish or used as a reference tool to troubleshoot problems as they arise.

Camp Alsing: Camp Alsing is a traditional, co-ed, sleepaway summer camp in Maine for young people who might struggle socially. We embrace the unique personality of each of our campers and help them build the social and community connections they seek. We spend our days engaged in all the typical camp activities and optimize the organic situations that happen every day in a camp environment to build confidence and understanding in our amazing campers. Alsing campers might not have a specific diagnosis or come to us with diagnoses like Autism, ADHD, NVLD, and/or anxiety. All our campers want to make friends and build connections – and of course, have an awesome summer!

Seven Stars: Seven Stars is a program within the Elevations program, a Residential Treatment and Educational Center licensed to provide services for adolescents between the ages of 13 and 17. Seven Stars is an all-gender facility that bases its therapeutic environment on a strengths-based relational and social learning model. Within this structured milieu, a host of therapeutic activities take place. All activities are goal-oriented and address specific emotional and behavioral problems, developmental skills, and knowledge deficits.

National Autism Center at May Institute

Autism Parenting Magazine - everything you need to support your family

Special Needs Education | K-12 Education | With ACCEL: We are a nonprofit organization serving children and adults who have developmental disabilities, including autism spectrum disorder, behavior disorders and intellectual disabilities.

Autism PDC (unc.edu): The National Professional Development Center on Autism Spectrum Disorder (NPDC) was funded by the Office of Special Education Programs in the US Department of Education from 2007-2014. The NPDC developed free professional resources for teachers, therapists, and technical assistance providers who work with individuals with ASD. Resources include detailed information on how to plan, implement, and monitor specific evidence-based practices.

The Ultimate Resource Guide for STEM Students With Autism - UT Austin Boot Camps (utexas.edu)

Autism Treatments | Association for Science in Autism Treatment (asatonline.org): We promote safe, effective, science-based treatments for people with autism by disseminating accurate, timely, and scientifically sound information, advocating for the use of scientific methods to guide treatment, and combating unsubstantiated, inaccurate and false information about autism and its treatment.

Autism Education & Resources | Autism Speaks

The Arc's Autism Now Center | Autism Resource for parents, teachers, employers and individuals | National initiative of The Arc: Welcome to the Autism NOW Center. The nation's source for resources and information on community-based solutions for individuals with autism, other developmental disabilities, and their families. A national initiative of The Arc.

Autism Society: For 58 years and counting, the Autism Society, including our nationwide network of affiliates, connects people to the resources they need through education, advocacy, support, information and referral, and community programming.

Autistic Self Advocacy Network (autisticadvocacy.org): The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us.

Resource Library - Autistic Self Advocacy Network (autisticadvocacy.org)

Asperger / Autism Network (AANE) We are here for you!: The Asperger/Autism Network (AANE) provides individuals, families, and professionals with information, education, community, support, and advocacy

Brothers, Sisters, and Autism: A Parent's Guide to Supporting Siblings PDF

Life as an Autism Sibling: A Guide for Teens | OAR (researchautism.org): Life as an Autism Sibling: A Guide for Teens is a handbook for teenage (and even pre-teen) siblings that offers guidance on how to productively address feelings and challenges that may arise as an autism sibling. The resource covers a variety of topics; from explaining autism to friends and peers, to coping with a family dynamic that's different from what friends may experience. It also features testimonials from other teenage and young adult siblings who have "been there, done that."

Life as an Autism Sibling: A Guide for Teens

Organization for Autism Research | Helping Families Today (researchautism.org)

Action Behavior Centers: Five short years ago, we started off with one center in Austin, one BCBA, and big aspirations. After observing the lack of quality options for children with Autism, we set out to create Action Behavior Centers with a vision of transforming the lives of children with Autism and the clinicians who support them. In our quest to create something special, we ignited a movement. Today, with centers in Texas, Arizona, Colorado, and Illinois, we're well on our way to accomplishing our mission. Through our community of more than 3000 autism professionals, we serve thousands of children and families with Autism.

Created by: Sierra Phillips @mrs.phillijt

CHRONIC ILLNESS RESOURCES:

Center for Chronic Illness: CCI promotes well-being and decreases isolation for those impacted by chronic illness through support and education.

Chronic Illness Mental Health Professionals List - Google Sheets

MEDICAL, ADAPTIVE, AND ASSISTIVE DEVICE RESOURCES:

TKEN: As a non-profit 501c3, we're dedicated to connecting children with special needs to durable, adaptive equipment that helps them thrive. By growing our financial resources, we're better able to provide equipment to every family with little to no funding that requests assistance at no cost. This helps kids with special needs—from birth to age 21—embrace their lives and become active, independent members of their communities.

GPS SmartSole: SmartSole® is a GPS tracker hidden and sealed within a water-resistant shoe insert. THE KEY ADVANTAGE: SmartSole® is discreet and your loved one won't forget to bring it with them!

MEC Disabilities: Our Charity's Mission is to help motivate, elevate, and celebrate disabilities by helping educate the public, get adaptive equipment for children with disabilities, and getting ADA playground equipment for schools across the United States. Every child deserves an equal opportunity to learn, grow, and play no matter their abilities.

WAWOS | Wear: We believe that all children should be seen as the dynamic and exceptional beings they are. WAWOS Wear is a truly unique way for a child who uses assistive devices, to express their spirit and individuality. The simple design comes in small, medium and large sizes with five velcro straps to attach easily to different types of walkers.

Lending Libraries | AACcessible: We have composed a list of AT and AAC Lending Library programs across the country. We will make every effort to keep this listing up to date. If you know of a resource not listed here, please submit the listing to us and we'll add it to the directory.

PUMPER CAR: Pumper Cars originally were sold as fun toys for young kids. To Mike's surprise, he learned that his toy was becoming a very popular exercise therapy device at children's hospitals and with physical therapists treating children with special needs. Maybe it was fate that a guy who never got the chance to go into medicine ended up inventing a device that has been dramatically improving the lives of children with everything from Down syndrome and autism to cerebral palsy and spina bifida.

MobilityWorks: Our mission is what drives us to assist our clients in mobility so they can Be There for routine daily activities and special life events. We do this by training our team to listen to our clients' unique needs to fit them with the best mobility solutions, by maintaining the largest inventory in the nation of wheelchair accessible vehicles, by certifying our service teams and by making the products and services we offer accessible to everyone through our 90+ locations and Buy Direct program

WonderFold Cares – Wonderfold Wagon: WonderFold has had the privilege of donating to numerous wagons to nonprofits, organizations and even families in need. If you or a loved one are in need of a WonderFold Wagon, we would love to hear from you. Submit your story below for the opportunity to receive a WonderFold Wagon, on us.

BILLY Footwear | Fashion and Function For All: Smashing fashion with function, BILLY Footwear incorporates zippers that go along the side of the shoes and around the toe, allowing the upper of each shoe to open and fold over completely. Thus the wearer can place his or her foot onto the shoe footbed unobstructed. Then with a tug on the zipper-pull the shoe closes and secures overtop the user's foot. It's simple. It's easy.

Cubby Beds: Smart Beds for Special Needs.

UpLyft®: UpLyft® is the first seated self-transfer system between bed and wheelchair for people with limited mobility.

State Funding | BraunAbility: Many states have programs or services to help aid residents in acquiring the mobility equipment they need. Some grants are condition-based, while others are community-based. You can begin your state-by-state search below.

Ariana Rye Foundation: The Ariana Rye Foundation was developed to help families in need of medical equipment for their children with disabilities. We help dozens of families each year get equipment that insurance companies deem unnecessary or non-essential for these children. Not only is this equipment necessary for proper development, it helps build confidence in the children and eases the burden on the families caring for them.

McLindon Family Foundation: The mission of the McLindon Family Foundation (MFF) is to provide adaptive bikes to children with special needs so that they can build critical core strength, boost confidence and nurture friendships, all of which help these children maximize their potential and participation in society.

Open Wheelchair Foundation: The Open Wheelchair Foundation is a collaborative group of people, working together to make a low cost, light weight, easy to build, and easy to operate, motorized pediatric wheelchair for small children who are in need.

AACcessible: We believe that communication is essential to connection and opportunity and should be accessible to everyone-without limits.

Abilitare: Disability must not mean giving up our independence, our freedom to fulfill our dreams or contribute to the society. Our mission at Abilitare is to empower the disabled with the same level of communication and computer access as everyone else.

SonicCloud Personalized Sound: SonicCloud's speech intelligibility algorithm brings out unprecedented clarity while maintaining a completely natural sound quality. Our proprietary signal processing and patented self-tuning capabilities deliver unrivaled, personalized speech understanding across the entire spectrum of hearing ability.

Enabling Devices: What can you do today? What do you want to do tomorrow? Discover a range of products for people with special needs that put goals within reach. Working with individuals, parents, teachers and therapists, we find—or invent—the devices, toys and tools that help build more joyful fulfilling lives, From learning and play, to communication and independence, our products make the impossible, possible.

Chive Charities: Each week, we provide critical grants for recipients with life-altering or life-threatening needs. From therapy equipment like adaptive tricycles and robotic walkers to service dogs, wheelchair-accessible vans, and a wide range of mobility items, Chive Charities fills the gaps where insurance and other resources cannot.

Athletes Helping Athletes: Adaptive bike for individuals that have a permanent physical disability (severe mobility impairment - i.e paraplegia, quadriplegia, amputation etc).

BridgingApps: BridgingApps, a program of Easter Seals Greater Houston, is a community of parents, veterans, therapists, doctors, educators, and people with disabilities who share information on how apps and mobile devices can help people of all abilities reach their highest levels of physical, social and cognitive development.

Bellas Bumbas: Providing Wheelchairs to Young Children with Any Type of Mobility Challenge.

Control Bionics: Control Bionics offers a suite of assistive technology, including dedicated speech generating devices, to assist people living with complex communication and physical needs.

CSB CARE: CSB CARE's mission is to give clients independence through assistive technology. CSB CARE specializes in electronic braille for the blind and eye tracking communication and computer access for ALS and other neurodegenerative disorders.

FairPlay: FairPlay is a women-led, speech-language pathologist founded 501(c)(3) nonprofit organization that strives to make play accessible and affordable for all children, including kids with disabilities who may not be able to play with toys as they come off-the-shelf.

AngelSense: Unlike any other tracker, AngelSense was designed to provide maximum protection for those with special needs and dementia. It's important to keep in mind that watches, tiles, bracelets, etc. are not made to prevent wandering and are limited in their ability to help during an emergency when every second counts. Due to their size, they can't update in real-time all day, this limits their ability to provide an exact location if your child elopes.

Pediatric Rehab, Car Seats, Seating & Positioning, Walking Aids, Bathing, and Toileting. (inspiredbydrive.com): Special needs families inspired our product line, designed to provide positioning and mobility support at home, school, and on the go. Our products give families the freedom to play, engage, and participate in daily life, from sunup to sundown.

Laughing At My Nightmare, Inc.: At Laughing At My Nightmare, Inc., we work to improve the quality of life for people living with disabilities by providing free adaptive and medical equipment and assistive technology to people in need! We aim to supply devices and technology that enhance the lives of our clients and helps them live healthier, more comfortable, and more productive lives.

Variety's Care Program: Variety's Care Program delivers critical life-saving medical equipment and services, healthcare and well-being to individual children and children's health organizations.

Created by: Sierra Phillips @mrs.phillijt

AdaptAbilities: providing affordable switch adapted toys and devices that serve all age ranges, giving anyone with special needs the accessibility they deserve. AdaptAbilities seeks to stay on the cutting edge of children's toys, anticipating the latest trends and hottest buys to make sure they are available and accessible for everyone. Kids are constantly growing and want new toys to play with, so we want our toys to grow with them!

Special Tomato - Pediatric Adapted Equipment: Combining the experience of our therapists, engineers & seating specialists with Tim Bergeron, the original founder of Tumble Forms, the Special Tomato design team innovates new products that truly are clinically sound, versatile and affordably priced.

See Me Thrive: See Me Thrive Adapted Toys is a registered 501c3 tax-exempt, non-profit organization. We want to give anyone that needs an adapted toy the opportunity to have one at an affordable cost.

Cargo Trikes for Children with Special Needs or Disabilities: If you're considering a Bunch Bike for a family member with a disability, medical condition, or adaptive need, we'd love to help!

MaxMods: MaxMods is a 501c3 nonprofit corporation founded to assist people with physical limitations with modifications and adaptions of toys and devices. We conduct an event called Santa's Little Hackers that provides adapted toys for disabled individuals.

Santa's Little Hackers: Santa's Little Hackers is a seasonal toy drive to adapt toys. We make simple modifications to the electronics of toys and give them away. These adaptations make the toys accessible to individuals with disabilities so they can play independently. Santa's Little Hackers is an annual event put on by MaxMods. MaxMods is a 501(c)3 not-for-profit corporation chartered to 'make the world accessible for all' by identifying adaptations and modifications to make the world work for individuals living with disabilities.

MERU | Disabilities To Possibilities: Designing & building assistive equipment for people with disabilities.

itaalkautism: iTaalk Autism Foundation is a 501c3 non-profit organization dedicated to providing resources, education and assistive technology to individuals with autism and their stakeholders for the purpose of developing greater independence at all stages of life.

Danny Did Foundation: the Danny Did Foundation cautions that not all devices listed on this page are approved by the United States Food and Drug Administration. Unless noted, these resources are consumer products and not medical devices. Further, the Danny Did Foundation encourages and strongly recommends your communication with the manufacturers of these products, as well as consultation with doctors, to determine the possible efficacy of such devices for your situation.

Sensory Jungle: The highest quality sensory integration products at affordable prices. We want all parents to be able to provide the best for their kids. We're here to help parents, teachers, and therapists find high quality toys for their children with special needs.

Mobility and Access, Inc.: Mobility & Access, Inc. is a family owned and operated company located outside of Pittsburgh, Pennsylvania. We have been importing mobility products from Europe since 1995 and distribute them in the USA and in Canada and Australia. Our main goal is to promote outdoor recreation and enjoyment for special needs individuals and their families. Allowing inclusion and fun for the whole family.

Jonah & The Whale Foundation: Having trouble meeting your child's DME Needs? Jonah & The Whale Foundation wants to help! We can provide assistance in seeking out supplies from organizations that deal in donated durable medical equipment.

EazyHold: Our patented EazyHold design gives children and adults the ability to hold onto tons of items with ease. EazyHold straps are made of soft, flexible food-grade silicone, hypoallergenic and latex free. Wash in the dishwasher or clean with disinfectant wipes. These silicone cuffs can be sanitized at temperatures up to 500 degrees and won't degrade!

Friendly Shoes - The Shoe for All Abilities: Our goal is to create comfortable, functional, and stylish shoes allowing anyone to put on and take off easily. Friendly Shoes® increase mobility and independence by discretely accommodating more adaptive needs than any other shoe technology — without sacrificing fashion, comfort, or support.

Variety's Freedom Program: Variety's Freedom Program delivers vital life-changing equipment and services for mobility, independence and social inclusion to individual children and children's organization.

Freedom Concepts Inc.: Working with medical professionals, therapists, and families, each Freedom Concepts product is thoughtfully designed and hand built to accommodate the needs of individuals living with limited mobility due to cerebral palsy, spina bifida, muscular dystrophy, Angelman syndrome, Rett syndrome, visual impairment, and many others.

Gus Gear: Gus Gear's mission to improve the safety and quality of life for those facing medical challenges began more than a decade ago by its founder and CEO, Sarah Palya, in response to the ongoing medical journey of Gus, her son, who faced a myriad of medical challenges that left Sarah feeling overwhelmed and wanting to find a way for Gus to live a more "normal" life. Her biggest obstacle was protecting, securing, and taking care of his central line. Out of this challenge came our flagship product, the Central Line Vest. Since then, we've increased our product line and created a community for support.

Hannahtopia: At Hannahtopia we help you take the medical look out of your daily lives. Through products that are colorful to always brighten your day. No more boring drab pillowcases and incontinence pads for any of us!

Kids Mobility Network: Kids Mobility Network is a 501(c)3 non-profit organization providing children with disabilities with complex rehab technology and durable medical equipment such as wheelchairs, standers, adaptive bikes, activity chairs, and other medical equipment. We operate our organization with caring and integrity.

The M.O.R.G.A.N. Project: helping families of children living with diagnoses of so-called orphan diseases who needed help adapting to life in a world not designed for them.

J ROB FOUNDATION: We want to make a difference by providing adaptive sporting equipment to children with physical disabilities or challenges, who are 18 years of age or younger. The adaptive sporting equipment may include, but is not limited to racing wheelchairs, hand cycles, monoskis and bi-skis.

Christopher's Promise Christopher's Promise is a grass-root, non-profit initiative to provide children with special circumstances with the proper adaptive equipment.

Lili's Lift: Lili's Lift is a not-for-profit organization that seeks to empower and assist children with disabilities (as well as their families, friends and communities) through education, advocacy and volunteer opportunities. How do we do that? With your help, we provide the capital, building materials, and in-kind donations necessary to achieve one-time home renovation projects that will significantly assist children with disabilities and their families. It's a simple plan, really; we seek to improve the lives of those living with disabilities, one home at a time.

Click. Speak. Connect.: Click.Speak.Connect is a consultation agency which partners with clients such as educators and parents to promote better access methods, faster access, and superior overall device experiences in order to promote ease of learning new apps and language skills related to Augmentative and Alternative Communication (AAC). The end result we want to see is AAC users practicing and developing social skills. We also sponsor AAC support groups and have launched a new flagship product called the NadPen Stylus.

Mclindon Family Foundation: The mission of the McLindon Family Foundation (MFF) is to provide adaptive bikes to children with special needs so that they can build critical core strength, boost confidence and nurture friendships, all of which help these children maximize their potential and participation in society.

JOEY'S FRIENDS TOO: Our Mission is to assist in the purchase of medical equipment deemed necessary to promote independence and enhanced quality of life for children.

Kiddie Pool: The Kiddie Pool is a FREE Service Program that works like a fundraiser. Your family joins the program and a custom webpage is created for your child with special needs.

Life Rolls On: Life Rolls On is dedicated to improving the quality of life for people living with various disabilities. Believing that adaptive surfing and skating could inspire infinite possibilities beyond any disability.

May We Help – Creating Independence: Sometimes, a device is all that stands in the way of an individual with a disability achieving independence or pursuing their passion. When that device is not available in the marketplace, that's when May We Help's volunteers step in. They are a team of engineers, industrial designers, inventors, welders, woodworkers, seamstresses, doctors, occupational and physical therapists whose skill sets come together to design, build and deliver custom devices at no cost to hundreds of recipients every year.

Mighty Well: To transform the patient experience by providing innovative adaptive medical wear, digital learning, and a supportive community that enable patients and caregivers to maintain dignity and confidence.

Mike's Kids: The purpose of this foundation is to provide assistance via services, equipment, education, special care and respite support to children with special needs and their families.

Created by: Sierra Phillips @mrs.phillijt

My Gym Foundation: nonprofit dedicated to helping children with disabilities and those struggling financially by awarding critically-needed gifts that improve their quality of life.

NAA's Give A Voice Program: The intent of NAA's Give A Voice program is to provide the opportunity for meaningful, effective communication to individuals with autism who are nonspeaking or unreliably speaking, and whose communication challenges put them at increased risk of injury or harm.

Official Site of LifeVac | Choking Rescue Device that Saves Lives

RareWear Program: The RareWear program connects rare disease patients to medical device providers to offer free devices to help patients better monitor and manage their condition. RareWear is an ongoing program and patients are welcome to apply throughout the year.

Rehabilitation Engineering and Assistive Technology Society of North America: RESNA, the Rehabilitation Engineering and Assistive Technology Society of North America, is the premier professional organization dedicated to promoting the health and well-being of people with disabilities through increasing access to technology solutions. RESNA advances the field by offering certification, continuing education, and professional development; developing assistive technology standards; promoting research and public policy; and sponsoring forums for the exchange of information and ideas to meet the needs of our multidisciplinary constituency. RESNA is a 501 (c) 3 not-for-profit membership association.

Resource Directory | Assistive Technology Product Guide: The Resource Directory is a culmination of an extensive, year-round search for the latest software, hardware and other assistive technology products that are on the market today, as well as their producers. It is a tool to assist members, discover, research and compare.

Tadpole Adaptive | MobilityFunder®: We all know how limited funding options & high costs make it difficult (or impossible) to get the adaptive gear you need. Sometimes we all need a little extra help. Tadpole Adaptive is proud to offer

Suzy Foundation: a certified 501 C-3 non-profit specializing in helping special needs individuals with the cost of assistive devices. Today, Suzy is doing great in school, happy, and

The Parker Lee Project: The Parker Lee Project is a 501c3 nonprofit organization dedicated to helping the families of children with medical needs obtain the supplies/equipment, education, and support they need.

MobilityFunder® as a flexible crowdfunding or group gifting solution. It's unlike the other options that may have hidden fees, platform costs, and always have transaction charges. It's a simple, powerful and easy way for you to "Thrive from Your Hive!"

The Cooper Foundation Cleveland: Our mission is to assist children and young adults with disabilities get the help they need. The assistance may be funding for therapy, a summer camp, or devices/equipment to help with everyday living. We want to provide the "extra help" these individuals need to reach their full potential.

Variety of The United States: Variety's Future Program delivers crucial life-enriching communication equipment and services, education and self-esteem to individual children and children's organizations. Together through the Future program we enrich children's lives by granting items and services that provide communication, education and self-esteem. Grants under the Future program are made to individual children and children's organizations.

The Jiselle Lauren Foundation: The Jiselle Lauren Foundation exists to provide financial support and a sense of community to as many children and their families as possible, regardless of disability or diagnosis.

The LENN Foundation: The LENN Foundation is a 501(c)(3) charity that provides grant opportunities for children with cerebral palsy to receive the pediatric intensive therapies they need to thrive.

The MobilityWorks Foundation: The MobilityWorks Foundation was founded in 2011. Headquartered in Akron, Ohio, The MobilityWorks Foundation is a non-profit organization that offers transportation support and services to special needs individuals, families, and organizations throughout the United States.

The Safety Sleeper: We are honored to contribute to the special needs community with the innovation of The Safety Sleeper and serve families around the globe as a Woman-owned Business. And we're proud of the recognition we receive for our commitment to safe sleep and special needs!

thriving. Please join us in helping enrich the lives of individuals with special needs.

Wheelchairs 4 Kids: nonprofit dedicated to improving the lives of children with physical disabilities by providing wheelchairs, home and vehicle modifications as well as other assistive equipment at no charge to the families.

Created by: Sierra Phillips @mrs.phillijt

Welcome to Friends of Man: At Friends of Man we are a 501(c)(3), non-profit, tax-exempt charity using 100% of donations for charitable assistance. We work through Referring Professionals (caseworkers, case managers, healthcare workers, social workers, school counselors, teachers, clergy) who apply on behalf of their patients and clients needing mobility equipment, prosthetics, glasses, dentures, hearing aids, and much more!

ADAPTIVE CLOTHING AND SPECIALIZED CLOTHING RESOURCES:

Abilitee Adaptive: I started Abilitee with one goal: to design stylish adaptive clothing and accessories for chronically ill and disabled people. Over the past few years, we've grown our mission to include advocacy, sustainability, and community-building, because we believe all of these to be necessary parts of a changing global industry. Why is this important? Because in a truly inclusive world, 'adaptive' won't be its own separate clothing category, it will be a consideration for all designers to think through, when designing mainstream fashion lines.

AdaptableSnapables: AdaptableSnapables clothing for G-tubes & ostomies.

Amanda Hope Rainbow Angels : Amanda Hope Rainbow Angels supports the here and now needs of families impacted by childhood cancer and other life-threatening illnesses through Comfort and Care counseling, Comfycozy's for Chemo adaptive apparel, Financial Assistance, and Major Distractions events.

Benik Corp.: Benik Corporation is a family-owned company with pride in our American-made products. Established in 1983, Benik has a long history of developing quality medical and athletic neoprene products for adults and children. The availability of individually fitted and custom designed products has distinguished Benik as a leader and innovator in its field. Our product line features many original designs, including our patented method of joining custom-moldable thermoplastic and neoprene materials to form a supportive and comfortable splint.

BILLY Footwear: Smashing fashion with function, BILLY Footwear incorporates zippers that go along the side of the shoes and around the toe, allowing the upper of each shoe to open and fold over completely. Thus the wearer can place his or her foot onto the shoe footbed unobstructed. Then with a tug on the zipper-pull the shoe closes and secures overtop the user's foot. It's simple. It's easy.

C.C. Moo LLC Adaptive Clothing: Offering stylish and discreet adaptive clothing, changing the quality of children's lives one zip and snap at a time.

Cape Ivy: Cape Ivy, a 501(c)(3) nonprofit provides warmth, comfort and support to children who have chronic or critical illnesses and their families. Cape Ivy provides fleece ponchos to children in the hospital because robes, sweaters and jackets don't work well with IV lines and other medical equipment. Cape Ivy is a resource for families experiencing long-term hospitalization of children.

Clothing | Helps For Heroes

Fearfully and Wonderfully Made| Compression Onesie| Support Binder: The Compression onesie is patent pending and handmade with love by me! My hope is that this compression onesie will help so many other children as it has helped my son and give a little bit of relief to the parents out there too!

Houdinies: Houdinies, a product we're proud to stand behind, and a product that not only helps those who have similar stories as ours, but one that's versatile and can also be helpful for children with special needs. On this journey we've learned through our amazing community that Houdinies reaches children with autism, sensory processing disorders (SPD), and motor skills disorders. We're proud to provide parents an escape-proof pajama they can depend on.

ikiki | Shoes Kids Love: Because the squeaker is placed in the heel of the shoe the sound encourages children to step "heel first", bringing their weight down on the heel of the foot and then transferring it to the toe as they step forward. This produces the delightful squeak that kids love so much about our shoes and motivates them to correctly put weight on their heels first. It's a great way to break that toe walking habit.

Koolway Sports: Koolway Sports designs and manufactures outerwear for individuals with disabilities, enabling them to achieve their maximum level of independence in all aspects of their life!

Kozie Clothes: Kozie Clothes is committed to serving the unique need for stylish, fun, and therapeutic clothing and products for the Pediatric Special Needs community. At Kozie Clothes we believe that all children are unique, and deserve to feel comfortable and happy every day. We have a wide range of sensory engineered clothing and solutions for kids of all ages, as well as products designed for toddlers, newborns, and preemies who require ongoing medical care.

Little Keeper Sleeper: Our goal is to help as many people with children who remove their sleepers and diapers. We have heard some extreme stories about what happens once that diaper comes off! (We'll spare you the details.)

Littlest Warrior: Spreading joy, awareness and inclusion one rad tee at a time. We believe that everyone has value and we want to shout their worth from the rooftops.

LUKE'S FASTBREAKS: Luke's FastBreaks supports children, adolescents and young adults diagnosed with cancer or chronic/extended illnesses. We strive to promote normalcy and restore dignity during treatment by replacing the hospital gown with our unique medical shirts. #BeStrong #NoMoreHospitalGowns

Patti + Ricky: Patti + Ricky is the Adaptive Fashion Marketplace for adults and kids with and without disabilities, chronic conditions, patients, seniors, and caregivers.

Ready Set Romper®: Comfy, practical, soft, and G-tube friendly, our bamboo baby rompers are easy to put on and off, making everyday dressing hassle-free. Free from snaps, clips, and zippers, our rompers make diaper changes a breeze, with no need to remove the entire outfit, keeping baby warm and happy during their diaper changes. Plus, the clever arm and leg cuffs are designed to 'grow' with your child, allowing them 3-4x the typical wear time out of their comfy romper.

See Kai Run Adaptive Footwear: Get to know our Adapt styles specially designed to accommodate orthotics such as AFOs, SMOs and custom insoles. This sneaker is customizable for any child. Extra long straps fit around orthotics but can also be cut to fit.

SPIO: SPIO's parent company, Children's Therapy Center, is the largest and most comprehensive independent nonprofit pediatric therapy program in Washington State. Since 1979, they have provided essential services for children with special needs including physical, occupational and speech therapy; early intervention services; and parent education and support. Last year, Children's Therapy Center served over 3,000 children in Western Washington. All proceeds made through the sales of SPIO® are used to help fund Children's Therapy Center's mission of serving children with special needs, and their families.

Spoonie Threads: Spoonie Threads, a female-founded company, brings a unique understanding of both medicine and fashion to our line of adaptive apparel and accessories. Our designs are created from expert opinions—yours! Because it's about time your self-expression, confidence and overall fearless-ness were combined with products that meet your individual needs. We want you to feel life is easier, better, and more manageable because you found a product that makes you feel great.

StomaStoma: We feel there is something powerful about using humor and joy to tell our stories. Our deepest hope is that these designs can help empower you to do just that. We know that art on shirts isn't going to change the world but we believe it can be one part of taking an overwhelming situation and make it a little bit better.

The Charlotte Letter: Clothing made with medically necessary adaptions.

TheraTogs: TheraTogs are orthotic undergarment and strapping products that give individuals with sensorimotor impairment a highly effective modality for improving postural alignment and stability, movement skill and precision, and joint stability. TheraTogs are an FDA-registered Class I medical device.

Tubesies – Tube Feeding Friendly Bodysuits: Our bodysuits were created by a Neonatal Intensive Care Unit (NICU) Nurse who saw a need for an easier way to access a child's feeding tube port. Each bodysuit has a waterproof flap, medical grade velcro, and a compartment to hold and change out gauze. Designed to be compatible with a gastrostomy tube (G-tube), jejunostomy tube (J-tube), and PEG-tube.

ZooVaa: Childrens Clothing

Created by: Sierra Phillips @mrs.phillijt

FEEDING TUBE RESOURCES:

Tubie-Tums | Belfast | Facebook: I'm a art teacher and become a tubie mum in 2020 at the start of a global pandemic and now I enjoy making tubie supplies!

PegPads - softest, most absorbent g-tube pad: Softest, most absorbent g-tube/j-tube pad.

NoTubes experts for tube weaning and feeding therapy: We treat children and adolescents who have difficulty eating, and we specialize in weaning tube-fed children.

3Dtubiedad - Etsy: maker of amazing accessories to make tube feeding easier!

4EverBold Program Details - Oley Foundation: To enrich the lives of those living with home IV nutrition or tube feeding through advocacy, education, community and innovation.

Baby-care-products-chart-TLG-9-2016-1.pdf (lookingglass.org)

G-PACT: G-PACT is a 501(c)(3) non-profit organization that provides services to patients who suffer from digestive tract paralysis including Gastroparesis, Chronic Intestinal Pseudo-obstruction, and Colonic Inertia. We reach out to over 35 countries and all 50 states. We focus on a variety of options and provide services and information completely free of charge. We are staffed completely by volunteers, so 100% of donations go to support our activities.

Access Cards | G-PACT: The access cards below may be printed and used as needed. To download the card, simply right click on the image and save the image to your computer.

Tubie Solutions: We became a Tubie Family with our daughter Lacey and have struggled, like most, with common Tubie problems. Using Richard's 20 years of CAD design experience, we started producing 3D printed products for our own personal use which quickly turned into a series of creative solutions to solve storage and organization, priming, filling, continuous feeding, traveling, and so much more.

Adorabelly Designs: Our mission is to make every belly adorable! Children and adults alike who have g-tube, j-tube or other medical assistance deserve to feel special...because they are. Our mission is to create fun, functional and fashionable tubie covers (gtube pads) to help reduce granulation tissue and skin irritation.

Amazon.com: My belly has two buttons: A Tubie Story: 9780997771312: Lee, Meikele, Robertson, Rebecca: Books

ASPEN (nutritioncare.org): Leading the Science and Practice of Clinical Nutrition.

Avery's Hope - Avery's Hope Caring for Rare #CaringForRare (averys-hope.org): Avery's Hope provides financial assistance to the rare, ultra-rare and undiagnosed pediatric GI patient families facing out-of-pocket and insurance denied expenses.

Feeding tube care packages | Jude's Totally Tubular Packages (judestotallytubularpackages.com): Here at Jude's Totally Tubular Packages, we are driven by a single goal; to do our part in making tubie lives just a little bit easier, and to brighten days with our packages and products. All of our relationships are built on the foundation of making the world a better place for our children and yours. We strive to build productive relationships and make a positive impact with all of our pursuits.

Dysphagia Food Bank — Dysphagia Outreach Project: The mission of The Dysphagia Outreach Project's Dysphagia Food Bank is to provide tangible assistance to low-income individuals with dysphagia across the lifespan by providing access to thickeners, pre-modified foods, therapy tools, oral care supplies, and adaptive equipment. Insurance coverage for the above-mentioned supplies is inconsistent, and more often than not, insurance companies refuse to pay for dysphagia supplies, resulting in a significant financial burden for many individuals with dysphagia.

Dysphagia Outreach Project: Providing Assistance for Individuals with Swallowing Disorders Across the Lifespan. Our mission at The Dysphagia Outreach Project is twofold. Part one is to help provide assistance for those individuals for whom accessibility of dysphagia supplies is limited due to financial hardship. The other part of our mission is to provide education and support to the dysphagia community at large about when it is appropriate to recommend and utilize these same supplies.

U Deliver Medical: Making life easier for the home tube feeder is at the heart of everything U Deliver Medical does. Tube feeding supplies designed for nutrition delivery in hospitals do not meet the needs of the home tube feeder. We have the feeding tube supplies that the home tube feeder needs.

Tubesies – Tube Feeding Friendly Bodysuits: Our bodysuits were created by a Neonatal Intensive Care Unit (NICU) Nurse who saw a need for an easier way to access a child's feeding tube port. Each bodysuit has a waterproof flap, medical grade velcro, and a compartment to hold and change out gauze. Designed to be compatible with a gastrostomy tube (G-tube), jejunostomy tube (J-tube), and PEG-tube.

Enteral Feeding Tube Supplies & Resources | TubeFed: A comprehensive guide to tube feeding, all in one place.

Everything You Need as a Tubie Parent: Emergency G-Tube Kits – welcome to hour life (itshourlife.com)

Feeding Matters - Serving Kids with Pediatric Feeding Disorder: Feeding Matters is the first organization in the world uniting families, healthcare professionals, and the broader community to improve the system of care for children with pediatric feeding disorder through advocacy, education, support, and research.

Feeding Tube | 10 Myths Every Feeding Tube Family Wants You to Know (kidnurse.org)

FreeArm (freearmcare.com): Consistent feeds and infusions anywhere, anytime. With the FreeArm's bendable arm, you can take the guesswork out of how high to hold the gravity syringe and keep lines free from kinks.

Friendship Circle / Resources: 15 Companies Providing Clothing and Accessories for Children with Feeding Tubes.

Growing Independent Eaters Feeding Tube Weaning Services (gieaters.com): Our goal is to provide parents of tube-fed children a path towards joyful, relaxed oral eating while providing the support their families need throughout the process: whether you're just beginning, in the middle or near the end of a wean, we are here to help you succeed.

GTube Family Support | QuinnEssentials: We created this organization to support pediatric families making the transition to tube feeding with the goal of sharing our knowledge to make your journey as smooth as possible.

Gus Gear Central Line Vest and More | Gus Gear: Gus Gear's mission to improve the safety and quality of life for those facing medical challenges began more than a decade ago by its founder and CEO, Sarah Palya, in response to the ongoing medical journey of Gus, her son, who faced a myriad of medical challenges that left Sarah feeling overwhelmed and wanting to find a way for Gus to live a more "normal" life. Her biggest obstacle was protecting, securing, and taking care of his central line. Out of this challenge came our flagship product, the Central Line Vest. Since then, we've increased our product line and created a community for support.

Kids With Tubes: support for parents and caregivers of tube-fed children.

Hospital gifts for kids | Kids Hope Chest: We strive to provide a fun and safe alternative to traditional retention tape and dressings.

How-to's & Education on Tube Feeding | Nestlé Health Science USA (nestlehealthscience.us): Mytubefeeding is an online resource for caregivers, parents and individuals who are new to tube feeding and the options available to them.

Kate Farms | Plant-Based Tube Feeding Formulas & Shakes: Plant-based products scientifically designed to provide you with everything you need and nothing you don't.

KulCreations - Etsy: maker of tubie pals from Newport News Virginia.

Medi Teddy Non Profit (medi-teddy.org): Providing Comfort to Pediatric I.V. and Enteral Feeding Patients.

Mica Hammond Fund - CHARITYSMITH: Mica Hammond Fund wants to help special needs families who have decided to bear the expense of making food for the G-tube kids.

Mica Hammond Fund | G-tube diets form - CHARITYSMITH: The Mica Hammond Fund intends to give awards totaling approximately $2000 annually, periodically as needed, to help pay valid noninsured expenses related to and incurred by needs-based families that use blended diets for G-tubed special needs children.

My Tubey - Welcome to My Tubey Books! Children's books for tube fed kids: A colorful and educational book collection for tube fed kids and their families! My Tubey Books gives tube fed kids stories and characters they can identify with, while helping to educate, raise awareness, and normalize the many ways that people receive nutrition.

A Simple Patch: We design and manufacture adhesives that help make life a little easier for those needing extra security for their medical devices or wanting to add colour and fun!

NASPGHAN - Home: The mission of NASPGHAN is to be a world leader in research, education, clinical practice and advocacy for Pediatric Gastroenterology, Hepatology and Nutrition in health and disease.

Neocate Product Access | Insurance Coverage & Reimbursement: The health insurance landscape can be confusing. At Neocate, we offer a free reimbursement service that can help you find the Neocate product access and coverage so your child can thrive. This service is called Nutricia Navigator and it helps you do just that, navigate.

NgBuddies: We provide tubie tape in a variety of beautiful designs. Perfect for all ages. Our tape is Hypoallergenic and so soft and gentle on your little ones cheeks they will barely know it is there. So many designs to choose from, hopefully putting a bit of fun into the not so nice bits of having a feeding tube.

Oley Foundation: To enrich the lives of those living with home IV nutrition or tube feeding through advocacy, education, community and innovation.

Functional Formularies: The world's first shelf stable real, whole foods feeding tube formula made from certified organic, plant-based ingredients. We are proud to serve patients, care givers, and clinicians around the world with the best nourishment humanly possible to help them thrive.

QuirkyDad - Etsy: Creator of the Flying Squirrel Pump holder and more!

Ready Set Romper® | Game Changing Bamboo Baby Rompers: Comfy, practical, soft, and G-tube friendly, our bamboo baby rompers are easy to put on and off, making everyday dressing hassle-free. Free from snaps, clips, and zippers, our rompers make diaper changes a breeze, with no need to remove the entire outfit, keeping baby warm and happy during their diaper changes. Plus, the clever arm and leg cuffs are designed to 'grow' with your child, allowing them 3-4x the typical wear time out of their comfy romper.

Real Food Blends: Meals For People with Feeding Tubes | Real Food Blends

Skin Care for Feeding Tube Sites - Together by St. Jude™ (stjude.org): If your child needs a feeding tube for enteral nutrition, it is important to take care of the skin around the tube. This will reduce discomfort and lower the risk of infection and other problems. It is important to know what skin problems can occur, why they happen, and how to address them if they develop.

Spoonie Threads | Adaptive Apparel | Diabetes, Ostomy & Tubie Care – SpoonieThreads: Spoonie Threads, a female-founded company, brings a unique understanding of both medicine and fashion to our line of adaptive apparel and accessories. Our designs are created from expert opinions—yours! Because it's about time your self-expression, confidence and overall fearless-ness were combined with products that meet your individual needs. We want you to feel life is easier, better, and more manageable because you found a product that makes you feel great.

There's More Than One Way to Eat!: A My Tubey Book: Merritt-Rubadue, Rhiannon, Merritt-Rubadue, Rhiannon: 9781461065739: Amazon.com: Books

TotallyTubularCo - Etsy: Patterned or Custom Tubie Tape from Virginia.

Tubie Friends – Taking the fear out of feeding tubes, one Tubie Friend™ at a time…: Tubie Friends a non-profit group that is administered by volunteers who have family members with feeding tubes and want to use their experiences to make life easier for the thousands of children relying on feeding tubes for their nutrition. Tubie Friend Surgeons (TFS) are volunteers who care for or love tube feeders and donate their time and resources. Many of us are still in the trenches with you, which means that sometimes our kids have surgeries, procedures, tests, or hospital stays that takes our time away from Tubie Friends applications and processing.

PEG Feeding Tube Comfort Care | Facebook: We are a small, female owned business striving to make feeding tube care a little more comfortable.

Tubie Buddies | Maidstone | Facebook: Tubie Buddies is a way of helping children, adults and families with feeding tubes. Based in the UK.

Tubie Life Adapted Tube Feeding Backpacks, Tubie Tape and Accessories: My products bring fasion together with self confidence growing designs and putting our own stamp on the equipment that keeps us alive. It all started when I was sent home with a bag from the home feeding company that was... well... boring, black and inpractical. I couldnt carry anything but my feed and pump and felt my medical needs were becoming my personality. I wanted to change this to help others in my position, so Tubie Life was created.

Tubie Pockets: Providing discretion & comfort for anyone with NG, NJ or G-Tube feeding systems!

TubieeGo™ | Feeding tube bags, backpacks and accessories for all ages – TubieeGo Ltd: Our bags are different to other feeding tube bags because they include a lightweight and strong insert to hold your feed securely. The TubieeGo™ insert is not only light, it also creates an ergonomic support for your back by distributing the weight of your feed. This ensures no pressure points develop whilst you are wearing the bag - either on your body or within the feed containers and feeding tubes.

TubieProud - Etsy: Custom made unique gifts for medically complex children and families.

TubieTalk: TubieTalk is an online community, backed by healthcare professionals, where tube feeding families can connect by sharing first-hand experiences and valuable knowledge to create advocacy.

Created by: Sierra Phillips @mrs.phillijt
Tummy Tunnels | When you need a tunnel to your tummy:
Adaptive clothing for tube fed children.

Tyler Takes a Taste - Feeding Matters: Tyler Take's a Taste is the story of a happy, busy young boy who loves to move his body: he loves to run, jump, climb, swim and dance! But he does NOT love to eat! Written as a "read together" book for parents and children to share, Tyler Takes a Taste follows Tyler and his family on a journey to better nutrition and happier, less stressful mealtime

Wallypop & Boulevard Designs: medical and tube feeding accessories.

PT/OT/SLP RESOURCES:

Able Appetites | Facebook: Resources + community for parents feeding kiddos with #downsyndrome.

Best Special: Best Special aims to reduce the amount of time dedicated to researching, purchasing, testing, and wasting money on children's products that may not work for their child, allowing caregivers to direct precious time at helping their child progress. Our most immediate knowledge is of products related to hypotonia, sensory issues, and developmental delay, and most we describe have been recommended or approved by speech, feeding, occupational, and physical therapists. However, recommended items for these conditions often parallel needs for other conditions and can be leveraged to children with adjacent needs.

The Speech Solution: To minimize planning and set-up time for speech pathologists, teachers and parents while maximizing a child's therapy time.

Tar Heel Reader | Books for beginning readers of all ages: Welcome to the Tar Heel Reader, a collection of free, easy-to-read, and accessible books on a wide range of topics. Each book can be speech enabled and accessed using multiple interfaces, including touch screens, the IntelliKeys with custom overlays, and 1 to 3 switches.

Medical SLP Collective | Membership for Medical Speech Language Pathologists: FREE TOOLS FOR MEDICAL SLPS.

GalileoUSA: A pioneer in the field of side-alternating whole body vibration (WBV) training and therapy, Galileo leads the industry as an innovator in the development of devices for professional facilities and individual users alike.

Dynamic Movement Intervention: Dynamic Movement Intervention (DMI) is a comprehensive intervention used by physical and occupational therapists to treat children with gross motor impairments.

PUMPER CAR: Pumper Cars originally were sold as fun toys for young kids. To Mike's surprise, he learned that his toy was becoming a very popular exercise therapy device at children's hospitals and with physical therapists treating children with special needs. Maybe it was fate that a guy who never got the chance to go into medicine ended up inventing a device that has been dramatically improving the lives of children with everything from Down syndrome and autism to cerebral palsy and spina bifida.

Project Core: The Project Core implementation model is designed to empower teachers and classroom professionals to provide students with access to a flexible Universal Core vocabulary and evidence-based communication instruction.

Hypervibe USA: From medical organizations, to professional sports teams, to recognized universities, Hypervibe is the preferred partner for Whole Body Vibration therapy.

Crawligator: The Ultimate Crawling Toy for Babies: Developmental crawling toy.

Smart Toys - The ultimate guide: At Smart-Toys.Info, we pride ourselves on using our years of industry knowledge to recommend the best toys for developing minds. We strive to bring you expert opinions on play and child development.

Floreo | Research-based Virtual Reality Therapy for the Neurodiverse: At Floreo, we believe in creating safe, supportive digital spaces for neurodiverse people to practice critical skills and thrive. Floreo's research-based simulations are developed by clinicians, therapists, engineers and neurodiverse people.

Created by: Sierra Phillips @mrs.phillijt

TalkTools - Speech & Feeding Therapy Tools, Techniques, & Training: Our signature items, like the Horn and Straw Hierarchies and Jaw Grading Bite Blocks, are now household names in the oral placement field. Leaders in the industry for 30 years, TalkTools® has positioned itself as the authoritative worldwide source for oral placement, sensory, and feeding therapy supplies.

Bridging Child Development: Online courses that support your child's language development and ensure academic and social success

Communicative Disorder Adapted Books | Fastsnail Publisher: At Fastsnail Books Publisher, we believe that when one book closes, another opens. That's why we want to be sure that you conveniently find your next favorite for your kid so the adventure never ends. Pick a story by visiting the book's page. We make AAC Adapted books for children who either can not read, are partially impaired, have a language barrier, communicative disorder, or are autistic.

American Speech-Language-Hearing Association | ASHA: Making effective communication, a human right, accessible and achievable for all.

Blazepod Flash Reflex Training System: BlazePod's Flash Reflex (FRX) Training helps patient recovery in any case of reduced cognitive or physical ability.

Apraxia Kids: Apraxia Kids is the leading nonprofit that strengthens the support systems in the lives of children with apraxia of speech. Since our inception in 2000, Apraxia Kids has provided support to tens of thousands of families and professionals.

Communication Junction: At Communication Junction, we are a team of speech pathologists and early educators that teaches families how to communicate and connect with their children through sign language, so they can develop a lifelong love of learning.

Crushing Dyslexia

Virtual Play Activities | Get Your Play On(line) (getyourplayonline.com): At Get Your Play On(line), we're committed to supporting children through play. Since April 2020, we've been working to provide virtual play opportunities to children right from home. We have already evolved so much and we are adding more and more to our platform every day.

Dr Sarah's Favorites's Amazon Page: Pregnancy. Postpartum. Pediatrics. A compilation of favorite items from a mama of 5 kids and Physical Therapist to moms and babies for nearly 15 years. No product recommendation is intended as medical advice.

Ivy Rehab Network | Physical Therapy and Rehab Professionals: Founded in 2003, Ivy Rehab is a rapidly growing network of best-in-class outpatient physical, occupational, speech, and ABA therapy clinics in the Northeast (CT, DE, NJ, NY, PA, RI), the Midwest (IL, IN, MI, OH), and the Southeast (NC, SC, VA). The Ivy Rehab Network consists of multiple brands dedicated to providing exceptional care and personalized treatment to get patients feeling better, faster. With backing from leading middle-market private equity firm Waud Capital Partners, Ivy Rehab will continue to grow and further expand its U.S. footprint.

NAPA Center I World-Renowned Pediatric Therapy: Your child is unique with very specific needs. NAPA embraces these differences with an understanding that individualized programs work better. For this reason, no two intensives are alike. We work with you to incorporate our wide range of therapies into a customized intensive program specific to your child's needs and your family's goals.

FairPlay: FairPlay is a women-led, speech-language pathologist founded 501(c)(3) nonprofit organization that strives to make play accessible and affordable for all children, including kids with disabilities who may not be able to play with toys as they come off-the-shelf.

Find a Pediatric Therapist Nearby (funandfunction.com)

Free Materials and Other Valuable Resources | Rainbow Readers

Fun & Function | Sensory Toys & Products for Kids: Like many great things in life, our company was born of the desire for change. We started Fun and Function because we couldn't find kid-friendly sensory tools that would fit our family's needs. So we channeled our frustration and turned it into a passion for creating the best sensory toys and tools on the planet.

Helps For Heroes: Hi, I'm Denise, and I'm mom to a son with autism, who is my own Superhero. I started this site because I know what it's like to scour the internet to find educational, appropriate, and interesting products for my son. At Helps for Heroes, our mission boils down to one thing – we want to be your one stop source for what you need.

Babies with iPads: This blog is designed to document infants/toddlers with disabilities using an iPad to promote their development. I hope to show how this new technology can help children with disabilities develop their communication, play, pre-literacy, cognitive, visual/auditory and motor skills.

Occupational Therapy tools as recommended by The Sensory Project – StomaStoma: We were so fortunate to have Rachael from The Sensory Project share some amazing occupational therapy tips and trick with our StomaStoma family on Instagram Stories. She mentioned a lot of tools that families could purchase on Amazon, and we wanted to create a quick list of all those products for you to easily access.

Play Therapy Supply: Play Therapy Supply was started with a vision to provide quality sand tray starter kits at a reasonable price with a diverse selection. We knew a wide variety at a good price is what sand tray therapists need to get started. After a surprising demand for our introductory kit, we've grown to produce 5 custom starter kits for sand tray therapy. Ever expanding, we offer over 30 other custom products for mental health practitioners.

Resource Library – TalkTools

Sensory Box: Welcome to Sensory Box, a unique subscription box delivering fun and one of a kind sensory items to your door each season! Sensory Box is founded by Christina Kozlowski, an occupational therapist and the creator of Sensory TheraPLAY Box.

Sensory Jungle: The highest quality sensory integration products at affordable prices. We want all parents to be able to provide the best for their kids. We're here to help parents, teachers, and therapists find high quality toys for their children with special needs.

Sensory Spectacle | Sensory Processing: We are passionate about raising awareness and educating about Sensory Processing Differences. We do this through immersive learning combine with sharing theoretical knowledge and lived experience to provide a deeper level of understanding and support.

Sensory TheraPlay Box: Toys that bring a smile to your child's face, delivered to your door monthly. Wonderful items to help your child self regulate... or simply for fun therapeutic play!

Small Steps In Speech: charitable non-profit organization which provides grants on behalf of children with speech and language disorders for therapies, treatments, communicative devices, and other services aimed at improving their communication skills.

TalkTools - Speech & Feeding Therapy Tools, Techniques, & Training: To make a contribution to the world by improving the lives of those with disabilities and their families.

The LENN Foundation: The LENN Foundation is a 501(c)(3) charity that provides grant opportunities for children with cerebral palsy to receive the pediatric intensive therapies they need to thrive.

Fun & Function | Sensory Toys & Products for Kids (funandfunction.com): Our mission is to empower different. We create tools that help kids thrive.

The Orange Effect Foundation: foundation that empowers children and young adults with speech disorders to effectively communicate through technology and speech therapy.

Therapy resources for families of children with additional needs - Special Needs Jungle

THRIVE : At Thrive, helping kids overcome feeding challenges is not just our job, it’s our passion. We know that having a kid who struggles with food and eating issues isn’t easy. The stress of mealtimes and the worry about their health and future make it all so hard. We get it. That’s why our team of professional therapists and medical experts have developed evidence-based feeding, tube-weaning, and family mealtime coaching strategies designed to meet every child’s specific needs.

Young Wild and Friedman | Young + Wild and Friedman: At Young + Wild & Friedman, you'll find inspiringly fun and simple ideas to keep your children's days full of adventure and joy! Our fun sensory play activities and kits are loved by kids of all ages.

Zoe's Toolbox: 501(c)(3) Non-Profit that provides early Developmental therapy tools to families in the Down Syndrome Community for babies 6 Months- 2 Years Old.

THERAPY ANIMAL RESOURCES:

About Us - paws4people / ADDIE's Way - Assistance Dog Placement - Wilmington, NC: paws4people® trains and places Assistance Dogs in assisting users to transform their lives for a better tomorrow. We believe every person is deserving of priceless and well-deserved independence.

Created by: Sierra Phillips @mrs.phillijt

ASSISTANCE DOGS - PAWS WITH A CAUSE: Paws With A Cause breeds and custom-trains Assistance Dogs for people with physical disabilities, hearing loss, seizures and autism.

Canines For Disabled Kids Canines For Disabled Kids (caninesforkids.org): increasing independence for children with disabilities and their families by promoting service dog partnerships, understanding and awareness throughout the community.

Home - NEADS World Class Service Dogs Funding for Assistance Dog Placements in Penngrove, California (assistancedogunitedcampaign.org): NEADS® trains a wide range of Service Dogs and Assistance Dogs to meet the needs of people with a variety of disabilities or hearing loss.

Great Danes | Service Dog Project Inc. | Ipswich: We train our dogs to address balance and mobility difficulties with the use of minimal equipment, free of charge. While each dog receives extensive training for balance before being paired with an applicant, the dog continues to adjust to the needs of their owner throughout the partnership. Our working service dogs have been placed with individuals with Multiple Sclerosis, Parkinson's disease, Cerebral Palsy and other disabilities.

Little Angels Service Dogs: Little Angels Service Dogs is a charitable nonprofit 501c3 corporation that reaches across all of the United States partnering service dogs with the disabled. We are dedicated to providing the highest quality dogs to assist in the daily lives of our recipients. Locations on both East and West coast.

4 Paws for Ability: 4 Paws for Ability is a 501(c)(3) non-profit organization that enriches the lives of children and adults with disabilities by the training and placement of quality, task trained service dogs to provide increased independence for the partner and assistance to their families.

https://themalinoisfoundation.org/programs/children-with-special-needs: The Malinois Foundation is a 501(c)3 non-profit organization created to provide individuals suffering with PTSD, physical disabilities and other special needs with a dog that can comfort and assist them.

List of Service Dog Qualifying Disabilities | ADA Assistance Dog Registry

Paws Giving Independence - Illinois Service Dog Program - Paws Giving Independence: The objective of PGI is to train service dogs to assist people with a variety of different disabilities while providing support to encourage independence. PGI educates the public about the benefits of service dogs and encourages animal rescue by obtaining many of our animals from shelters and rescue groups.

Service Dogs for People with Disabilities | CPL (k94life.org): The mission of Canine Partners for Life is to increase the independence and quality of life of individuals with physical, developmental, and cognitive disabilities or who are in other situations of need. We achieve our mission by providing and sustaining professionally trained service and companion dogs. CPL's primary efforts will be focused on an area within a 250 mile radius of Cochranville, Pennsylvania, but we look forward to continuing to place dogs with recipients from across the nation who come to us because our dogs and services are held in such high regard.

Service Dogs for People With Disabilities | UDS Foundation (udservices.org): UDS service dogs are trained from pups for over two years by a team of dedicated volunteers and professionals. Then, they're partnered with people who have a mobility disability, autism or PTSD to help them live fuller lives. We're here to provide help with get a service dog in PA.

Start Here | ServiceDogsforKids: Empowering our youth to take back their lives, one child, one dog, one day at a time. Here at Service Dogs for Kids, we aim to obtain, gift and train a psychiatric service dog to a child that has suffered sexual abuse and/or undergone any sort of trauma that results in a diagnosis of PTSD, severe depression and/or self-harm.

CHILD LIFE RESOURCES:

Child Core: Child Core is rooted in the foundation of Child Life – compassion, empathy, equity, and partnership. By empowering the support systems of children, we strengthen the entire family foundation as well as the community.

NillyNoggin's Help Kids During EEG Testing for Seizures (hannahtopia.com): The NillyNoggin EEG Cap reduces much of the "scary" associated with the test and brings some happy and fun to the whole experience. NillyNoggin EEG Caps are colorful and come in a wide assortment of patterns. Children get to choose their own NillyNoggin EEG cap – giving them some control during the medical procedure. The caps are perfectly designed for kids or even adults to wear while they receive an ambulatory or prolonged EEG tests.

Carmen's Miracle Makers: Our mission is to inspire and equip parents of critically ill children with tools used to encourage bonding and memory making while enduring a lengthy PICU stay and beyond!

Timmy's Playrooms in Children's Hospitals Around the World: With eleven locations in hospitals across the United States, as well as one more in the Philippines, Timmy's Playrooms exist as a simple and fun way to bring Faith, Hope and Love to children in need. These rooms, filled with the latest technology, games, toys, multi-media activities and more, allow the children to take their minds off their medical conditions and treatments, and just be kids again. Every room, though customized to fit the form and function of the individual hospital, also contains many football-themed design elements such as a football field floor, goalpost, and lockers.

COMFORT CUDDLES BY ERIN: Comfort Cuddles by Erin was created in July of 2019. We strive to bring comfort and smiles to those facing hardships. Contact us to request a blanket for your child or yourself. We have sent over 650 packages both in the US and internationally.

SHADOW BUDDIES: The mission of the Shadow Buddies Foundation is to provide emotional support through education regarding illness, disability, or medical treatments. The foundation accomplishes this through unique programs designed to enhance the lives of children and adults. In pursuit of that mission, the foundation will continually raise funds, develop new programs and build relationships between organizations with complimentary goals.

Lily's List: Lily's List works with pediatric patients that have a need for home health nursing. No matter what the need, we work to ensure the hospital-to-home transition is as smooth as possible. Our demographic ranges from birth to 18.

Child Life On Call: At Child Life On Call, we provide tools and solutions to help you create an effective, impactful healthcare experience for everyone.

Child Life Mommy: Supporting Families Coping With Trauma, Illness, and Loss.

Brave Gowns: Our gowns are the perfect way to bring comfort and fun when patients have to get something scary done! We use our fun designs to give everyone a little hope and normalcy at a time they need it most. Available in both children and adult sizes.

Jesschildlife: I decided to start this blog so I could share my journey into the child life field and of course share my creative interventions. I will share tips for the internship application process, my journey through internship, certification. and as a practicing CCLS. Through this blog I also want to connect and collaborate with other aspiring and practicing CCLS, so feel free to reach out to me!

Buzzy - Needle Fear & Pain Relief – Pain Care Labs: Buzzy uses natural "gate control" pain relief by confusing the body's own nerves, thereby dulling or eliminating sharp pain. In the same way that rubbing a bumped elbow helps stop the hurt, Buzzy controls sharp pain. The premise is that when nerves receive non-painful signals such as vibration or cold, the brain closes the gate on pain signals.

Request A Song (A Kid Again) - Songs of Love: The Songs of Love Foundation is a national nonprofit 501(c)(3) organization that creates free, personalized, original songs to uplift children (ages 1-21) facing tough medical, physical, or emotional challenges. Each 'song of love' is delivered on USB and/or digital format with professionally produced music and lyrics containing the child's name and references to all of his or her favorite things. Since 1996 the Songs of Love Foundation has reached out to over 38,000 children in over 600 hospitals and health care facilities in all 50 states and the world.

Cellie Coping Company: Cellie Coping Kits include Cellie, a booklet for the caregivers, and flash cards for kids! Cellie is a stuffed coping friend who can be snuggled, cried on, talked to, or can "gobble" up worries. Each coping kit is illness-specific and is catered to your child's needs.

Medi Teddy Non Profit: Providing Comfort to Pediatric I.V. and Enteral Feeding Patients.

Project Sunshine: To deliver the healing power of play to children with medical needs through trained and dedicated volunteers.

TinySuperheroes: TinySuperheroes starts with a cape, but the journey doesn't end there. We're growing a community that lifts each other up and makes every TinySuperhero in the world feel strong, able, and proud of the qualities that make them Extraordinary.

The Christmas Tree Project: Our mission is to give away fully decorated Christmas trees to families in need. The focus and heart of this project remains the thousands of families who cannot afford a tree, want a good Christmas and are thrilled and touched when they receive a Christmas tree as a gift.

Created by: Sierra Phillips @mrs.phillijt

Binkeez Blankets: Binkeez for Comfort® executes this mission by donating bespoke, certified safe blankets to infants and children struggling with a life-threatening illness, a developmental or neurological disorder, or a severe burn. Binkeez for Comfort® is privileged to provide comfort to these infants and children while simultaneously supporting their siblings as well as their parents and caregivers.

HUG Bags — Patches of Light: The Hug Bag program is a Patches of Light initiative that hopes to bring a bit of sunshine into a critically ill child's life. Using items found on an interest form (which is located below, a hug bag is assembled and delivered to the hospital or to the child's home. Items in the hug bag reflect the interests of the child and hopefully bring some respite from worry.

Coming up Rosies: Our mission is to restore confidence, happiness and pride to anyone struggling with low self-esteem during their medical journey, especially bald children. Our vision is a world where every child goes to sleep proud of their differences. We accomplish this by donating Smile Kits inclusive of paints, brushes and canvases to children's hospitals and charity organizations around the world. Children can paint and customize their very own head scarves, neck scarves and superhero capes.

Starlight Children's Foundation: We deliver happiness to seriously ill children and their families at more than 800 children's hospitals and health care facilities in the US. Our state-of-the-art programs like Starlight Virtual Reality, Starlight Hospital Wear, and Starlight Gaming entertain and distract kids - helping them get through the pain and stress of their illness.

Beads of Courage: is a non-profit organization that is dedicated to improving the quality of life for children and teens coping with serious illness, their families, and the clinicians who care for them through our Arts-in-Medicine Programs. We believe in creating a context for caring transactions to transpire through our community and encouragement programs.

Cape Ivy: Cape Ivy, a 501(c)(3) nonprofit provides warmth, comfort and support to children who have chronic or critical illnesses and their families. Cape Ivy provides fleece ponchos to children in the hospital because robes, sweaters and jackets don't work well with IV lines and other medical equipment. Cape Ivy is a resource for families experiencing long-term hospitalization of children.

RARE Bear Program: The RARE Bear Project is a community driven initiative and is supported by the ever-growing RARE Bear Army of volunteers that help make one of a kind bears for special one of a kind kids. Gifted RARE bears will have a serial number specifically made for a child in our program. Some RARE bears will also be made for gifts for those who donate a certain amount to our programs to support rare disease research!

Bags of Hope | Love That Surpasses: Bags of Hope currently serves children who receive a prenatal or postnatal (up to 1 year) disability diagnosis. The bags are free and are shipped domestically and internationally-filled with faith-based gifts and resources for the child and their family.

The Jared Box Project: The mission of the Jared Box Project is to entertain and put a smile on the faces of children in the hospital.

Pediatric Rare Disease | Kids Rare Disease | Royal Oak - Defying Rare: To enrich the lives of children who have a rare disease or other pediatric disorder through our Golden Gifts program and by helping expand access to therapy and service animals for the patients we serve.

Ari's Bears: Ari's Bears delivers brand new stuffed bears and other animals to children fighting illness in hospitals and respite houses. We also include siblings as they often feel left out or forgotten. Not only have we hand delivered but we have mailed many bears out of state.

COUNSELING RESOURCES:

Digging Deep: At the Digging Deep Project, we envision a world where every young person has access to the tools he or she needs to build emotional resilience. With support from philanthropist and survivor of young adult brain cancer, Sheri Sobrato, we built Shadow's Edge, the first FREE self-help mobile game designed for teens and young adults to tap into their healing power of self-expression.

Cellie Coping Company: Cellie Coping Kits include Cellie, a booklet for the caregivers, and flash cards for kids! Cellie is a stuffed coping friend who can be snuggled, cried on, talked to, or can "gobble" up worries. Each coping kit is illness-specific and is catered to your child's needs.

Amanda Griffith Atkins: Amanda Griffith-Atkins is a licensed marriage and family therapist whose clinical background, combined with her own experience as the mother of a disabled child, has given her a unique and refreshing perspective on parenting.

Center for Resilient Children: Our mission is to promote social and emotional development, foster resilience, and build skills for school and life success in children birth through preschool, as well as to promote the resilience of the adults who care for them. Our nationally standardized, strengths-based assessments, strategy resources, and professional development are grounded in resilience research, and for over 25 years have been used by thousands of programs across the U.S. and internationally.

National Training & Technical Assistance Center (nttacmentalhealth.org): NTTAC is a SAMHSA-funded initiative to increase the access to, effectiveness of, and dissemination of evidence-based mental health services for young people (ages 0-21) and their families, including young people experiencing serious mental illness or serious emotional disturbance (SMI/SED).

Resources (nttacmentalhealth.org): This Resource Directory was created for clinicians, administrators, educators, service providers, families, peers, and all who want to learn more about children's, youth, and family mental health.

PALLIATIVE AND HOSPICE CARE RESOURCES:

Casey Cares Foundation |: We help keep families' spirits high by arranging palliative programming - whether it's a simple movie night and a fresh pair of pajamas or attending a major sporting event. Casey Cares makes life a lot better by adding a personal touch throughout the year and making lasting memories for families throughout the Mid-Atlantic region, Florida and portions of the Midwest.

Pediatric Palliative and Hospice Care | NHPCO: NHPCO is committed to improving access to hospice and palliative care for children and their families – both nationally and internationally.

Hospice Foundation Of America - Home: The mission of Hospice Foundation of America (HFA) is to provide leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the U.S. health care system and the role of hospice within it. HFA does not monitor or regulate hospice providers.

Tools and Training for Clinicians | Palliative Care Programs | Center to Advance Palliative Care (capc.org)

NEW Home - Child Life Mommy: Supporting Families Coping With Trauma, Illness, and Loss.

CaringInfo: Resources for Serious Illness & End-of-Life Care: Understanding and using the resources available to you, whether you are a patient or caregiver may be overwhelming. Whether its medical resources such as palliative care and hospice, financial resources such as Medicare and insurance, or other items like advance directives or bereavement care, we will help you navigate them so you can have the experience that is best for you.

Children's Hospice International (chionline.org): Children's Hospice International (CHI) is a non-profit organizationestablished in 1983 that has pioneered and promoted the idea that critically ill children should have access to hospice/palliative care along with curative care from the time their life-threatening illness has been diagnosed.

GRIEF AND LOSS RESOURCES:

Created by: Sierra Phillips @mrs.phillijt

A Bed for My Heart – A Place to Rest Your Grieving Heart

A Million Dreams for Emi – It took a soul shattering loss for this Mommy to begin her soul healing journey . . .: There was a very cool rainbow story surrounding Emi's death. I have transformed that story into a children's book, in hopes that it will bring hope and comfort to children who have experienced loss. Emi's Rainbow is expected to be released on July 22, 2023.

Youth & Funerals Resource - Funeral Service Foundation: Through the generous support of our donors, the Funeral Service Foundation created a booklet, ebook and video in collaboration with NFDA, funeral service professionals and bereavement experts committed to helping families and caregivers understand the important role funerals and memorization play in the lives of youth.

For Siblings - SUDC Foundation: The SUDC Foundation offers you resources and referrals in helping your child cope with the death of his or her sibling at no cost to you. Click on the state names below to see the list of grief camps available.

Open To Hope, Support for Dealing with Death, Grief, Loss, Bereavement: Open to Hope ® is a non-profit with the mission of helping people find hope after loss. We invite you to read, listen and share your stories of hope and compassion.

Child Loss & Infertility - Still Standing Magazine: Still Standing Magazine, LLC, shares stories from around the world of writers surviving the aftermath of loss, infertility - and includes information on how others can help. This is a page for all grieving parents. If you grieve the loss of your child, no matter the circumstances, you are welcome here.

Kai's Journey - A Series for Families Navigating Grief | New York Life Foundation

Bereavement Support | New York Life Foundation: New York Life's dedicated online resource for bereaved families and those who want to support them.

griefHaven - Support For The Grieving | Grief Support: Providing loving guidance, education, and support to those who are grieving, want to support someone who is grieving, or working in the grief industry.

Grieving Dads – To the Brink and Back: A collection of candid stories from grieving dads that were interviewed over a two-year period. The book offers insight from fellow members of, in the haunting words of one dad, "this terrible, terrible club," which consists of men who have experienced the death of a child. This book is a collection of survival stories by men who have survived the worst possible loss and lived to tell the tale.

Helping Parents Heal: Helping Parents Heal is a non-profit organization dedicated to assisting bereaved parents. Through support and resources offered, we aspire to help individuals become "Shining Light Parents"—meaning a shift from a state of emotional heaviness to one of hopefulness and greater peace of mind.

The Remember Shop | Facebook: We create glowing remembrance orbs to help you remember someone you love when the world seems dark.

Eluna (mybigcommerce.com): Support a child or teen impacted by grief, addiction, and suicide with a personalized care package. Each care package is accompanied by an Eluna Resource Center report with recommended therapeutic activities and resources.

Eluna Network: Explore the Eluna Resource Center, a comprehensive online library of high-quality tools designed to support children and families impacted by grief, addiction, and related complex challenges. The Resource Center also offers personalized support including warm referrals to local programs and resources to anyone who reaches out.

RPBF - Resilient Parenting for Bereaved Families (bereavedparenting.org): We provide information and practical tools to parents and caregivers, as well as providers who provide services to bereaved families.

Bereaved Parents of the USA - Bereaved Parents USA: Together we celebrate the lives of our children, siblings, and grandchildren, sharing the joys and the heartbreaks as well as the love that will never fade. Together, strengthened by the bonds we create, we offer what we have learned from one another to every bereaved family, no matter how recent or long ago the death. We are the Bereaved Parents of the USA. We welcome you.

Camp Erin Twin Cities - Brighter Days Family Grief Center (brighterdaysgriefcenter.org): Camp Erin is a free, weekend bereavement camp for youth who are grieving the death of a significant person in their lives. Children and teens ages 6 to 17 attend a weekend camp experience that combines grief education and emotional support with fun, traditional camp activities. Led by bereavement professionals and caring volunteers, campers are provided a safe environment to explore their grief, learn essential coping skills, and make friends with peers who are also grieving.

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camps - Brighter Days Family Grief Center (brighterdaysgriefcenter.org): list of camps for those impacted by loss of a loved one.

Caregiver Support - Brighter Days Family Grief Center (brighterdaysgriefcenter.org): resources for caregivers.

Centering | Your Grief Resource Center

Comfort Zone Camp: Comfort Zone Camp is a nonprofit 501(c)3 bereavement organization that transforms the lives of children who have experienced the death of a parent, sibling, primary caregiver, or significant person. Our programs are free of charge and include trust-building activities and age-based support groups that break the emotional isolation grief often brings. Comfort Zone's programs are offered to children ages 7-17, and their families for the family programs, plus we offer young adult programs for 18-25-year-olds. Held year-round across the country, our primary locations are California, Massachusetts, New Jersey, North Carolina, and Virginia (HQ). We also partner with organizations to serve their local or specific communities through our Partnership and Community by Design Programs.

COPE Foundation | Free Grief Support Programs for Adults and Kids: COPE is a nonprofit grief and healing organization dedicated to helping parents and families living with the loss of a child.

Faith's Lodge (faithslodge.org): As the first dedicated retreat facility, Faith's Lodge provides hope, connection, and support to parents and families coping with the death of a child.

Fly High Foundation (theflyhighfoundation.org): Fly High Foundation is dedicated to honoring infant angels by helping create lasting memories and committed to establishing long-term partnerships with like-minded foundations to help comfort and aid grieving families.

Funeral Financial Assistance – With Angel Wings: Our organization, With Angel Wings, may be able to assist a family that is planning a funeral for their child, up to the age of 18. It is our hope that we can assist with minimizing the overwhelming stress parents can feel during this very difficult time in their lives.

Grief Support Resource Library - NACG: The death of a family member, friend, or other significant person is a lifelong loss for children. It is important to note that grief reactions in children are varied, wide-ranging, and unique to each individual. These resources were created as a tool for those supporting a child that is grieving, and we encourage you to use and share them freely.

Grief_CaregiverGuide.pdf (sesamestreet.org): Sesame Workshop is the nonprofit educational organization that revolutionized children's television programming with the landmark Sesame Street. This is a caregiver's guide to grief.

Grief_Storybook.pdf (sesamestreet.org): Finding ways to celebrate and remember someone who has died can provide both comfort and a feeling of connection. For children, and even grown-ups, it can be hard to know where to begin. In this story, you and your child will join Elmo's cousin Jesse as she discovers simple everyday ways to remember her father through familiar routines, favorite songs, stories, and special comfort items. Talk together about the different things that she does. Some might be just right for you and your child to try, too.

GriefShare - Grief Recovery Support Groups - GriefShare: GriefShare seminars and support groups are led by people who understand what you are going through and want to help. You'll gain access to valuable GriefShare resources to help you recover from your loss and look forward to rebuilding your life.

Healing Hearts Connection: Healing Hearts Connection serves families and individuals who are devastated by the death of a loved one. Adults and children who struggle with feelings of fear, regret, and disconnection. Their isolation is broken by joining other people who are experiencing similar heartache. Together in the safe and compassionate setting of Hearts of Hope Family Grief Camps, we make deep connections that provide support and understanding. Isolation is replaced with connection.

HealingtheSpirit | LifeNet Health

Homepage - Experience Camps: Experience Camps is an award-winning national nonprofit that transforms the lives of grieving children through summer camp programs and innovative, year-round initiatives. Through compassion, connection, and play, we allow grieving children to embody a life full of hope and possibility. By amplifying their voices, we are creating a more grief-sensitive culture.

Hope for the Mourning: Dedicated to helping families find hope in Jesus after the death of an infant or child.

MISS Foundation | Support for Bereaved/Grieving Parents & Families: Welcome to the MISS Foundation's website where you will find quick access to counseling resources, advocacy information, research on traumatic grief, education for healthcare providers and community members, and support services for those grieving the death, or impending death, of a child. This is also the home of the Selah Carefarm and the

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beloved 50 rescued animals who help traumatically bereaved families from around the world every day.

Missing Grace: Missing GRACE Foundation's mission is to provide support, resources and education for families and professional care providers when there is loss of a baby, infertility, or adoption challenges. We offer hope and healing opportunities to G.R.A.C.E. – Grieve, Restore, Arise, Commemorate and Educate.

Molly Bears: Create weighted teddy bears for families coping with any form of infant loss.

NACG: If you are supporting a child who is grieving, we are here to connect you to resources and local support. The alliance is a national organization of professionals dedicated to supporting children and the networks and communities surrounding them.

Now I Lay Me Down to Sleep | Now I Lay Me Down to Sleep: Providing the gift of remembrance portraits to parents experiencing the death of a baby.

Oaklyn Foundation: Regardless of gestation or age, the loss of a child is a pain carried for a lifetime. This pain often leaves families feeling alone, isolated and, oftentimes, hopeless for tomorrow. The Oaklyn Foundation walks alongside families of all loss by offering the support needed immediately after loss and for years to follow. We feel that no one should walk this painful journey alone.

Selah's Rest | Free Rentals for Moms — Selah's Heart (selahsheart.org): Selah's Rest provides mom's a peaceful place to get away and rest. We currently have 2 Air BnB locations in Lancaster, Pennsylvania where moms are able to

Special Gifts for Bereaved Siblings | United States | Charlie's Guys (charliesguys.org): Our mission is to remind children who have lost a loved one that they are loved and not forgotten and provide them with support while they are on their grief journey.

The BeliEve Foundation: The BeliEve Foundation helps grieving families in Minnesota facing hardship after the death of their child by providing immediate and practical financial assistance and partnering with other organizations to offer ongoing emotional support and healing.

The Compassionate Friends Non-Profit Organization for Grief: The mission of The Compassionate Friends: When a child dies, at any age, the family suffers intense pain and may feel hopeless and isolated. The Compassionate Friends provides highly personal comfort, hope, and support to every family experiencing the death of a son or a daughter, a

Planting seeds of hope, one tree at a time (p52.org): Losing a child is the worst experience a parent can face. As a living memorial to a dear family member lost, we donate and plant trees to the families who have lost a loved one.

While our focus is on families who have lost children, we also donate and plant trees for children who have lost parents. We understand that a tree won't fill the void of the loss, but we hope that as family and friends watch it grow and change with the seasons, it brings peaceful thoughts of the loved one.

Resources - Comfort Zone Camp: a list of grief resources.

Resources - The BeliEve Foundation: The following resources are trusted partners that offer local grief support programs for parents and families.

Return to Zero: H.O.P.E. (rtzhope.org): We are here with valuable resources and inclusive support for anyone whose life has been touched by loss, including miscarriage, termination for medical reasons (TFMR), stillbirth, infant or toddler death, loss through surrogacy and failed adoption.

Selah's Heart (selahsheart.org): helping anchor other mom's who have also experienced the turmoil of infant loss, while empowering the communities surrounding bereaved moms to stay actively involved and present in the discomfort of grief. Seeing to it that no mama feels alone and no baby is ever forgotten

take some time for themselves, free of charge. If you're interested in staying at one of these locations for a few days, let us know.

brother or a sister, or a grandchild, and helps others better assist the grieving family.

The Dougy Center for Grieving Children & Families | Portland, OR: Dougy Center provides support in a safe place where children, teens, young adults, and families who are grieving can share their experiences before and after a death. We provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children in grief.

The TEARS Foundation – Helping bereaved families honor the life of a child.: The TEARS Foundation seeks to compassionately lift a financial burden from families who have lost a child by providing funds to assist with the cost of burial or cremation services. We also offer parents comprehensive bereavement care in the form of grief support groups and peer companions.

Therapy Stipend | mysite (charliesguys.org): We know how important mental health is to our well-being. We want to provide children who need grief therapy services with a stipend to ensure they can get the care they need. The stipend program will cover about 5 therapy sessions.

Whats your Grief - A Grief Website for the Rest of Us: You don't have to grieve alone. What's Your Grief? is a place for grief articles, courses, creativity, sharing, community & more.

When Families Grieve: Caring Cards: Cut out these caring cards. Use them as a family to find strength together.

When Families Grieve: Feelings Journal: Start a feelings journal to help everyone in your family express emotions. Photocopy this page several times. Then put the pages in a binder or clip them together. Together, fill out a page each day.

With Angel Wings: Our mission is to provide continual emotional and financial support while creating a safe haven for fellowship to families experiencing grief related to infant and pregnancy loss, sudden death, and medical conditions.

DISABILITY RESOURCES:

Claiming Disability LLC: Creating a deeper understanding of #DisabilityPride & #DisabilityCulture.

Ability Corps: Our purpose is to create a world of inclusion and awareness for people with disabilities – through art, media, housing, employment, and volunteer opportunities. ABILITY Corps is working to break down Unconscious Bias toward people with disabilities. We believe in alliances and partnerships to strengthen and speed up this social and civil rights issue.

Faith and Light: Christian communities made up of persons with intellectual disabilities, their families and friends who meet together to share faith, friendship and celebrate life!

Relevant Resources - ConnectMed International: One of our most pressing goals is to help support and bring together the communities of patients with congenital and acquired differences and their families. To that end, we have compiled the following resources which may be relevant to this community.

Intellectual Disabilities and Dementia Resources | The NTG (the-ntg.org)

Supported Decision-Making | National Resource Center: Helping people with disabilities lead amazing lives through supported decision making.

SSI Guide - Introduction – Exceptional Lives: You can use the SSI Guide from any state. We have more Guides that are specific to Massachusetts and Louisiana, but if you are from another state you can still learn about the general topics and processes of getting SSI and how to find support for your child.

International Society of Wheelchair Professionals | ISWP: Our mission is to serve as a global resource for wheelchair service standards and provision through advocacy, education, standards, evidence-based practice, innovation and a platform for information exchange.

Home - NMEDA: NMEDA is the certifying body for the nationally recognized Quality Assurance Program (QAP) accreditation. Established in 1989, we are a 501(c)(6) non-profit trade association serving the auto mobility industry in the US and Canada. We provide education & training to our members and partners, and advocate for our industry before Congress, state legislatures and federal regulatory agencies.

Paralympic Sport Development: The United States Olympic & Paralympic Committee (USOPC) is based in Colorado Springs, Colorado. U.S. Paralympics, a division of the nonprofit USOPC, is dedicated to becoming the world leader in the Paralympic Movement and promoting excellence in the lives of people with disabilities, including physical disabilities and visual impairments.

fabricATe: Our mission is to address the issue of access to no-tech/low-tech assistive tools for individuals with disabilities and/or developmental delays.

The Administration for Community Living: The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. By funding services and supports provided primarily by networks of community-based organizations, and with investments in research, education, and innovation, ACL helps make this principle a reality for millions of Americans.

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Guide to Room-by-Room Repairs for Easy Accessibility for Disabled Loved Ones - HomeAdvisor

No Such Thing Co. – No Such Thing As Normal: No Such Thing Co. is a company providing resources of encouragement, empowerment and support for all. We have our inclusive and advocacy brand, No Such Thing As Normal that educates and advocates for disabilities and differences.

#AUCD4All – April 19, 2023: Join the Association of University Centers on Disabilities (AUCD) on April 19 from 6:00 – 9:00 PM in Washington, DC for the annual AUCD for All Gala. This year, we will focus on Creating Inclusive Communities and the important work being done around the AUCD network to meet the needs of people with disabilities and their families. The AUCD for All celebration brings together leaders from all sectors who are advocating for disability rights, equity, and inclusion.

U.S. Access Board:The Access Board is an independent federal agency that promotes equality for people with disabilities through leadership in accessible design and the development of accessibility guidelines and standards.

Easterseals Project Action: Easterseals Project Action, a division of Easterseals, Inc., provides customized training solutions and technical expertise on the Americans with Disabilities Act and accessible transportation for transportation providers, human service agencies, states, regional agencies, tribal nations, and communities with the goal of working together to build accessible communities for all!

Guide to Disability Rights Laws | ADA.gov

Knowbility – Digital accessibility advocacy, training and consulting – Knowbility: Knowbility, Inc. is a nonprofit organization based in Austin, Texas and an award-winning leader in accessible information technology. Our mission is to create an inclusive digital world for people with disabilities.

TASH: TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

Disability Rights Education & Defense Fund: Disability Rights Education and Defense Fund (DREDF), founded in 1979, is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities.

The Woody Foundation: The Woody Foundation, Inc. is a 501(c)(3) not for profit organization formed in 2011 to transform the quality of life of those living with paralysis and their caregivers.

Home and Community Positive Behavior Support Network: The Home and Community Network of the Association of Positive Behavior Support (HCPBS) is a nonprofit organization dedicated to expanding and enhancing the application of PBS principles across home and community settings, contexts, and the lifespan for people with behavioral challenges (including intellectual and developmental disabilities, mental health diagnoses and seniors who require memory care and other related services) and the systems that support them. Our website is loaded with practical resources, video's, stories of how PBS positively impacted people, and much more. Read more below to start exploring our website.

Our Ability, Inc. – AI Powered Employment for People with Disabilities: Our Ability uses a combination of latest technology, a dedicated team of people with and without disabilities with expertise in accessibility and usability, and a group of designers and engineers to provide feedback on the accessibility of your digital collateral. This not only helps you meet legal compliance but also widens your reach and demonstrates your commitment to inclusion and equitable access for all.

Directory of Community-Based Organizations Serving People with Disabilities: This directory provides an overview of these organizations, the populations they serve and support, ways the organizations can complement LHD efforts, and links to websites that provide information about local affiliates/chapters in various jurisdictions. NACCHO selected the organizations listed within because they were nationally recognized disability organizations, had local chapters nationwide, and provided services to persons with various types of disabilities. While this directory is not exhaustive, it illustrates how LHDs can collaborate with community-based disability organizations.

Unfixed: Unfixed is a multi-media production company that shares and elevates stories of humans living with chronic illness and disability. People love fixer-upper stories, miracle cures and answers but many wake up each day without any of these. Our world needs more models for how to live a meaningful, unfixed life - a life liberated from fixed notions of how we must feel in order to live fully. Unfixed humans may be in pain but they are learning to integrate it into a larger definition of themselves. The Unfixed portfolio of projects demonstrates that living well is not about eradicating our wounds and weaknesses but understanding how they complete our identities and equip us to help others.

Night to Shine | Tim Tebow Foundation: Night to Shine is a complimentary event for people with special needs hosted by local churches around the world. The event is open to anyone living with disabilities, ages 14 and older. Although each event is a little bit different, some activities included are a red carpet entrance, limousine rides, dancing, karaoke, gifts, a catered dinner, a Respite Room for parents and caregivers, a crowning ceremony where every honored guest will receive a crown or tiara, and more – Night to Shine is a celebration of God's love for YOU, our Kings and Queens!

Shine On - A Tim Tebow Foundation Ministry: After the success and explosive growth of Night to Shine, families and church leaders expressed the deep need for community and celebration beyond one amazing night a year. Following much prayer and relationship-building with world-class organizations, Shine On was created in 2018 to equip and encourage churches to embrace and offer belonging to families living with disabilities year-round. As the need to meet these families where they are became more apparent, a way of bridging the gap of support was developed through the Shine On website and companion mobile app.

Inclusion | Changing Spaces Campaign: Advocating for Accessible Restrooms With Universal Changing Tables.

Labeled and Loved | Lifelines for Disabilities: is to embrace and strengthen families with disabilities by providing connective experiences and educational resources igniting personal growth and systemic change within the community.

Invisible Disabilities® Association: The Invisible Disabilities® Association (IDA) is a 501(c)3 nonprofit. IDA is about believing. We believe you! The frequently invisible nature of illness and pain may lead to disbelief about that illness or pain by those surrounding the person who lives daily with invisible disabilities. This disbelief can lead to misunderstandings, rejection by friends, family and health care providers. It may also lead to accusations of laziness or faking an illness. We are passionate about providing awareness that invisible illness, pain and disabilities are very real! Our mission is to encourage, educate and connect people and organizations touched by illness, pain and disability around the globe. Envision with us, a world where people living with illness, pain and disability will be Invisible No More®.

Disability Insider - World Largest Platform on Disability: Disability Insider in an initiative launched by Techbility to provide users with information on the latest statistics, research and global news catalogued country wise on disability, accessibility and universal design with a special focus on accessible travel and technology. Our information is not just limited to country data but we also aim to provide you with the latest news in the world of disability and accessibility.

UpLyft® | The World's First Seated Self-Transfer System: UpLyft® is the first seated self-transfer system between bed and wheelchair for people with limited mobility.

Yachad:: Yachad is dedicated to enriching the lives of Jewish individuals with disabilities and their families, by enhancing their communal participation and their connection to Judaism through social and educational programs and support services.

Deliver the Dream: Deliver the Dream provides therapeutic programs to special populations including families facing a serious illness, crisis or disability. Most of our participants live in the state of Florida, however, we serve families throughout the United States. Our programs restore hope, strengthen relationships and change perspectives to provide inspiration for the future.

McLindon Family Foundation: The mission of the McLindon Family Foundation (MFF) is to provide adaptive bikes to children with special needs so that they can build critical core strength, boost confidence and nurture friendships, all of which help these children maximize their potential and participation in society.

Babies with iPads: This blog is designed to document infants/toddlers with disabilities using an iPad to promote their development. I hope to show how this new technology can help children with disabilities develop their communication, play, pre-literacy, cognitive, visual/auditory and motor skills.

Babycare Products for Parents with Disabilities

BACKBONES: Welcome to BACKBONES. Connecting people with spinal cord injury and their families is what we do. Through one-on-one pair ups or an event near you, BACKBONES makes it easy to meet others with similar background, injury and interests.

Best Buddies International: Best Buddies International is a nonprofit 501(c)(3) organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, leadership development, and inclusive living for individuals with intellectual and developmental disabilities (IDD).

Challenged Athletes Foundation: to provide opportunities and support to people with physical challenges, so they can pursue active lifestyles through physical fitness and competitive athletics. The Challenged Athletes Foundation believes that involvement in sports at any level increases self-esteem, encourages independence and enhances quality of life.

The Exclusive Inclusion Club

Christopher & Dana Reeve Foundation

Christopher Douglas Hidden Angel Foundation: Christopher Douglas Hidden Angel Foundation's primary goal is to promote the use of multi-sensory environments in therapeutic, recreational, and educational settings with the intent of enriching the lives, health, and social well-being of individuals with cognitive, emotional, and physical impairments. We aim to enable productivity, inclusion, independence and self-determination. Our focus is on the design, development, and implementation of Multi Sensory Environments. We support innovative initiatives that demonstrate new approaches to advance education, therapy, recreation and inclusion of special needs populations. To date The Christopher Douglas Hidden Angel Foundation, USA and Canada, has funded and built over 80 Multi Sensory Environments from Miami, Florida to Portland, Oregon and from Bay of Islands, Newfoundland to Calgary, Alberta."

Common Ground Society™:We share the stories of our lives to educate and empower our community to be more compassionate, accepting, and inclusive of people with disabilities. Common Ground Society™ ensures that all families feel a sense of belonging through meaningful connections and local support.

Dani's Twins Film: We're committed to sharing our story and messages with audiences far and wide. This is more than a film--it's a movement to reshape the disability narrative and challenge ingrained biases through our film and educational outreach.

Disabled But Not Really | DBNR: Our mission is to empower and inspire individuals with disabilities to overcome challenges and reach their potential by fostering a mindset of courage, confidence, and competence. We aim to do this by restoring hope, peace, and love, and by promoting inclusivity and accessibility in the community. Our goal is to inspire and empower not only individuals with disabilities but also their support network and the wider community.

Disability Horizons Magazine: All articles are sourced directly from our community of readers, making Disability Horizons a lifestyle publication about disabled people, for disabled people. Articles span topics from technology, relationships, sports, employment and travel.

Disability Rights Education & Defense Fund: Disability Rights Education and Defense Fund (DREDF), founded in 1979, is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities.

Disability Unite: Disability Unite is proud to bring you a diverse array of exciting virtual events in collaboration with Partners around the country, and even the world. Don't miss the next upcoming event coming soon to Disability Unite!

Disabled Parenting Project: The Disabled Parenting Project, which is part of the National Research Center for Parents with Disabilities, is on a mission to leverage technology in order to create opportunities for parents and prospective parents with disabilities to connect and interact, and serve as an information clearinghouse for relevant information about adaptive parenting. The DPP also seeks to inform social policy through the development of resources, created by and for the disabled parenting community, and to promote social justice for disabled families.

All Access Life: Our mission is to empower people with disabilities to live their best life! We do this by showcasing adaptive products.

Featured Products | All Access Life: Here are all the products that All Access Life has reviewed! Each of these products have a special place in our hearts and have opened up all new possibilities! We hope they can do the same for you!

Friends of Disabled Adults and Children | FODAC: With a strong network of volunteers and partners, FODAC provides refurbished equipment and services for adults and children with disabilities to improve their overall quality of life. Over the years, our model to assist individuals with disabilities has remained the same: to provide free or low-cost wheelchairs and other home medical equipment (HME), vehicle and home adaptations and more. Above all, our staff is like a family that works together to make every day a little easier, and a little more affordable, for people in need.

FunAbilities: FunAbilities is the world's first search service for people of all abilities. Patent Pending.

Maxmods: MaxMods is a 501c3 nonprofit corporation founded to assist people with physical limitations with modifications and adaptions of toys and devices. We conduct an event called Santa's Little Hackers that provides adapted toys for disabled individuals.

Inclusive Play: At Inclusive Play our vision is to design, develop and manufacture quality products that enable children – no matter what their ability – to play together.

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Inclusive Playgrounds: As exclusive representatives for Landscape Structures, we are able to offer our clients outstanding inclusive playground designs and products. With a wide variety of products, and regular innovation in this product category, Landscape Structures is the leading designer and manufacturer of inclusive playground equipment. Committed to creating play spaces available to all ages and abilities, together we are the go-to local sales agency for inclusive playgrounds in PA, NJ and DE.

Journey Forward: Journey Forward is a 501(c)3 non-profit organization dedicated to bettering the lives of those with spinal cord injuries or disability. We provide an intense, exercise based program working to achieve some of the most basic lifelong functions and benefits for our clients. Exercise is important to everyone and even more so for those living with paralysis.

Joyful, Brave & Awesome: I started my website – Joyful, Brave & Awesome – as a way to process parenting a disabled child. By sharing my experiences, I hope to encourage braver, deeper conversation about parenting, disability, inclusion and more!

Kids Together, Inc.™ : The Goals of Kids Together, Inc.™ include a desire to remove barriers that exclude people with disabilities. We support the belief that children with disabilities, like all children, have the need to be welcomed, cherished, and embraced in our communities.

KultureCity: We are the nation's leading nonprofit on sensory accessibility and acceptance for those with invisible disabilities.

Landscape Structures, Inc. | Playground Grants: Although Landscape Structures does not directly provide playground grants, we have curated online grant resources with national, state and regional organizations that offer grant funding for commercial entities.

Laughing At My Nightmare, Inc.: At Laughing At My Nightmare, Inc., we work to improve the quality of life for people living with disabilities by providing free adaptive and medical equipment and assistive technology to people in need! We aim to supply devices and technology that enhance the lives of our clients and helps them live healthier, more comfortable, and more productive lives

Magic Wheelchair: Magic Wheelchair is a nonprofit organization that builds epic costumes for kiddos in wheelchairs — at no cost to families.

Miracle® Recreation: At Miracle® Recreation, we believe that every kid deserves to play, feel exhilarated and experience new environments. That's why we offer a variety of playground solutions that provide accessibility and sensory benefits to create truly inclusive play spaces that are exciting, challenging and help kids of all ages and abilities enjoy playing together.

Ms. Wheelchair America: The mission of Ms. Wheelchair America is to provide an opportunity of achievement for women who happen to be wheelchair users to successfully educate and advocate for the more than 64 million Americans living with disabilities. Unlike traditional beauty pageants, Ms. Wheelchair America is not a contest to select the most attractive individual. It is instead a competition based on advocacy, achievement, communication and presentation to select the most accomplished and articulate spokeswoman for persons with disabilities. The selected representative must be able to communicate both the needs and the accomplishments of her constituency to the general public, the business community, and the legislature.

National Core Indicators: National Core Indicators (NCI)® is a voluntary effort by public developmental disabilities agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety.

National Research Center for Parents with Disabilities | The Heller School at Brandeis University: The National Research Center for Parents with Disabilities conducts research and provides training and technical assistance to improve the lives of parents with disabilities and their families.

Open Wheelchair - Official Site: The Open Wheelchair Foundation is a collaborative group of people, working together to make a low cost, light weight, easy to build, and easy to operate, motorized pediatric wheelchair for small children who are in need.

Pieces of Me: If you are new around here, let me introduce myself. My name is Amanda Owen and through Pieces of Me, I share my journey of being a sibling to someone with a rare disability, a founder and director of a nonprofit serving those with intellectual disabilities, and finding balance as a working

Puzzle Pieces: our mission is to provide a safe environment for individuals with intellectual disabilities and promote independence, life skills, community access and involvement, social interaction, communication skills, self-worth, and trusting relationships between clients, staff, and families.

Created by: Sierra Phillips @mrs.phillijt

Ramps.org - working to create access for everyone: Ramps.org is here to help you decide what type of wheelchair ramp is right for your specific situation.

ReelAbilities International: ReelAbilities Film Festival is the largest festival in the US dedicated to promoting awareness and appreciation of the lives, stories and artistic expressions of people with disabilities.

Runway Of Dreams: Runway of Dreams empowers people with disabilities to have confidence and self-expression through fashion and beauty inclusion. We work to give people with disabilities access to fashion that excites and empowers them. We raise awareness, educate consumers, advocate for industry change, develop the next generation of design innovators and provide access to fashionable adaptive apparel.

Rylan Gelb Memorial Resource Library

See Me Thrive | Switch Adapted Toys: See Me Thrive Adapted Toys is a registered 501c3 tax-exempt, non-profit organization. We want to give anyone that needs an adapted toy the opportunity to have one at an affordable cost.

State Funding | BraunAbility: Many states have programs or services to help aid residents in acquiring the mobility equipment they need. Some grants are condition-based, while others are community-based. You can begin your state-by-state search below.

State Grants for Wheelchair Vans | The Mobility Resource: If you need assistance in buying a handicap van, you should know that states offer various grants and other assistance programs for those who qualify. These grants and other programs could help you finance a wheelchair van, scooter, wheelchair lift, adaptive driving equipment, or other mobility product.

https://mydiversability.com/

The Brave Girl Collective: An online shop & community for women with chronic illness and disability to feel supported and seen.

The M.O.R.G.A.N. Project | Disability Resources: As the old saying goes, Knowledge is power. And in the case of disease and disability, nothing could be truer. It is, in fact, the only thing that effectively chases away the fear of the unknown. In that spirit, we've collected a substantial library of information and links to sites designed to inform you. Browse our Resource Library below for information on different diseases, disabilities, resources for patients and families, and more.

The Nora Project | Resources: These free resources are for families and community groups like workplaces, clubs, and local organizations.

Through the Looking Glass: At TLG our mission is: To provide and encourage respectful and empowering services—guided by personal disability experience and disability culture— for families that have children, parents, or grandparents with disability or medical issues.

Kya's Krusade: Kya's Krusade identifies and creates programs, services and tools that enable children with physical disabilities to reach their maximum potentials and support their families throughout their special journeys. We provide support, education and assistance through our website, provision of resource information and Art Therapy and Financial Assistance Programs. We strive to form a diverse community network and provide opportunities to enable equal access to all available informational, emotional, medical and financial sources of support.

https://disabilityisbeautiful.com/?fbclid=PAAaZPzegzB2vOV6CxvxIQ3hF1gVt00tdHrnCpWFCqZqTx_YPJ8e38rzAGKaU

EDUCATION RESOURCES:

The Nora Project: The Nora Project provides comprehensive resources to support the work of participating schools throughout the year. On this page, you'll find a handful of free resources anyone can use anytime.

RISE Educational Advocacy: Rise Educational Advocacy was founded on the belief that parents and schools can get high quality training to Build a Better IEP™. With online courses and workshops, Rise simplifies the special education journey for everyone.

DaSy Center: Welcome to the DaSy Center. This section of the website is for families of young children who want to know more about early intervention and preschool special education data.

Created by: Sierra Phillips @mrs.phillijt

Listing of Early Learning Consortium (ELC) Participating Organizations

A Teacher's Guide to Neuromuscular Disease: The Muscular Dystrophy Association (MDA) is committed to keeping families at the heart of all we do. We have created this booklet to help provide information and support to teachers of students with a neuromuscular disease. It is our goal that this booklet will help you better understand the challenges faced by children and adolescents affected by neuromuscular conditions, including muscular dystrophy, spinal muscular atrophy and Charcot-Marie-Tooth disease. This guide suggests general strategies to enhance your student's school experience both academically and socially, and it addresses school issues that may arise throughout K-12 education.

ECPC Home | The Early Childhood Personnel Center (ecpcta.org)

Easterseals | Nationwide Directory of Child Development Centers: Use our nationwide directory to find an Easterseals Child Development Center in your community.

National Center for Pyramid Model Innovations: The National Center for Pyramid Model Innovations (NCPMI) is funded by the Office of Special Education Programs to improve and support the capacity of state systems and local programs to implement an early childhood multi-tiered system of support to improve the social, emotional, and behavioral outcomes of young children with, and at risk for, developmental disabilities or delays. The goals of the Center are to assist states and programs in their implementation of sustainable systems for the implementation of the Pyramid Model for Supporting Social Emotional Competence in Infants and Young Children (Pyramid Model) within early intervention and early education programs with a focus on promoting the social, emotional, and behavioral outcomes of young children birth to five, reducing the use of inappropriate discipline practices, promoting family engagement, using data for decision-making, integrating early childhood and infant mental health consultation and fostering inclusion.

Inclusive Schools Network | Supporting Inclusive Education Worldwide: The Inclusive Schools Network (ISN) is a web-based educational resource for families, schools and communities that promotes inclusive educational practices. This resource has grown out of Inclusive Schools Week™, an internationally-recognized annual event created by Education Development Center, Inc. (EDC) and now sponsored by Stetson & Associates, Inc. ISN's mission is "to encourage, embolden and empower people to design and implement effective inclusive schools, by sharing insights and best practices and by providing opportunities for connection."

State Work - National Center for Pyramid Model Innovations (challengingbehavior.org)

Project Core – A Stepping-Up Technology Implementation Grant Directed by the Center for Literacy and Disability Studies: The Project Core implementation model is designed to empower teachers and classroom professionals to provide students with access to a flexible Universal Core vocabulary and evidence-based communication instruction.

STEMIE | (unc.edu): The STEM Innovation for Inclusion in Early Education (STEMI2E2) Center aims to: Develop and enhance the knowledge base on engagement in STEM (science, technology, engineering, and mathematics) learning opportunities for young children with disabilities (0-5) Implement high-quality technical assistance and professional development to increase engagement for young children with disabilities in STEM opportunities; and Engage partners and stakeholders from diverse disciplines and industry in work to increase the inclusion of young children with disabilities in early high-quality STEM learning experiences.

Tar Heel Reader | Books for beginning readers of all ages: Welcome to the Tar Heel Reader, a collection of free, easy-to-read, and accessible books on a wide range of topics. Each book can be speech enabled and accessed using multiple interfaces, including touch screens, the IntelliKeys with custom overlays, and 1 to 3 switches.

Special Needs Education | K-12 Education | With ACCEL: We are a nonprofit organization serving children and adults who have developmental disabilities, including autism spectrum disorder, behavior disorders and intellectual disabilities.

Education-A-Must: Education-A-Must Inc. is a nonprofit corporation providing advocate services for the child or youth with physical, emotional, behavioral, or learning disabilities. Our goal is to assist parents and caregivers in finding help for the child with special needs. EAM works with local, state and federal agencies to secure the necessary services and education for all who qualify.

UCEDD Resource Center: The UCEDD Resource Center (URC) web site provides University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) with up to date information that will support the implementation of the OIDD core grant. This web site is supported through OIDD's contract with AUCD to provide technical assistance to the national network of UCEDDs.

Office of Special Education Programs Technical Assistance Network (nasdse.org)

Created by: Sierra Phillips @mrs.phillijt

DEC Recommended Practices: The DEC Recommended Practices provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities. Developed by the DEC Recommended Practices Commission.

Optimizing Outcomes for Students who are Deaf or Hard of Hearing | Educational Service Guidelines: This purpose of these guidelines is to supplement and update the information needed by teachers, leaders, families, school instructional support personnel and other stakeholders to have the knowledge, skills and vision to help children be successful. Persons using these guidelines must understand the guidelines supplement and update what they need to know and do in working on behalf of children and youth who are deaf or hard of hearing; the guidelines do not provide the totality of what they need. Fast emerging knowledge and technological advances make it imperative that continuous learning be an important goal.

National Charter School Resource Center: The National Charter School Resource Center (NCSRC) is an initiative of the U.S. Department of Education's Charter School Programs (CSP). NCSRC is a source of high-quality resources for charter school stakeholders, including case studies, webinars, reports, and toolkits. NCSRC is also a source of technical assistance for CSP grantees. The NCSRC is currently managed by Manhattan Strategy Group in partnership with WestEd.

National Alliance for Public Charter Schools: The National Alliance for Public Charter Schools is the leading national nonprofit organization committed to advancing the charter school movement. Our mission is to lead public education to unprecedented levels of academic achievement by fostering a strong charter school movement.

National Association of Charter School Authorizers | NACSA: NACSA advances and strengthens the ideas and practices of authorizing so students and communities—especially those who are historically under-resourced—thrive.

The National Consortium for Physical Education for Individuals with Disabilities | NCPEID: The National Consortium for Physical Education for Individuals with Disabilities (NCPEID) is a national organization that plays a pivotal role in influencing the direction and development of the adapted physical education/activity field. Its mission is to promote, stimulate, and encourage legislative mandates, professional preparation, advocacy, and research in physical activity, physical education and recreation for individuals with disabilities.

NASISP – National Alliance of Specialized Instructional Support Personnel: The National Alliance of Specialized Instructional Support Personnel (NASISP) represents more than one million Specialized Instructional Support Personnel (SISP) nationwide. SISP professionals provide and support school-based prevention and intervention services to address barriers to educational success, ensure positive conditions for learning, and help all students achieve academically and ultimately become productive citizens. SISP works with teachers, administrators, and parents to ensure that all students are successful in school.

Council of Administrators of Special Education | CASE: CASE is an international professional organization that provides leadership to advance the field of special education through professional learning, policy and advocacy.

CONSORTIUM FOR CONSTITUENTS WITH DISABILITIES (c-c-d.org): The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

National Association of State Directors of Special Education | NASDSE: Founded in 1938, The National Association of State Directors of Special Education (NASDSE) is a premier membership organization that supports state leaders of special education throughout the United States and its Territories. Our mission and vision is to improve individual and organizational success for state leaders of special education by providing relevant services that guide positive systemic change and results thereby ensuring students with disabilities will live, learn, work and participate in their communities.

Office of Special Education Programs Technical Assistance Network (nasdse.org)

ECTA Center: Improving Systems, Practices and Outcomes: The ECTA Center supports state IDEA Part C and Part B, Section 619 programs in developing more equitable, effective, and sustainable state and local systems, that support access and full participation for each and every young child with a disability, and their family.

Homepage | NCII (intensiveintervention.org): Intensive intervention helps students with severe and persistent learning and behavioral needs, including students with disabilities. Data-based individualization (DBI) is NCII's approach to intensive intervention.

National Center on Educational Outcomes (NCEO) | NCEO: The National Center on Educational Outcomes (NCEO) focuses on the inclusion of students with disabilities, English learners, and English learners with disabilities in instruction and assessments. The scope of NCEO's work includes issues related to accessibility of assessments across the comprehensive assessment system including formative assessment practices, classroom-based assessments, diagnostic assessments, interim assessments, and summative assessments.

CADRE | The Center for Appropriate Dispute Resolution in Special Education: CADRE, the National Center on Dispute Resolution in Special Education, supports State Education Agencies (SEAs), Lead Agencies (LAs), and federally funded Parent Centers in 1) building local level capacity to prevent and resolve disputes, and 2) developing more effective and equitable dispute resolution systems.

Center on PBIS: Funded by the U.S. Department of Education's Office of Special Education Programs (OSEP) and the Office of Elementary and Secondary Education (OESE), the Center on PBIS supports schools, districts, and states to build systems capacity for implementing a multi-tiered approach to social, emotional and behavior support. The broad purpose of PBIS is to improve the effectiveness, efficiency, and equity of schools and other agencies. PBIS improves social, emotional, and academic outcomes for all students, including students with disabilities and students from underrepresented groups.

Welcome to OSEP's IDEAs That Work Website | OSEP Ideas That Work: The Office of Special Education Programs (OSEP) is dedicated to improving results for infants, toddlers, children and youth with disabilities ages birth through 21. OSEP, directly and through its partners and grantees, develops a wide range of research-based products, publications, and resources to assist states, local district personnel, and families to improve results for students with disabilities.

The Short-and-Sweet IEP Overview: An Individualized Education Program (IEP) is a written statement of the educational program designed to meet a child's individual needs. Every child who receives special education services must have an IEP. That's why the process of developing this vital document is of great interest and importance to educators, administrators, and families alike. Here's a crash course on the IEP.

Evaluation: an overview: What to expect when your child's learning strengths and needs are evaluated.

Individualized Education Program (IEP) goals: The Basics: Learn about goals and objectives (or benchmarks), which are the core of your child's IEP.

Think Inclusive: Think Inclusive exists to build bridges between families, educators, and disability rights activists to advocate for inclusive education.

How to Make a One Page Profile For Your Child for School: About 5 years ago I attended a learning session on how to create a Person Centered Plan and the One Page Profile. Roberta Dunn, the Founder of FACT was leading the session and it was so eye opening for me. Person Centered Planning is a positive, strengths-based approach to mapping out your child's future. Your child's team comes together to create strategies to help them be their best self, as well as find solutions for support in the areas where they may be struggling. And as Ellie grows, she will be driving this process of determining her future. Roberta explained that this method can be used when your child enters a new grade, moves to a new school, if they are transitioning from Early Intervention into the school system, or even going to a new daycare. In any situation where you want your child's team to have a better understanding about your child this would be the time to use it.

About HCPBS - Home and Community Positive Behavior Support Network (HCPBS): The Home and Community Network of the Association of Positive Behavior Support (HCPBS) is a nonprofit organization dedicated to expanding and enhancing the application of PBS principles across home and community settings, contexts, and the lifespan for people with behavioral challenges (including intellectual and developmental disabilities, mental health diagnoses and seniors who require memory care and other related services) and the systems that support them. Our website is loaded with practical resources, video's, stories of how PBS positively impacted people, and much more. Read more below to start exploring our website.

ADEPT Training | Center for Excellence in Developmental Disabilities | UC Davis MIND Institute: ADEPT (Autism Distance Education Parent Training) Interactive Learning is an original MIND Institute/CEDD 10-lesson interactive, self-paced, online learning module providing parents with tools and training to more effectively teach their child with autism and other related neurodevelopmental disabilities functional skills using applied behavior analysis (ABA) techniques.

Education Advocate - Special Education Advocacy, Larry Davis: Due to the complex nature of kids today, educational advocacy resources are now one of the primary tools informed-parents seek out within the special needs process. As a result, we have been working with families across the country. Also, I recently served as a District Special Education Director, Behavior Specialist, and Autism & Social Emotional Learning Trainer; so I bring to the conversation insights and expertise way beyond IEP and 504 paperwork; it reaches into the classroom and creates supports for children and teachers. As a result, I also coach and train special education advocates so they can serve parents nationwide due to the never-ending need for advocacy for "no one should never go it alone!"

Resource Repository | National Center on Improving Literacy: Find recommended websites, downloads, and videos from reliable sources.

Topic: Advocacy | National Center on Improving Literacy

A Parent's Guide to Response-to-Intervention: NCLD has written this Parent Advocacy Brief to provide an overview of the RTI process, describe how it is implemented in schools and offer questions that parents can ask.

CAST: Until learning has no limits®: CAST is a nonprofit education research and development organization that created the Universal Design for Learning framework and UDL Guidelines, now used the world over to make learning more inclusive. The acronym "CAST" derives from the original name of our organization, Center for Applied Special Technology. Now we're simply CAST. Our CAST of characters includes over 50 talented employees, including world-class educators, learning scientists, instructional designers, literacy experts, policy analysts, UX and graphic designers, software engineers, and a first-rate administrative and executive staff.

NASET - National Alliance for Secondary Education and Transition (nasetalliance.org): The National Alliance for Secondary Education and Transition (NASET) is a national voluntary coalition of more than 40 organizations and advocacy groups representing special education, general education, career and technical education, youth development, multicultural perspectives, and parents.

TIES Center: TIES helps educators, parents, and administrators create and support inclusive school communities.

PEAK Parent Center: EAK Parent Center is a 501(c)3 nonprofit organization that has been serving families and self-advocates across the State of Colorado, and beyond, since 1986! Since its inception, PEAK has maintained a steadfast commitment to ensuring that people with all types of disabilities can be fully included in their neighborhood schools, their communities, and in all walks of life.

Conference on Inclusive Education | PEAK Parent Center: Inclusive education is a process of school reform that creates equity in education and increases achievement for ALL students. In inclusive schools, students, families, general and special educators, administrators, support staff, and community members work together to make curriculum accessible to all learners and to differentiate instruction. This conference brings members of each of these distinct groups together to learn and collaborate, and focuses on strategies that support the inclusion of students with all types of disabilities in general education.

Tools for Inclusive Understanding and Support.pub (squarespace.com)

Unscripted Podcast: Welcome to SWIFT Unscripted. SWIFT podcasts gives you the listener the opportunity to hear the inside story and be part of the conversation with leaders in the field of inclusive education and schoolwide transformation.

SWIFT Education Center: – Leading the nation in equity-based Multi-tiered System of Support education research and services.

Resource Shelf | SWIFT Education Center: Check out the SWIFT Shelf Tools, which include free downloadable Assessment Tools and other helpful district and school resources. Search SWIFT Shelf Stories provide free downloadable mini-films—Whatever It Takes, Together, and MTSS: Universal, Additional and Intensified Support, and Issue Briefs of interest to practitioners. Visit the Research section for Research-to-Practice Briefs and a Bibliography of scholarly papers that analyze SWIFT partner outcomes.

More than a Teacher Initiative: The More Than a Teacher Initiative, with the help of some incredible partnerships, will be taking applications to provide fully equipped sensory spaces for teachers who are in need for their students.

Classroom Accommodations for Students with Visual Issues (bouldervt.com)

Genetic Education Materials for School Success (GEMSS) | New England Regional Genetics Network (negenetics.org): Genetic Education Materials for School Success (GEMSS) provides a family-friendly starting point to help family members learn more about genetic conditions and offers ideas to encourage inclusion and participation in the classroom. GEMSS shares condition-specific information and resources for multiple audiences, including families, professionals, healthcare providers, and schools. Contributors to GEMSS come from clinical, public health, advocacy, and academic settings. All content has been vetted by clinical and family experts.

ZERO TO THREE | Early Connections Last a Lifetime: To ensure that all babies and toddlers have a strong start in life. At ZERO TO THREE, we envision a society that has the knowledge and will to support all infants and toddlers in reaching their full potential.

Ivdu Schools: IVDU is where students with mild-to-moderate learning, social, and developmental differences learn to embrace their strengths, believe in their abilities, and pursue a vibrant future that's all their own. Run with true Torah values, endorsed by mechanchim, and supported by an experienced clinical team focused on outcomes that are grounded in best practices and evidence-based research, IVDU is an outpouring of warmth, growth, and extensive high-level resources to carry your child from who they are right now to who they truly can be.

Council for Exceptional Children: CEC advocates for appropriate governmental policies, sets professional standards, provides professional development, and helps professionals obtain conditions and resources necessary for effective professional practice. CEC is known as THE source for information, resources, and professional development for special educators.

National Center for Learning Disabilities | NCLD: The mission of NCLD is to improve the lives of the 1 in 5 children and adults nationwide with learning and attention issues—by empowering parents and young adults, transforming schools and advocating for equal rights and opportunities. We're working to create a society in which every individual possesses the academic, social, and emotional skills needed to succeed in school, at work, and in life.

OSEP_EC_TA_Centers.pdf (familyconnectionsc.org): The U.S. Department of Education's Office of Special Education Programs (OSEP) has funded national TA Centers to support state Part C & Part B 619 agencies and a network of parent centers to provide information and training to families of children with disabilities. The Centers are working to assist states, administrators, programs and families in enhancing outcomes for young children with disabilities and their families.

PACER Center - Champions for Children with Disabilities: PACER Center enhances the quality of life and expands opportunities for children, youth, and young adults with all disabilities and their families so each person can reach his or her highest potential. PACER operates on the principles of parents helping parents, supporting families, promoting a safe environment for all children, and working in collaboration with others. With assistance to individual families, workshops, materials for parents and professionals, and leadership in securing a free and appropriate public education for all children, PACER's work affects and encourages families in Minnesota and across the nation.

Partner Solutions Directory | Council for Exceptional Children: The Council for Exceptional Children (CEC)'s Partner Solutions Directory is an online resource for special education products, services, and programming support!

Reading Rockets | Launching Young Readers: Reading Rockets is a national multimedia project that offers a wealth of research-based reading strategies, lessons, and activities designed to help young children learn how to read and read better. Our reading resources assist parents, teachers, and other educators in helping struggling readers build fluency, vocabulary, and comprehension skills.

Rylan Gelb Memorial Resource Library: Our Rylan Gelb Memorial Resource Library details hundreds of books and other texts that relate to the themes and topics presented in The Nora Project programs. Many entries have associated lesson plans.

Teach RARE - Special Education Teaching and Learning: We began by uniting our small community with the common goal to help our children succeed and develop. Today we are joining forces with other communities under the rare disease and undiagnosed diseases. In addition, we support children with special needs.

The Compassion Foundation: Compassion Clubs unite students in spreading compassion within their schools and throughout the community. Through weekly student-led discussions of values like friendship, kindness, empathy, and forgiveness, participants gain a sense of belonging and connection with those around them.

https://allbelong.org/

TRANSITION RESOURCES:

Created by: Sierra Phillips @mrs.phillijt

Financial Advocacy in RARE: Navigating the U.S. Health System for Young Adults - Global Genes - powered by HappyFox

Got Transition®

Autism Career Pathways

Future Planning (thearc.org): Planning for the future is important for all families. You can't do it just once. It's an ongoing process.The Build Your Plan ® tool helps people with intellectual and developmental disabilities (I/DD) think about and plan for their future. The interests, preferences, and skills of the person with I/DD are the main focus.

Transitions (rareiscommunity.com): Whether it's moving from pediatric to adult medical care, starting school, taking on a career, or making plans to ensure financial security later in life, #RAREis Transitions is here to help you prepare with guidance and connections to the right resources.

transitioning - National Organization for Rare Disorders (rarediseases.org)

Transitions of Care Hub - Child Neurology Foundation

The Breakaway: A Parent's Guide to Transitioning the Autistic and Twice Exceptional Adolescent Into Young Adulthood: Welch Psy.D., Thomas W.: 9798656424431: Amazon.com: Books

NTACT:C | National Technical Assistance Center on Transition: The National Technical Assistance Center on Transition: The Collaborative (NTACT:C) is a Technical Assistance Center co-funded by the U.S. Department of Education's Office of Special Education Programs (OSEP) and the Rehabilitation Services Administration (RSA). We provide information, tools, and supports to assist multiple stakeholders in delivering effective services and instruction for secondary students and out of school youth with disabilities.

Parallel: Parallel partners with individuals and stakeholders worldwide to build pipelines that create inclusive opportunities, architect support ecosystems, and develop sustainable strategies for communities and businesses where Neurodiversity thrives. Our philosophy is prepare, educate, inspire, change, and create. We build opportunity on the post-secondary pipeline by preparing pathways to inclusive settings, educating for inclusion, inspiring meaningful corporate change, and creating supportive ecosystems. Together, we can make the world a more inclusive place.

Parallel | The Roadmap Lab Book: The RoadMap Lab™ is a tool that helps individuals and their collaborative teams build more strategic, more sustainable, human-centered transition plans. While anyone can use The RoadMap Lab™, it was intentionally designed to support Neurodiverse teens and young adults as they transition from secondary schooling to post-secondary schooling, the community, and/or the world of work. The RoadMap Lab™ is simply designed to help the user build a bridge of support to the next stop in life's journey.

NASET - National Alliance for Secondary Education and Transition (nasetalliance.org): The National Alliance for Secondary Education and Transition (NASET) is a national voluntary coalition of more than 40 organizations and advocacy groups representing special education, general education, career and technical education, youth development, multicultural perspectives, and parents.

Welcome to NSTTAC | NSTTAC: The National Secondary Transition Technical Assistance Center (NSTTAC) is directed and staffed by the Special Education Program at the University of North Carolina at Charlotte, in partnership with the Special Education Program at Western Michigan University. NSTTAC provides technical assistance (TA) and disseminates information to State Education Agencies, Local Education Authorities, schools, and other stakeholders to (a) implement and scale up evidence-based practices leading to improved academic and functional achievement for students with disabilities, preparing them for college or other postsecondary education and training and the workforce; (b) implement policies, procedures, and practices to facilitate and increase participation of students with disabilities in programs and initiatives designed to ensure college- and career-readiness; and (c) achieve 100% compliance with IDEA, Part B Indicator 13 (I-13).

ADVOCACY RESOURCES:

Created by: Sierra Phillips @mrs.phillijt

#RAREis Global Advocate Grant: A program launched by Horizon Therapeutics in 2022 to support and empower the rare disease community around the world.

#RAREis Representation: The global rare disease community faces many challenges, including access to diagnosis, appropriate care and treatment, resources, and broader representation. In 2022, #RAREis and Horizon Therapeutics launched #RAREis Representation, a program to address the global unmet need for diversity, equity, inclusion and allyship in rare disease.

A+J Patient Advocacy: A+J Patient Advocacy provides free health navigation, advocacy, and education services to people with chronic illness.

Ability Corps: Our purpose is to create a world of inclusion and awareness for people with disabilities – through art, media, housing, employment, and volunteer opportunities. ABILITY Corps is working to break down Unconscious Bias toward people with disabilities. We believe in alliances and partnerships to strengthen and speed up this social and civil rights issue.

Advocate Like a Mother: Throughout the season we hope to gather tangible tools and resources for you to find confidence in the advocacy process. Often, we find much of our courage in relating with each others experiences. And with the right tools in front of us, we can point others along the way. We hope these links help you as much as they have helped us.

ASGCT | Policy & Advocacy

ASGCT | The Advocate Magazine

Chronic Care Collaborative: The Chronic Care Collaborative (CCC) is made up of 50 different voluntary health organizations representing a wide range of chronic diseases. The CCC is dedicated to improving access to quality, affordable, and integrated healthcare.

COMBINEDBrain: The Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders is devoted to speeding the path to clinical treatments for people with severe rare genetic non-verbal neurodevelopmental disorders by pooling efforts, studies and data. We are a non-profit consortium led by patient advocacy foundations, working with the clinicians, researchers and pharmaceutical firms that are developing treatments for the disorders they represent.

Complicated — Open Eye Pictures: COMPLICATED takes the viewer into the hidden world of children coping and

Aware of Angels: Aware Of Angels advocates for children who have genetic, rare or undiagnosed disorders. An accurate and conclusive diagnosis for these children will not only give direction for proper treatments and improve their quality of life, but in some cases it may save their life. By sharing their stories and images, we are advocates for families to the medical and research fields, as well as connect families in similar situations.

Beyond The Diagnosis: Beyond the Diagnosis unites art and science to inspire research and innovation of treatments for people living with rare and neglected diseases.

Burden of Rare Disease Study: The study is the first of its kind, providing the most comprehensive assessment of the total economic burden of rare diseases (RDs) in a single year. The results help to ensure that the experience of the rare disease community is reflected accurately in policy discussions. This powerful tool can also increase public awareness of the public health crisis of rare disease.

Caring Across Generations: Every day we're telling our stories and taking action so that we can have the freedom to make the care choices that are right for us and our families.

Chartbook State Data (ciswh.org): The State Data Chartbook is designed to help visitors understand the multiple dimensions of care for Children and Youth with Special Health Care Needs (CYSHCN). It contains a selective list of health indicators for all 50 states as well as Puerto Rico and the District of Columbia. Drawing from a range of trusted sources and updated regularly, it provides data in areas that include demographics, economics, child health services, insurance availability, and factors impacting coverage for CYSHCN.

trying to live their lives with rare, complex and invisible illnesses, parents facing impossible choices to help them, and providers who dismiss them as "too complicated" or risk it all to save them.

EveryLife Foundation for Rare Diseases: We empower the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

Global Genes: Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally.

Good Apple: The challenges, limitations and unique circumstances of the rare disease market can render drug launches an overwhelming endeavor for pharmaceutical companies. That's why we're here. We use modern advancements in media targeting technology to find rare disease patient audiences with increased efficiency. The third-party data tools we use enable us to draw insights from media consumption habits and competitive advertising activity to narrow our reach and stay one step ahead of your competition at all times.

Hope Knows No Boundaries: Hope Knows No Boundaries helps connect the dots between patients, medical specialists, and insurance companies. Educate patients to advocate for their medical needs, use their voice in their treatment, and create a team environment between the medical specialists, the patients, and the insurance companies.

Impact through Insights |TREND Community: We're a digital health analytics company that turns the conversations of rare, chronic, and emerging disease communities into actionable insights. Our partnerships support community members, health care providers, researchers, pharmaceutical sponsors, and regulatory agencies as we advance our mission to facilitate understanding, strengthen advocacy, and spark scientific progress. Our proprietary technology listens to the online conversations happening within underserved rare, chronic, and emerging disease communities and derives actionable insights for community stakeholders, medical teams, researchers, scientists, biotechs, pharmaceutical companies, and regulatory agencies. We learn through listening, and we spark progress through insight.

Impact through Insights |TREND Community: We're a digital health analytics company that turns the conversations of rare, chronic, and emerging disease communities into actionable insights. Our partnerships support community members, health care providers, researchers, pharmaceutical sponsors, and regulatory agencies as we advance our mission to facilitate understanding, strengthen advocacy, and spark scientific progress.

Little Lobbyists: Little Lobbyists seek to protect and expand the rights of children who have complex medical needs and disabilities through advocacy, education, and outreach. We are families of children with complex medical needs and disabilities, who've learned through experience to be strong and effective advocates. We became political activists in response to the threat posed to our children by the policies and legislation being advanced by the current administration and Congress.

LYNZEBRA – A Rare Disease Patient and Advocate: After spending most of my life in and out of hospitals, I've gained a ton of wisdom a long the way about living with a rare disease. Now I help people across the world, especially teenagers, to help them learn the skills they need to not only survive, but thrive.

National Association of State Directors of Developmental Disabilities Services | NASDDDS: The NASDDDS mission is to assist member state agencies in building person-centered and culturally and linguistically appropriate systems of services and supports for people with intellectual and developmental disabilities and their families.

No Such Thing Co. – No Such Thing As Normal: No Such Thing Co. is a company providing resources of encouragement, empowerment and support for all. We have our inclusive and advocacy brand, No Such Thing As Normal that educates and advocates for disabilities and differences.

NORD Special Training for Rare Disease Patient Advocates Resource List

Our Voyaging Hearts: At Our Voyaging Hearts, we offer products and services that provide direct support. From consulting services for parents, educators and clinics to a store full of products that aim to meet you where you are — as well as a waitlist for forthcoming case management and care coordination services — we show up for exceptional parents.

Patient Access & Affordability: The mission of the Patient Access & Affordability Project is to provide patient-powered pathways to help legislators, regulators, payers, and employers better understand the patient experience as they make critical coverage decisions for patients with rare and chronic diseases.

Patient Action Center: We started the Patient Action Network to give patient advocates the chance to make their voices heard by the people who represent them. You will find many great campaigns on issues critical to patient access and affordability as well as voting resources so you can make sure you're ready for November. Be sure to take a look around so you can continue your advocacy journey!

Patient Advocacy Groups: Patient Advocacy Groups (PAGs) are organizations that promote the needs and priorities of patients. One feature of the RDCRN is the direct involvement of patient groups in network operations, activities, and strategy. These patient groups collectively represent the perspective and interests of patients with rare diseases. Click on the tiles displayed below to find patient groups affiliated with each consortium.

Patient Advocate Foundation: Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization which provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.

Patient Worthy: Patient Worthy® is an online publication that provides relevant information to rare disease patients, caregivers and advocates alike.

Patients Rising Now: Patients Rising Now is a national nonprofit organization dedicated to advocating for the rights of patients with chronic and life-threatening illnesses. We work at community, state and federal levels to activate patients in support of reforms and legislation aimed at advancing patient access to and affordability of healthcare.

Patients Rising: Formed in 2015 as a 501(c)3, Patients Rising has developed a significant following of over 110,000 patients and caregivers and has guided more than 25,000 of them on their journeys to advocate for themselves and their loved ones to get the care and treatments they need to live a fulfilling life.

Rare & Ready: A Genetic Condition Coalition: Rare & Ready: A Genetic Condition Coalition believes state policies must make sure that patients with rare or genetic conditions can get the care they need. These patients deserve access to new FDA-approved therapies as soon as they are available. We need to mitigate state Medicaid program hurdles that limit access.

Rare Advocacy Movement: The Rare Advocacy Movement (RAM) is the first community-based network dedicated to protecting the interests of the global community of people living with rare conditions, chronic & progressive disabilities, medical complexities and their families.

Rare Disease Advisor: RareDiseaseAdvisor.com is the web's premier source of news, perspectives, and resources for clinicians who treat patients with rare diseases. The website addresses the unmet informational needs of healthcare professionals seeking the latest insights into the rare diseases they treat through fresh, original, and authoritative content.

Resources Archive - Center for Innovation in Social Work & Health (ciswh.org)

RISE Educational Advocacy: Rise Educational Advocacy was founded on the belief that parents and schools can get high quality training to Build a Better IEP™. With online courses and workshops, Rise simplifies the special education journey for everyone.

Rare Disease Day: Raising awareness and generating change for the 300 million people worldwide living with a rare disease, their families and carers.

Rare Diseases Community Resources | NCATS: NCATS offers free materials and resources to help patients, caregivers, patient support organizations, health care providers and scientists learn about rare diseases and help advance research on them. You can use the resources below on social media, on web pages, or at meetings, clinics and other places to raise awareness and to connect with the rare diseases community.

Rare Diseases Working Group | Alliance for Patient Access: AfPA's Rare Diseases Working Group is a network of policy-minded health care providers who advocate for patient-centered care. By participating in advocacy initiatives and the development of educational resources, working group members ensure that the clinician's perspective informs policy discussions that impact health care for people living with a rare disease.

Rare Genomics Institute: At Rare Genomics, we are more than just an organization. We are a community dedicated to helping rare disease patients find hope for a cure. We work alongside patients and their families, providing them with the necessary tools, knowledge, and connections so that they can better understand the cause of their disease. We bring together scientists, entrepreneurs, innovators, and professionals, who share our passion for helping rare disease patients and leverage the crowdfunding capabilities of the Internet to bring the hope of a cure to our patients.

Rare Revolution Magazine: To bring about a dramatic and wide-reaching change in conditions and attitudes for the rare disease community.

RareLaunch®: NORD's RareLaunch program provides dynamic, hands-on courses that will help you launch and grow a rare disease nonprofit!

Reclaimed Hope Initiative: We are a support and advocacy organization founded to strengthen and empower families navigating foster care, adoption, and children with disabilities.

SABE | Self Advocates Becoming Empowered: To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends, and to learn from their mistakes.

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SARTAC: The mission of Self Advocacy Resource and Technical Assistance Center (SARTAC) is to strengthen the self-advocacy movement by supporting self advocacy organizations to grow in diversity and leadership.

Share4Rare: Share4Rare is going to be piloted with three groups of conditions: rare tumours, neuromuscular disorders and undiagnosed. Besides, we publish quality medical content for these conditions and more, and other diseases are constantly being added to our activities.

some1likeyou: Our mission is to connect individuals with health conditions WHILE PROMOTING THE MANTRA TO BE KIND THROUGH ADVOCACY, YOUTH DEVELOPMENT + THE BE KIND PROJECT.

Take Part Foundation: Take Part Foundation is a 501(c)(3) that allows anyone to “take part” in fighting for possible. We identify existing medical research for rare pediatric conditions that likely will not be able to find funding elsewhere, and fund it until it reaches the point where the research team can apply for funding from larger organizations and foundations. Take Part is also committed to assisting and equipping families who have a little warrior with a rare medical condition by giving them a platform to share their story.

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The Haystack Project: Haystack Project is a non-profit enabling rare and ultra-rare disease patient advocacy organizations to highlight and address systemic obstacles to patient access. Our core mission is to evolve health care payment and delivery systems to make innovative quality treatments accessible to the patients they were meant to reach.

Ultragenyx Patient Advocacy : The rare community is made up of millions of unique experiences. But shared experiences, common challenges, similar passions, and united voices tie everyone in it together. These Rare Journey Resources are designed to provide access to information for many of the common phases of the rare journey and empower you to reach out and get involved.

who have a little warrior with a rare medical condition by giving them a platform to share their story.

TASH: TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

The Community of Practice for Support Families of Individuals with Intellectual & Developmental Disabilities: The Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities exists to enhance and drive policy, practice, and system transformation to support people with intellectual/developmental disabilities within the context of their families and communities. Nineteen member states are committed to developing systems of support for families throughout the lifespan of people with intellectual and developmental disabilities (I/DD) and their family, and receive technical assistance, products, opportunities for shared learning, and support from a National Team to integrate innovative practices into existing and ongoing state systems change efforts.

The E.WE Foundation: The E.WE (/ē/·/wē/) Foundation is an IRS approved 501(c)(3) healthcare advocacy organization established to provide resources and support to families affected by Edwards Syndrome, commonly known as Trisomy 18, and other rare diseases.

United Advocates for Children and Families: Improving the quality of life for all children and youth with mental, emotional, and behavioral challenges and to end institutional discrimination.

Watch — Becoming Incurable: Becoming Incurable is a documentary feature film that explores the transformation of three individuals who became diagnosed with chronic, incurable illnesses.

Your Voice: #RAREis brings together a chorus of individuals speaking out to the world about rare disease and what #RAREis means to them. It is a community that raises awareness of rare diseases by sharing stories, accomplishments, hopes, fears and dreams.

CONFERENCES AND EVENTS:

Upcoming Events – National Organization for Rare Disorders

Rare Impact Awards: To celebrate NORD's 40th anniversary, the 2023 Rare Impact Awards will be hosted in our nation's capital, the place where rare disease patients and families testified in front of Congress to pass the Orphan Drug Act in 1983. This very special event will honor those individuals and organizations doing remarkable work on behalf of the rare disease community. The awards ceremony will take place in the historic National Portrait Gallery on May 4, 2023.

Living Rare, Living Stronger Patient and Family Forum: We will bring the rare disease community together in our nation's capital for a day of learning, networking and fun! Join others to learn more about living your best life while navigating your rare disease journey.

RNE Annual Conference — Rare New England: Improving Health Care Experiences in the Rare Disease Community.

Clinical Trials: The Patient Experience - 04/13/2023 | FDA: The FDA's Center for Biologics Evaluation and Research (CBER) Office of Therapeutic Products (OTP) hosted a public virtual workshop on Thursday, April 13, from 11:00 a.m. – 3:00 p.m. ET. The workshop, Clinical Trials: The Patient Experience, featured a panel of rare disease patients, caregivers, and advocates who shared their experiences with gene therapy clinical trials. Through participation in clinical trials, patients can help advance the science of gene therapy and further the development of rare disease treatments.

Gene Therapy Patient Engagement Summit: uniting patient advocacy and engagement experts from leading gene therapy and gene editing drug developers, along with patient groups and patients themselves. Talks, workshops, and group discussions will shed a light on how to better integrate the patient voice into gene therapy programs at crucial stages of the drug development process.

Annual Meeting - Association for the Advancement of Blood & Biotherapies (aabb.org): The AABB Annual Meeting brings blood and biotherapies professionals together to share cutting-edge research, unique perspectives, networking with colleagues and practice-changing solutions.

ISSCR 2023: The world's best and brightest in stem cell research and regenerative medicine convene once a year for the ISSCR Annual Meeting, and you are invited! Join more than 4,000 scientists from around the globe at ISSCR 2023 to take part in a 4-day program comprising the year's most significant new advances in the field.

NHGRI National DNA Day 20th Anniversary Symposium (genome.gov): On National DNA Day this year, the National Human Genome Research Institute (NHGRI) will host a symposium to commemorate two special milestones: the 20th anniversary of the Human Genome Project's completion and the 70th anniversary of the discovery of the DNA double helix.

Join us to explore the evolution and future of genomics research, learn about the greater impacts of genomics on society and discover the wide array of careers in genetics and genomics — from scientists to social media specialists! The program will conclude with the annual Louise M. Slaughter National DNA Day Lecture. This event is free and open to the public. Join us in person or virtually.

World Orphan Drug Congress USA 2023: The World Orphan Drug Congress brings together leading pharmaceutical and biotech companies, government and regulatory authorities, patient advocacy groups, payers, investors and solution providers. The conference is a place to meet and brainstorm ways to advance orphan drug development and improve access to life-saving therapies.

American Society for Human Genetics Annual Meeting: The world's best and brightest in human genetics and genomics research convene once a year for ASHG's Annual Meeting, and you are invited! Join more than 8,000 scientists from around the globe at ASHG 2023 to take part in a 5-day program comprising the year's most significant new advances in the field. From Invited Sessions, to Workshops, to the

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Presidential Symposium and the Distinguished Speaker Symposium – there is something for everyone! Join for cross cutting issues, a celebration of ASHG's 75th anniversary and a demonstration of new products and innovations supporting research – it won't be the same without you.

Patient Education Series | Lunch & Learns | ASGCT

Immune Responses to AAV Vectors | FDA and ASGCT | ASGCT - American Society of Gene & Cell Therapy

ASGCT–FDA Liaison Meeting | ASGCT - American Society of Gene & Cell Therapy: The annual ASGCT–FDA Liaison Meeting is an opportunity for our subject matter expert members to engage directly with FDA staff. Each year Society presenters share information about the key challenges and new opportunities facing the field. In return, FDA provides a presentation relevant to ASGCT members' interests.

American Society of Gene and Cell Therapy's Annual Meeting : The American Society of Gene and Cell Therapy's (ASGCT) Annual Meeting is the premier event for professionals in gene and cell therapy. The meeting, which we've expanded to four full days in 2023, is the best place for people in the field to learn from the latest scientific research, stay up to date on new technologies, and make career-advancing connections with peers. Originally designed as a venue for academic researchers to share their work, the Annual Meeting has grown to serve a wide community encompassing clinicians, bio-industry development, regulatory agencies, equipment manufacturers, patient advocates, and more.

Annual Meeting: World's Premier Neurology Meeting | AAN

Policy Summit | Advocacy | ASGCT - American Society of Gene & Cell Therapy | ASGCT - American Society of Gene & Cell Therapy

WORLDSymposia - We're Organizing Research on Lysosomal Diseases: Thank you to everyone who attended, supported, and contributed to WORLDSymposium 2023, and for helping achieve the ongoing goal of providing the latest advances in lysosomal disease research and treatment to this global audience. Be the first to hear the latest news and updates about WORLDSymposium 2024 including registration, speakers, pre-conference events, and more!

Orphan Drugs & Rare Diseases Global Congress (orphandrugscongress.com): The two-day Congress will provide an interactive, cutting edge, and comprehensive discussion and networking format led by key experts with intimate knowledge in the industry. Gain practical strategies and best practices on challenges, innovations, technologies, and concepts surrounding orphan drugs and rare diseases.

Gene Therapy for Rare Disorders | Home (genetherapy-conference.com): As the gene therapy field continues to break records, there are still significant challenges to overcome relating to safety, efficacy, and accessibility. The 6th Annual Gene Therapy for Rare Disorders 2023 Summit remains devoted to showcasing the top case studies and strategic learnings from the past year. With an expert speaking faculty devoted to bringing safer and more effective gene therapies to rare disease patients, key questions will be answered on how best the field can overcome regulatory, clinical, manufacturing and pricing bottlenecks to progress gene therapies into and through the clinic.

International Conference on Rare Diseases and Indigenous Genetics ICRDIG in July 2024 in New York (waset.org): International Conference on Rare Diseases and Indigenous Genetics aims to bring together leading academic scientists, researchers and research scholars to exchange and share their experiences and research results on all aspects of Rare Diseases and Indigenous Genetics. It also provides a premier interdisciplinary platform for researchers, practitioners and educators to present and discuss the most recent innovations, trends, and concerns as well as practical challenges encountered and solutions adopted in the fields of Rare Diseases and Indigenous Genetics.

World Congress on Rare Diseases - 2023: International Conference Rare Diseases and its Treatment aims to bring together leading academic scientists, researchers and research scholars to exchange and share their experiences and research results on all aspects of Rare Diseases. It also provides a premier interdisciplinary platform for researchers, practitioners and educators to present and discuss the most recent innovations, trends, and concerns as well as practical challenges encountered and solutions adopted in the fields of Rare Diseases.

2023 World Pediatrics Conference - Asian Pediatric Conference (episirus.org)

Rarediseases 2023 | 8th International Conference on Rare Diseases and Orphan Drugs (conferenceseries.com)

American Epilepsy Society Annual Meeting: The AES Annual Meeting brings together healthcare providers, scientists, advocates, industry, and other professionals dedicated to better outcomes for people with epilepsy. Join us in Orlando, FL this December for five days of top-notch medical education, cutting-edge science, networking with colleagues from all over the world, and the latest in epilepsy treatments and diagnostic tools from more than 120 exhibitors.

Epilepsy Conferences | Epilepsy Congress | Neurology Conferences: Epilepsy 2023 is the gathering of Scientists,

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Neurologists, speakers, professors, business delegates and students all over the world to participate to discover the new novel therapeutics of Epilepsy, where people can get desired knowledge over Epilepsy and recent inventions on Epilepsy Treatment. We are glad to invite you at Epilepsy 2023 where you can experience a really sumptuous information and knowledge on Epilepsy management.

Neurology Conferences | World Congress Of Neurology 2023 | Neurology Conferences 2023 | World Neurology Conferences 2023 | Precision Group (neurologyworldconference.com)

Pediatric Neurology Conference | Neurology Congress | Neurology | Dublin | Ireland | 2023: The 22nd World Congress on Pediatric Neurology and Neuropathology, which is scheduled during June 12–13, 2023 as a Hybrid Event at Dublin, Ireland, will bring together all of the world's speakers and delegates once again. For the past six years, Conference Series has organised the premier international conference for professionals in the field of neurology. Join us! Come together and commit to advancing our understanding of people's thinking, choices, behaviours and innovative research through Pediatric Neurology 2023.

Annual Conference - ASET - The Neurodiagnostic Society: The ASET Annual Conference is the largest educational and networking event in the world for Neurodiagnostic professionals and industry partners. The conference offers educational seminars, poster presentations, high-level plenary session speakers, a symposium, Exhibit Hall and diverse opportunities to expand your network. Whether you want to score brand exposure or capture a lead, the conference is an excellent opportunity for your organization to engage with key industry players, including Neurodiagnostic technologists, laboratory managers, physicians, and supplier representatives.

EPILEPSY CONGRESS 2023 | 6th World Congress on Epilepsy and Brain Disorders (neuroconferences.com): With the success of previous conference we are very delighted to invite you to 6th World Congress on Epilepsy and Brain Disorders on June 05-06, 2023 Valencia, Spain with the ongoing theme “Challenges for improvement of Epileptic life”. We heartily welcome all the eminent researchers, students and delegates to make their valuable presence in this approach to witness the valuable scientific discussions and contribute to the longer term innovations in the field of Neuroscience, Brain disorders and Treatment, etc. The main theme of the conference is to provide unique ethical and responsive methods to all researchers towards Neurology cases and the upcoming medical care towards the neuroscience and to deal with most updated research.

World Neuroscience & Psychiatry Conference: brings together eminent neurologists, psychiatrists, psychologists and neuroscientists experiences from different countries and exchanges their views through scientific discovery, interactive sessions, keynote lectures, workshops and offers exceptional sessions, presentations with great education and networking opportunities for all levels of academic professionals and with leaders in the field of neurology, neuroscience, psychiatry and psychology.

Rare Disease Innovation & Partnership Summit: The Rare Disease Summit connects key stakeholders to drive therapeutic progress, propel commercial strategies and inspire impactful advocacy. You’ll generate solution-focused strategies surrounding patient access, reimbursement, commercialization, launch, partnering and more, as you unify in areas of unmet medical need.

2023 RARE Advocacy Summit - Global Genes: Each year, Global Genes convenes one of the world’s largest gatherings of rare disease patients, caregivers, advocates, healthcare professionals, researchers, partners, and allies at the RARE Advocacy Summit. This is an unparalleled opportunity to forge meaningful connections with others in the rare disease community for future collaboration. Sessions provide attendees with insights about the latest in rare disease innovations, best practices for advocating on an individual and organizational level, and actionable strategies they can take home and implement immediately to accelerate change. This year, the Summit will be held as a hybrid event, with meetings, workshops, and sessions held in San Diego, California and educational sessions live-streamed online.

Rare Drug Development Symposium 2023: Collaborate - Go Farther, Together - Global Genes: The RARE Drug Development Symposium, hosted by Global Genes and the Orphan Disease Center of the University of Pennsylvania, equips advocates with the knowledge, skills and connections they need to advance therapy development for their communities. RDDS 2023 focuses on collaboration – the foundation of success in rare disease research. You will meet individuals, advocacy leaders, industry, and research experts who have been there and done it, over two days of in-person only panel discussions, hands-on workshops, and expert office hours.

Rare Across America 2023: Rare Across America is the opportunity to meet with your Members of Congress at their in-district offices and educate them on the issues that are most important to the rare community.

NHF's Bleeding Disorders Conference: NHF is thrilled to announce that the 75th Annual Bleeding Disorders Conference (BDC) will take place from August 17 to 19, 2023, in National Harbor, Maryland (DC Area), at the beautiful Gaylord National Resort & Convention Center! Join us for three full days of educational sessions, networking opportunities, and access to our exhibit hall. Your registration includes entrance to our Opening Session, Awards Luncheon, and our exciting Final Night Event. We also have an Educational Kids Program available for children 12 years old and younger.

NORD Breakthrough Summit: Join the National Organization for Rare Disorders (NORD®) October 15-17, 2023 for the Rare Diseases and Orphan Products Breakthrough Summit. This exciting event brings together over 900 rare disease advocates, experts, and stakeholders from around the world to tackle the most pressing issues facing the rare disease community. With a focus on the most critical topics, including accelerated approval, newborn screening, and equitable access to care, the 2023 NORD Summit promises a full program of productive discussions and collaborative solutions.

LEGAL RESOURCES:

A Better Balance - nonprofit legal advocacy organization: ABB is a national, nonprofit legal advocacy organization. Our free and confidential legal helpline can help you understand your workplace rights around caring for yourself and your family members.

Guide to Disability Rights Laws | ADA.gov

National Disability Rights Network - P&A - CAP | NDRN: The National Disability Rights Network works in Washington, DC on behalf of the Protection and Advocacy Systems (P&As) and Client Assistance Programs (CAPs), the nation's largest providers of legal advocacy services for people with disabilities. NDRN promotes the network's capacity, ensures that P&As/CAPs remain strong and effective by providing training and technical assistance, and advocates for laws protecting the civil and human rights of all people with disabilities.

AEM Center: The National Center on Accessible Educational Materials for Learning at CAST: The National Center on Accessible Educational Materials for Learning at CAST provides technical assistance, coaching, and resources to increase the availability and use of accessible educational materials and technologies for learners with disabilities across the lifespan.

IRIS Center: The IRIS Center is a national center dedicated to improving education outcomes for all children, especially those with disabilities birth through age twenty-one, through the use of effective evidence-based practices and interventions.

Council of Parent Attorneys and Advocates, Inc. (copaa.org): COPAA's mission is to protect and enforce the legal and civil rights of students with disabilities and their families. Our primary goal is to secure high quality educational services and to promote excellence in advocacy.

Disability Rights Education & Defense Fund: Disability Rights Education and Defense Fund (DREDF), founded in 1979, is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities.

Protecting Rights and Preventing Abuse of People with Disabilities | ACL Administration for Community Living

GINAhelp.org - Your GINA Resource: The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment. Genetic discrimination is the misuse of genetic information.

Exceptional Consultants, LLC: Servicing families and Civil Litigants in all 50 States and United States Territories, Exceptional Consultants is a leader in providing special education advocacy services, consultative services to school districts and mediation services to civil litigants. With over 20 years of legal and educational advocacy services our team is comprised of educators and legal professionals dedicated to our client's success.

NDRN Member Agencies - P&A - CAP | NDRN: NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). There is a P&A/CAP agency in every state and U.S. territory as well as one serving the Native American population in the four corners region. Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States. Select your state to connect with your local center.

Special Needs Alliance -Attorneys For Special Needs Planning: The Special Needs Alliance (SNA) is a national organization comprised of attorneys committed to the practice of disability and public benefits law. Individuals with disabilities, their families and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena.

Planning Across The Spectrum | PATS: Planning Across the Spectrum is built from the ground up on an understanding of neurodiversity, not just from textbooks, but from lived experience that can't be replaced, taught or bought. We are neurodivergent individuals ourselves and active members of the community, living with disabilities, and caring for those with disabilities everyday. Our own lived experiences have taught us how important it is to find the right balance of individual needs and family care.

Council of Parent Attorneys and Advocates Inc.: Protecting the Legal and Civil Rights of Students with Disabilities and their Families.

EMPLOYER RESOURCES:

Cariloop - Home: Take care of your people in their most stressful caregiving moments. Our Care Coaches shoulder the load of caregiving tasks to help your team stress less and stay present at work and at home.

Child Death - Help transition your employee's return to work. (hopeworkshere.com): Hope Works Here is an employer-sponsored benefit that guides the transition of an employee's return to work after the death of a child.

The Caring Company (hbs.edu): By investing in a care culture, American companies can prepare themselves for the looming care crisis. The economics of care are misaligned in most companies. Employees don't get the support they need for their caregiving responsibilities and employers pay the hidden costs, including turnover, rehiring, presenteeism, and absenteeism.

The Caring Company (hbs.edu): How employers can help employees manage their caregiving responsibilities—while reducing costs and increasing productivity.

The Wellbeing Partners – Building wellbeing into the way communities grow and do business.: The Wellbeing Partners believes in the human potential of every person and sees that a secret ingredient to the growth of our economy, competitive talent, and vibrant neighborhoods is equity and inclusion as we work to ensure all people and places thrive for this and future generations.

Finding Jobs And Talent Just Got Easier - Hire Autism: Hire Autism is a free program led and run by the Organization for Autism Research (OAR). With an active jobs board and by offering resources for employers and job seekers alike, Hire Autism aims to expand opportunities for autistic individuals and serve as a continuing resource for them in their workplaces.

Superkin | Supporting Parents at Work: Comprehensive support for parents and caregivers is no longer a nice-to-have. It's business critical. Superkin is determined to change the status quo for caregiving employees. Behind every Superkin solution is a proprietary benchmark report, industry-relevant data, and an exclusive network of experts.

Homepage - Disability:IN (disabilityin.org): Disability:IN is the leading nonprofit resource for business disability inclusion worldwide. Our network of over 400 corporations expands opportunities for people with disabilities across enterprises. Our central office and 25 Affiliates serve as the collective voice to effect change for people with disabilities in business.

For Employers - An employee benefit for family caregivers (wellthy.com): Unlike other care companies, we aren't just resource providers or navigators, we are doers. By tackling the logistical and administrative tasks of care, Wellthy helps increase productivity, improve retention, and reduce time away, all while giving people the support they desperately need to care for themselves and their families.

FINANCIAL RESOURCES:

FINANCIAL PLANNING RESOURCES:

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National Disability Institute: We are the first national nonprofit committed exclusively to financial education & empowerment for people with disabilities.

Special Abilities Network: The trusted team at the Special Abilities Network develops customized, family-centered plans that are designed to bring your vision for today and tomorrow into fruition. First, we'll develop a clear picture of your current financial situation, including a review of your investment portfolio, insurance contracts, and estate plan. We'll also discuss your goals for the future, and then we'll develop a strategic plan to achieve those goals and successfully navigate each stage on the transition timeline.

Three Twenty One Financial Outfitters: expert financial planning, resources, and a dedicated go-to for families with loved ones with special needs.

FINANCIAL ASSISTANCE RESOURCES:

Accessia Health: Our programs provide financial assistance with copays, health insurance premiums, travel costs, and other medical expenses – all at no cost to you.

When health insurance is not enough - HealthWell FoundationHealthWell Foundation: 501(c)(3) independent non-profit organization providing financial assistance to adults and children to cover the cost of prescription drug coinsurance, copayments, deductibles, health insurance premiums and other selected out-of-pocket health care costs.

Patient Advocate Foundation: Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization which provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.

Patient Assistance | ThinkGenetic Foundation: The ThinkGenetic Foundation is working to secure future funding for a patient assistance program. In the meantime, below are some incredible organizations providing assistance with everything from reimbursing drug costs and paying for medical treatments, to cost-sharing and insurance reimbursement. While we are not directly affiliated with any of the below organizations, we applaud the work that they do.

Ariana Rye Foundation: The Ariana Rye Foundation was developed to help families in need of medical equipment for their children with disabilities. We help dozens of families each year get equipment that insurance companies deem unnecessary or non-essential for these children. Not only is this equipment necessary for proper development, it helps build confidence in the children and eases the burden on the families caring for them.

Alyssa V Phillips Foundation: The purpose of the Alyssa V Phillips Foundation is to support individuals with Cerebral Palsy ("CP") with a focus on assisting children with CP, the families of children with CP, or any individual impacted by CP in maximizing independence.

Amanda Hope Rainbow Angels : Amanda Hope Rainbow Angels supports the here and now needs of families impacted by childhood cancer and other life-threatening illnesses through Comfort and Care counseling, Comfycozy's for Chemo adaptive apparel, Financial Assistance, and Major Distractions events.

Apply for a Gift | My Gym Foundation: nonprofit dedicated to helping children with disabilities and those struggling financially by awarding critically-needed gifts that improve their quality of life.

Aubrey Rose Foundation: The Aubrey Rose Foundation helps families with children who are currently living with a life-threatening medical condition.

Catholic Charities USA: At Catholic Charities we help people, regardless of their faith, who are struggling with poverty and other complex issues. At CCUSA, our advocacy and disaster relief programs — and our support of member agencies in our network — is making tangible progress toward providing help and hope to our neighbors across the country.

Braylee Butterflies Family Assistance Fund. – With Angel Wings: The trauma of living with a rare disease can be devastating to a family. No one should have to worry about the mounting medical costs of treatment and travel associated with treatment. Braylee's Butterflies Family Assistance Fund can help eligible families receive aid for: Medical food, Mileage, Wheelchairs, Bathroom Adaptations/Equipment, Travel, and more. Donation to family may also be matched by With Angel Wings assistance fund. Q2 of 2023 Financial Assistance Application is due on May 10th. Q3 of 2023 Financial Assistance Application is due on Sept 6th. Q4 of 2023 Financial Assistance Application is due on Dec 13th.

Chai Lifeline : Fighting Illness With Love: Chai Lifeline is an international support network, providing social, emotional, and practical assistance to children, families, and communities impacted by medical crises and trauma through a variety of year-round programs and services.

Compassion Can't Wait: When compassion can't wait and single parent families are in despair, we help with urgent expenses to allow these caregivers to stay at their child's bedside during catastrophic illness. We provide swift financial assistance in an unprecedented turnaround time.

Dollar For - Medical Debt Forgiveness: Dollar For helps patients check if they are eligible for charity care, prepare and submit applications, and eliminate medical bills. Our services are completely free – no strings attached.

Financial Assistance For Patients With Rare Diseases | NORD: Our RareCare program helps patients obtain life-saving or life-sustaining medication they could not otherwise afford. The program also provides financial assistance with insurance premiums and co-pays, diagnostic testing assistance, and travel assistance for clinical trials or consultation with disease specialists.

Good Days | Effective Compassion | Copay Assistance: Copay Assistance, Travel Assistance, Premium Assistance, Diagnostic Testing Assistance

Holton's Heroes Nonprofit: not-for-profit charity, provides support, information and rehabilitative devices for children and their families affected by a post-birth brain injury.

Joshua Harr Shane Foundation: Joshua Harr Shane Foundation helps those in need of care, support, assistance and love. JHSF is different from most non-profits because we go directly to the people who need help. Cash is never given. All bills are paid directly to their sources.

June Jessee Memorial Foundation The June Jessee Memorial Foundation (JJMF) is a nonprofit organization that provides relief to help support and care for children with devastating medically complex, neurological conditions and their families, providing needed resources, services and connections to help make their lives easier.

Keep Swimming Foundation: Keep Swimming Foundation provides financial aid for patients and their families so that they may afford the essential, non-medical expenses required to remain together throughout long-term inpatient hospitalizations.

Miracles for Kids: We're one of the only organizations on the West Coast that provides monthly financial aid, subsidized housing, and counseling to families fighting for their child's life.

Molly Bear Foundation: to provide supplemental financial support to families raising children with Trisomy 18 and the organizations and professionals that care for them.

PAN Foundation: To help underinsured people with life-threatening, chronic, and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access and affordability.

Parker's Purpose: Any family, who has a minor child (18 and under) with a life altering illness or disability that is having financial crisis due to unforeseen medical expenses.

Patches of Light: Our mission at Patches of Light is to assist families with children facing catastrophic health issues and financial hardship. Our goal is to keep families together, and focused, during their child's diagnosis, hospitalizations, and hopeful recovery.

Pediatric Angel Network: The Pediatric Angel Network provides financial and material assistance to families of children with a long-term illness or disability. Families may be experiencing difficulty due to expenses not covered by insurance. Our 501 (c) (3) nonprofit organization was created to help these families ease some the hardships they may be encountering due to their child's illness or disability.

Pennies from Heaven: PENNIES FROM HEAVEN is dedicated to assisting families who have a critically ill child fighting for their life. We provide financial support so parents do not have to leave their sick child's bedside. Our help comes by way of covering rent or mortgage payments, electric or medical bills, groceries, transportation and more. No parent should have to prioritize a payment or job before the care of their sick child.

The Assistance Fund - TAF (tafcares.org): The Assistance Fund is an independent 501(c)(3) organization that helps patients and families facing high medical out-of-pocket costs by providing financial assistance for their copayments, coinsurance, deductibles, and other health-related expenses.

The Colette Louise Tisdahl Foundation: We provide financial assistance to families dealing with high-risk and complicated pregnancies, premature birth and NICU stays, or loss.

The Cooper Foundation Cleveland: Our mission is to assist children and young adults with disabilities get the help they need. The assistance may be funding for therapy, a summer camp, or devices/equipment to help with everyday living. We want to provide the "extra help" these individuals need to reach their full potential.

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The Jiselle Lauren Foundation: The Jiselle Lauren Foundation exists to provide financial support and a sense of community to as many children and their families as possible, regardless of disability or diagnosis.

The Parker Lee Project: The Parker Lee Project is a 501c3 nonprofit organization dedicated to helping the families of children with medical needs obtain the supplies/equipment, education, and support they need.

The Ray Tye Medical Aid Foundation: The Ray Tye Medical Aid Foundation's charter and mission is dedicated to funding in-hospital life saving medical treatment and surgeries for those who do not have medical insurance, and for which no other financial resources are available.

The Shannon Foundation: Working through social workers at various hospitals across the country to identify kids in need, the foundation has paid for medicine, medical tests and procedures, equipment (such as wheelchairs, ventilators, etc.), hospital visits, surgery, medical co-pays, chemotherapy, and physical therapy.

CROWD FUNDING RESOURCES:

Amplify Hope Resources — Rare Genomics Institute: The Amplify Hope Initiative is a new study to help families develop and launch crowdfunding campaigns to raise funds for sequencing while at the same time measure the impact of community engagement. Through this study, families will be trained, supported and coached on crowdfunding strategies and then given 30 days to launch and run their own crowdfunding campaigns. Anyone, anywhere can donate to and support the families to help fund the diagnosis of these children. When funding is completed, sequencing of the child and both parents occurs. Surveys will be given to measure impact and all responses will be unidentifiable.

Fundabilities - Click and Raise Crowdfunding:

Kiddie Pool (adaptivemall.com): The Kiddie Pool is a FREE Service Program that works like a fundraiser. Your family joins the program and a custom webpage is created for your child with special needs.

Tadpole Adaptive | MobilityFunder®: We all know how limited funding options & high costs make it difficult (or impossible) to get the adaptive gear you need. Sometimes we all need a little extra help. Tadpole Adaptive is proud to offer MobilityFunder® as a flexible crowdfunding or group gifting solution. It's unlike the other options that may have hidden fees, platform costs, and always have transaction charges. It's a simple, powerful and easy way for you to "Thrive from Your Hive!"

Help Hope Live: We support community-based fundraising for people with unmet medical expenses and related costs due to cell and organ transplants or catastrophic injuries and illnesses.

GRANT RESOURCES:

Chive Charities Grants: Each week, we provide critical grants for recipients with life-altering or life-threatening needs. From therapy equipment like adaptive tricycles and robotic walkers to service dogs, wheelchair-accessible vans, and a wide range of mobility items, Chive Charities fills the gaps where insurance and other resources cannot.

Golden Halo Foundation | Helping Children With Medical Conditions: The Golden Halo Foundation provides financial assistance, in the way of grants, to help those children with medical conditions that require specialized care. The financial assistance is to help seek medical treatment, diagnostic evaluations, durable medical equipment and expenses related to securing medical care. The Foundation currently serves families in the Midwest region.

WAWOS | Wishes: Every year, beginning on Giving Tuesday, new grantees will be awarded financial support. Qualifying organizations must be registered 501(c) (3) and be actively operating in the United States for a minimum of two years. Final decisions are at the discretion of our board of directors.

B Brave Foundation: B Brave Foundation provides customized grants tailored to each family and their individual journey. The funding is designed to ease financial stress on families and can cover a range of needs, including bills, medical expenses, lodging during hospital stays, funeral expenses and more.

Innovating Worthy Projects Foundation: IWPF was founded by Estelle and Irving Packer to foster innovative ideas and projects for children with challenges including special needs, acute illnesses or chronic disabilities. With our founder's intent in mind, we continue to support nonprofit organizations in order to create a future where all children can thrive, regardless of their life circumstances. We are humbled by the impact that our nonprofit grantees have made with IWPF support.

Bellows Fund - United Cerebral Palsy (ucp.org): The UCP Elsie S. Bellows Fund is a national program operated by UCP that provides funds to individuals with disabilities for assistive technology equipment. UCP affiliates submit an application on behalf of an individual to the UCP national office. Applications are reviewed for funding by the Bellows Committee.

Modest Needs®:Modest Needs offers grants designed to promote the self-sufficiency of individuals and families who, because they are working and live just above the poverty level, are ineligible for most types of conventional social assistance but who, all the same, are living one or two lost paychecks away from the kind of financial catastrophe that eventually leads to homelessness.

Giving Angels Foundation: At the Giving Angels Foundation, our mission is to enhance the daily functioning of a child with a physical disability from a lower income family by awarding grants for life-changing equipment, medical supplies, essential family bills, specialized camps, and therapeutic toys.

Bloomfield | The Episcopal Diocese of Virginia: Bloomfield's mission is to provide grants that assist physically disabled children and young adults with the unique demands of their daily lives. Additional grants provide attendance at various camps programmed for these individuals. Grants are not limited to the Commonwealth of Virginia. However, preference is given to support projects and individual requests within the geographic area from which Bloomfield receives its financial support.

Cerner Charitable Foundation: Cerner Charitable Foundation (formerly First Hand) is building healthier tomorrows and stronger communities around the world through individual medical grants and wellness programs, engaging volunteerism, community initiatives and strategic partnerships.

FINANCIAL ASSISTANCE FOR FAMILIES - Aubrey Rose Foundation: The Aubrey Rose Foundation helps families with children who are currently living with a life-threatening medical condition. Grants are awarded based on need. If a family has outstanding medical bills that insurance will not cover, our Foundation can possibly help out a family in need until our annual funds have been exhausted.

State Grants for Wheelchair Vans | The Mobility Resource: If you need assistance in buying a handicap van, you should know that states offer various grants and other assistance programs for those who qualify. These grants and other programs could help you finance a wheelchair van, scooter, wheelchair lift, adaptive driving equipment, or other mobility product.

General Grant Sites for special needs : General Grant Sites for special needs via lucasdd.org

The Orange Effect Foundation Grant: foundation that empowers children and young adults with speech disorders to effectively communicate through technology and speech therapy.

The Different Needz Foundation: The Different Needz Foundation has a mission to provide grants to individuals with developmental disabilities, their families and organizations that support them to provide medical equipment and/or services.

Nelson Family Foundation Grant: Nelson Family Foundation supports all causes related to children inpatient and ongoing, extensive medical care for babies and children.

GRANTS | New NCKF (napacenterkidsfoundation.org):

Grants for single mothers: Listed here are financial assistance programs that help single mothers with rent, utility bills, childcare, education, medication, housing, medical bills, and mortgage, among others. We have listed links to more than 1000 grants that you could apply for today. These are free grants, and no fee need to be paid.

Kaufman Children's Center Grants: Please note that each grant resource is from an independent organization; none are associated with the Kaufman Children's Center. The KCC has made every effort to provide high-quality and helpful grant information, but we cannot be held liable for errors or the quality of the grant sources. Information should be independently verified and confirmed. Questions about specific grants should be addressed to the organization offering the grant.

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Small Steps In Speech Grant: Application deadline May 1 2023

The LENN Foundation: The LENN Foundation is a 501(c)(3) charity that provides grant opportunities for children with cerebral palsy to receive the pediatric intensive therapies they need to thrive.

United Healthcare Children's Foundation: The mission of UHCCF is to provide medical grants to enhance the quality of life of children across the United States. Through these grants, kids can get the care they need.

SCHOLARSHIP RESOURCES:

#RAREis Scholarship Fund (scholarsapply.org): The RARE Scholars program is an annual scholarship opportunity for people living with a genetic condition. These scholarships recognize and support students who have demonstrated exceptional leadership and engagement in school and community activities.

Gottlieb Sibling Scholarships - NTSAD: The Jeffrey Alan Gottlieb and Stanley N. Gottlieb Memorial Scholarship Funds make monies available to college-attending healthy siblings of those who are or were affected by Tay-Sachs, Canavan, GM1, Sandhoff or an allied disease.

Scholarship Applications Open Letter (lpaonline.org): Little People of America, Inc., is a nonprofit organization that provides support and information to people of short stature and their families. Membership is offered to those individuals who have a medical or genetic condition that usually results in an adult height of 4'10" or shorter. Their short stature is generally caused by one of the more than 400 medical conditions known as dwarfism.

A Guide to Scholarships & Grants for Students with Disabilities | MoneyGeek.com

Financial Resources and Discounts for Students With Disabilities (couponfollow.com)

The Hannah Bernard Memorial Scholarship - The Coalition Against Pediatric Pain (tcapp.org): THE HANNAH BERNARD MEMORIAL SCHOLARSHIPS ARE AVAILABLE TO ANYONE FIGHTING COMPLEX PAIN CONDITIONS AND PURSUING THEIR EDUCATION, INCLUDING HIGH SCHOOL, COLLEGE AND ONLINE COURSES. TWO $1500.00 SCHOLARSHIPS WILL BE AWARDED TO THE WINNERS IN MEMORY OF HANNAH BERNARD IN JUNE 2023. APPLICATIONS FOR THE HANNAH BERNARD MEMORIAL SCHOLARSHIP 2023 WILL ONLY BE ACCEPTED JANUARY 1, 2023 – APRIL 30, 20223.

Mica Hammond Fund Education Reimbursement For Special Needs Families - CHARITYSMITH: The Mica Hammond Fund intends to award approximately two $1000 scholarships annually to needs-based families of children with rare or undiagnosed diseases to help those children or immediate family members attend college/education

RARE Scholars | Patient & Community Support - BioMarin: The RARE Scholars program is an annual scholarship opportunity for people living with a genetic condition. These scholarships recognize and support students who have demonstrated exceptional leadership and engagement in school and community activities.

Ruby's Rainbow – Scholarships for Adult Students with Down Syndrome (rubysrainbow.org): Supporting adult students with Down syndrome in achieving their dreams of higher education while spreading awareness of their capabilities and general awesomeness!! We provide college scholarships for students with Down syndrome attending post-secondary programs in the U.S., and shout their worth to the rooftops!!

Scholarships for the Epilepsy Community from CURE Epilepsy: This program is a one-time scholarship (up to $5,000) for those living with epilepsy, family members, or caregivers. These scholarships support coursework in scholars' chosen fields, so they can use their knowledge and skills to become agents of change in the epilepsy community.

OTHER FINANCIAL RESOURCES:

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Disability Savings Account | ABLE Account | Eligibility Quiz & News | ABLEnow

Ride To Give: Ride to Give is a 501c3 non-profit charity that turns athletic ability into fundraising power for families with children who are disabled, injured, or ill. Since March of 2013 Ride to Give has raised nearly $2,000,000 for 95 families in states throughout the U.S. We raise funds for medical equipment, travel expenses, and other out of pocket costs related to having a medically fragile child.

Go Shout Love: Go Shout Love is all about doing amazing things for amazing families with kids on rare medical journeys. We feature a different child each month and spend all month long shouting love and celebrating them in big ways. We believe in the power of being loud and we hope you will join us in making some noise for these families. Head over to our shop where you can apparel inspired by our featured families and other items where 85% of the net campaign funds during the month go directly to the family to help with items related to the care of the children.

Easterseals and Freddie Mac Present Financial and Housing Guidance: We've partnered with Freddie Mac to help more people in the military, veteran and caregiving communities as well as those with disabilities obtain affordable housing through renting or buying a home. Today, Freddie Mac has funded one in four home loans in the past year nationwide, and they want to help make homeownership a reality for you.

Home - Disabled Children's Fund | Empowering Children with Disabilities to Thrive (achildthrives.org): Disabled Children's Fund (DCF) is a humanitarian organization with a global mission of bringing medical treatment, mobility devices, and physical therapy programs to disabled children in need.

Home (lorisvoice.org): Lori's Voice is a 501(c)(3) non-profit organization which was founded and established to help young people with disabilities. This organization evolved from Lori Hastings great love for children and the realization of so many challenges young people face when living with a disability.

Christopher Douglas Hidden Angel Foundation – Multi Sensory Environments, Sensory Stimulation (cdhaf.org): Christopher Douglas Hidden Angel Foundation's primary goal is to promote the use of multi-sensory environments in therapeutic, recreational, and educational settings with the intent of enriching the lives, health, and social well-being of individuals with cognitive, emotional, and physical impairments. We aim to enable productivity, inclusion, independence and self-determination. Our focus is on the design, development, and implementation of Multi Sensory Environments. We support innovative initiatives that demonstrate new approaches to advance education, To date The Christopher Douglas Hidden Angel Foundation, USA and Canada, has funded and built over 80 Multi Sensory Environments from Miami, Florida to Portland, Oregon and from Bay of Islands, Newfoundland to Calgary, Alberta."

iTaalk Autism Foundation - Grant Database: The following database is a constantly growing list of resources for families of children with special needs. There are currently over 750 organizations in our database. You can search by disability, need type, specific state of residence and any other special concern or characteristic. Please note that because this list is constantly changing, you may contact an organization and find they are no longer offering assistance.

Neocate Product Access | Insurance Coverage & Reimbursement: The health insurance landscape can be confusing. At Neocate, we offer a free reimbursement service that can help you find the Neocate product access and coverage so your child can thrive. This service is called Nutricia Navigator and it helps you do just that, navigate.

Ronald McDonald House Charities | RMHC

Seizure Devices & Technology - Devices | Danny Did Foundation: Help families afford travel and lodging associated with an epilepsy surgery consultation. Funded in part by the parents of Danny Abel, a young boy who needed subtotal hemispherectomy to stop his seizures, this new program provides up to $1,000 in approved travel funds for scholarship awardees.

The Striped Stable: a community filled with fundraising resources and a real-life look at raising a child with a disability in America.

U.R. Our Hope – Assisting the Undiagnosed and Rare at any age and any stage (urourhope.org): U.R. Our Hope is a registered 501 (c)(3) non-profit organization that assists individuals and their families on their journey to diagnosis, or helps them navigate the healthcare system with a rare diagnosis.

RESPITE RESOURCES:

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Easterseals | Respite Services for People with Disabilities and Their Families

camp: HOPE FULL – Apricity Hope

Believe In Tomorrow Children's Foundation: Our beach and mountain respite properties operate year-round, allowing families with critically ill children the opportunity to get away, relax, and reconnect together in the midst of a child's treatment and recovery.

Our Locations - All Ways Caring HomeCare: To locate the care you need, you've come to the right place. In 24 states, All Ways Caring offers the resources, the experience and the caregivers to provide quality, compassionate care at home.

ARCH National Respite Network & Resource Center: ARCH does not provide respite care, but we may be able to help you find it in our local community through your State Respite Coalition or Lifespan Respite Program.

Respite | The Autism Project: The Autism Project is committed to providing support to families raising children with special health care needs. Caring for a child or youth with ASD, a developmental disability, or who is medically fragile can be stressful and overwhelming at times. Having the ability to take a brief break from responsibilities is important. The Respite Program gives parents or guardians a break from caregiving to recharge.

Exceptional Family Member (EFM) Respite Care: This program is available as a benefit to Navy families who have a child enrolled in the Navy Exceptional Family Member Program (EFMP) and meet the prescribed eligibility criteria. Caring for children with special needs is full time job which is physically and emotionally challenging. EFM Respite Care provides parents the opportunity to rest and rejuvenate with peace of mind, knowing their children will be well cared for.

A Mother's Rest: Here at AMR, we support parents & caregivers of just about EVERY CIRCUMSTANCE. As a secular organization, caregivers of all faiths and backgrounds are welcome. Many of our guests are "extra needs" parents, of children and adults. We do not require documented proof or a lengthy application. Your child does not need an IEP or have to be significantly cognitively delayed for you to participate. We also welcome ALL foster/adoptive parents (with or husbands/wives, spouses of Wounded Warriors, as well as those caring for their own parents facing Alzheimers/Dementia and other age related illnesses at home.without diagnosed disability), special educators, spouses caring for injured /chronically ill.

The Lucas Project: We believe that society is full of compassionate and kind individuals who want to help caregivers; however, if they don't know what our needs are, they can't help. Recognition is the first hurdle, and the second involves providing tangible relief for the families through respite options.

A Week Away Foundation: At A Week Away, we coordinate and finance respite weeks for families who are battling a life-threatening illness, with the goal of providing them the hope they need to continue their fight.

Mike's Kids: The purpose of this foundation is to provide assistance via services equipment, education, special care and respite support to children with special needs and their families.

Caregiver Respite | NORD: Caring for a loved one demands significant amounts of time, attention, patience and dedication. Our Respite Program provides financial assistance to enable caregivers a break to attend a conference, event or simply have an afternoon or evening away from caregiving.

Respite Care Notebook: The Respite Care Notebook was created by the Child Neurology Foundation. It is a tool to help guide the respite care provider in caring for your child. It includes fully customizable forms where you can fill out information about your child that the respite care provider should know. The periodical mentions that the notebook might also help remind other family caregivers of changes in medication or routine. It can also help build a record of the child's care, growth, and use of respite services.

CHILDCARE RESOURCES:

Apex Social Group: The live-in child care model allows for optimal flexibility and helps families to focus on reducing stress and creating a home environment that is structured, warm and positive for everyone Apex Social engages with Care Professionals who have a background in early childhood education, occupational, physical or speech therapy, ABA therapy, pediatric nursing, special needs education or another child development field to support interdisciplinary child care in the home environment. All of our Care

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Professionals are seeking full-time, live-in childcare positions with American families where they can become like a family member and share their traditions and culture. The live-in child care model allows for optimal flexibility and helps families to focus on creating a home environment that is structured, warm and positive for everyone.

SeeInMe: SeeIn Me was started by Risa, a clinical psychologist, mother to a neurodivergent son, and granddaughter to a (now deceased) Alzheimer's sufferer. SeeInMe was created so those who love, serve, and work with vulnerable individuals could advocate for and relate to them on a personal level. Provide personalized care with access to emergency contact information, personalized videos, and checklists

PARENT AND CAREGIVER RESOURCES:

COMMUNITY AND NETWORKING:

Comend Care: Comend connects caregivers for rare conditions. Find the support network personalized for you, on a platform designed for you.

Family Caregiver Alliance: Our Services by State tool helps family caregivers locate public, nonprofit, and private programs and services nearest their loved one—whether they are living at home or in a residential facility. Resources include government health and disability programs, legal resources, disease-specific organizations and more. Caregiving is challenging, but there are resources to help. Click on a state below for state-specific resources, or scroll to view national resources and organizations.

CARE Act Statewide Map: The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.

Verity's Village: Verity's Village provides support for families who receive a life-limiting diagnosis for their babies. Our private support group lets you ask questions and connect with others going through a similar journey so that you don't feel so alone.

Orange Socks: Orange Socks-Bridging the gap between the life you thought you'd have, and the one you were blessed with. We are a parent community for kids with disabilities. Our mission is to help families find a new normal as they navigate through the grief that comes when they're told that their little one will be different.

Moms of Heart | Facebook: For caregivers of children with medical challenges.

Steel Magnolia Moms - A Special Place For Special Moms: Many support groups within the special needs community are diagnosis centric for the purpose of discussing the children's needs. Steel Magnolia Moms, however, focuses on the Mom. Steel Magnolia Moms reminds these moms to take time out of their hectic schedules to focus on themselves. We share our knowledge and resources, but more importantly, we encourage moms to take a break, have fun, and connect. Local Chapters in D.C., Houston, and Austin.

Sisterhood Circles | Labeled and Loved: are safe spaces where messy moments are welcomed, stories and scars are embraced, and no label will ever prevent you from being loved. We offer Support Sisters who lead small break-out groups and guide you through specific discussion topics.

Moms Mingle | Labeled and Loved: Moms Mingles are free virtual and in-person events created specifically for moms who have children with disabilities. These evenings are filled with games, prizes, inspirational speakers and most importantly, opportunities to connect.

Parenting Videos | Labeled and Loved: weekly video series providing quick tips for parents to address common struggles, learning challenges and practical everyday life skills.

We Are Brave Together: A Supportive Community for Moms of Children with Disabilities and All Unique Needs.

Apricity Hope: The mission of The Apricity Hope Project is to empower, encourage, comfort and restore the caregivers of medically complex and disabled children, who are facing life-long diseases.

Amanda Griffith Atkins: Amanda Griffith-Atkins is a licensed marriage and family therapist whose clinical background, combined with her own experience as the mother of a disabled child, has given her a unique and refreshing perspective on parenting.

Center for Parent Information and Resources: Supporting the Parent Centers Who Serve Families of Children with Disabilities.

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ANGEL AID: ANGEL AID provides mental health and wellness services to rare families through sustainable psychosocial training, transformative retreats, and a connective caregiver-to-caregiver multilingual network. ANGEL AID believes in uplifting rare families by caring for the caregivers, particularly Rare Mothers™ who are the primary caregiver 82% of the time.

Courageous Parents Network: Courageous Parents Network is a non-profit organization that orients and empowers parents and others caring for children with serious illness, by providing resources and tools that reflect the experience and perspective of other families and clinicians.

Different Dream Living: If you're a caregiver, Different Dream offers resources to equip you to be a confident advocate and encouragement when you need a boost. You're invited to engage in the caregiving conversation by leaving comments about resources or advice you'd like to share with others.

Federation for Children with Special Needs: Provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families and encouraging full participation in community life by all people, especially those with disabilities.

Support for Parents of Children with Disabilities: we empower and support parents, nationwide. Why? Because we understand being a parent of a child with special needs can be a challenge — we've been there! The journey is filled with hills and valleys and sometimes feels a little overwhelming. So, we're driven to ensure no parent feels alone. Ever.

Exceptional Lives: Exceptional Lives encourages and guides families and providers caring for children with disabilities by offering information, advocacy and skill-building tools, and connections to other caregivers. We support family resiliency through clear, compassionate guidance grounded in our own personal experience.

Extra Lucky Moms: The journey of a special needs mom can be a lonely one. Our mission is to meet Moms wherever they are along their path. We are here to provide community, support and programs so all Moms can not only SURVIVE but THRIVE.

HOPE | Helping Outcomes for Parents of Exceptional Children: HOPE for Parents (Helping Outcomes for Parents of Exceptional children) is an organization promoting healthy relationships for parents of children with disabilities by providing opportunities to engage in activities within their community. Providing parents with the opportunity to embrace and renew their partnership to be strong for their children and maintaining the family unit.

Resources for Parents of Children with Special Needs - Parent Resource - Fraser: When you're the parent of a child with autism, mental health issues or special needs, you face some unique challenges. This page is a resource to help you address concerns and nurture your child's growth.

HopeKidsHopeKids - Restoring Hope. Transforming Lives: HopeKids provides ongoing events, activities and a powerful, unique support community for families who have a child with cancer or some other life--threatening medical condition. We surround these remarkable children and their families.

Family Caregiver Alliance: The mission of Family Caregiver Alliance is to improve the quality of the life for family caregivers and the people who receive their care.

Family Voices: Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities. We connect a network of family organizations across the United States that provide support to families of CYSHCN. We promote partnership with families at all levels of health care–individual and policy decision-making levels—in order to improve health care services and policies for children.

The Rare Village Foundation: Resources for rare families to connect, collaborate and create the change needed for their children.

The Lucas Project | Recognition & Respite for Special Needs Caregivers: We believe that society is full of compassionate and kind individuals who want to help caregivers; however, if they don't know what our needs are, they can't help. Recognition is the first hurdle, and the second involves providing tangible relief for the families through respite options

Rare Disease Caregiving | The National Alliance for Caregiving: a national research study capturing the experiences of more than 1,400 family caregivers of children and adults with a rare disease, condition, or disorder across 400 different diseases. Findings in this first-of-its-kind national snapshot paint a picture of friends and families facing emotional, financial, physical, and social strain with little support from outside resources.

Open Caregiving: Our mission is to support caregivers and the people they care for. We believe that better care starts with meeting people where they are, understanding their needs and wishes, and guiding them every step of the way.

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Special Needs Moms for Moms - Building Community by Engaging Mothers™:A social network for families of children with special needs to connect, find information, share and offer support, and be inspired.

Special Needs Jungle: Special Needs Jungle creates easy to understand resources, articles and information for parents and carers of children with special needs, disabilities and health conditions to better enable them to navigate the special needs system. We aim to inform, educate and empower families to self-advocate confidently, so their children get the help they need to live the best life they can.

Special Needs Resource Project : Special Needs Resource Project (SNRP) provides a basic guide for parents of children with chronic health issues, disabilities and special needs. This site is designed to help you get a jump-start in your search for helpful information and resources. Every situation is unique. Our aim is to help you learn the basic skills you'll need to obtain the specific resource information, equipment, and services your child and family needs. Though focused on children ages 0-22, most of the information we offer is applicable to adults as well.

Caregiving for Family and Friends — A Public Health Issue (cdc.gov)

Rising Above Ministries: Here are some resources & stories of hope that we want to share with you as you walk your journey as a special-needs parent.

Homepage - Grandfamilies & Kinship Support Network (gksnetwork.org)

Caring for Rare Disease Caregivers (rarecaregivers.org): Caregiver Action Network is the nation's leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with significant health needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer's disease. CAN (the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

CAREGIVER TOOLS, APPS, & SERVICES:

ACA Disability Navigator Health Insurance Enrollment Resources | NDNRC (nationaldisabilitynavigator.org): The mission of the National Disability Navigator Resource Collaborative (NDNRC) is to provide cross-disability information and support to Navigators and other enrollment specialists thereby ensuring people with disabilities receive accurate information when selecting and enrolling in insurance through the Affordable Care Act Marketplaces.

Care Plan Book (ppcc-pa.org): The Pediatric Palliative Care Coalition (PPCC) is pleased to provide this Care Plan Book with the hope that it will make the job of a caregiver a little bit easier. We understand how overwhelming and difficult that task can be. Our goal is that this reference guide, to be used by families, caregivers and medical professionals, will become an invaluable source for you and everyone involved in your journey.

imagine (dimagine.com): Imagine is the name I give my consulting practice which is dedicated to supporting people who experience disabilities and exhibit, what some have called, "difficult behaviors." In my view, what's most needed when a person engages in difficult behaviors is imagination. The story-line that is floating around about the person is a major part of the problem. What's needed is a new story. My practice is based upon a simple idea: difficult behaviors result from unmet needs. In a sense, difficult behaviors are messages which can tell us important things about a person and the quality of his or her life.

Patient Helpline: Welcome to the Patient Helpline, a free program that supports patients and caregivers by connecting you to free or reduced-cost services that are personalized to your needs.

Care Plan Book Editable PDF

CareZone | Easily manage multiple medications and health info

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Caring Village | FREE help for families and caregivers

Connecting Technology Driving Action for Local Children and Families in Crisis (careportal.org): Take meaningful action on the platform that's connecting the largest network of caring people to meet the needs of kids and families in crisis.

Daily Planners and Accessories for Parents of Special Needs Children – The Glory Days Co.: A daily planner and more uniquely designed for parents and caregivers caring for those with medical, developmental needs and more.

Lightning Bug App: The Lightning Bug app is a tool that gives caregivers access to a suite of indispensable tools to help organize health care data. This app is meant to streamline a caregiver's experience by providing them with tools and features to assist with their responsibilities.

Osmosis - Learning Medicine Made Simple: Our mission is to empower the world's clinicians and caregivers with the best learning experience possible.

Lotsa Helping Hands: A central place to coordinate meals and help for friends & family.

MediMom Caregiver Planners: Explore Our Planners & Spiral Notebooks that I use daily to track and navigate our complex treatment schedule as a Medical Momma.

My Family Health Portrait (cbiit.github.io): a free web-based tool, is helpful in organizing the information in your family health history. My Family Health Portrait allows you to share this information easily with your doctor and other family members.

My Mejo: a better way to simplify, organize and share your kid's most important medical & care information all in one web app.

Our Voyaging Hearts: At Our Voyaging Hearts, we offer products and services that provide direct support. From consulting services for parents, educators and clinics to a store full of products that aim to meet you where you are — as well as a waitlist for forthcoming case management and care coordination services — we show up for exceptional parents.

Patient Helpline Navigator: Patient Helpline Navigator program is an online and phone support service that is provided by a professional patient navigator that helps connect patients to the services they need.

Patient Helpline: Welcome to the Patient Helpline, a free program that supports patients and caregivers by connecting you to free or reduced-cost services that are personalized to your needs.

Red Treehouse - Ronald McDonald Family Resources: Supporting the well-being of families and children with challenges, disabilities, and health care needs. Find tools, organizations, and events in your community to meet your needs.

Resources for Patients and Families: A variety of government agencies and other organizations offer a wide range of information, resources, and services for patients, families, and patient advocacy groups. Many of these are dedicated to engaging the patient community throughout the translational science process.

Respite Care Notebook: The Respite Care Notebook was created by the Child Neurology Foundation. It is a tool to help guide the respite care provider in caring for your child. It includes fully customizable forms where you can fill out information about your child that the respite care provider should know. The periodical mentions that the notebook might also help remind other family caregivers of changes in medication or routine. It can also help build a record of the child's care, growth, and use of respite services.

Sara Camak Coaching: Life coaching for moms of children with rare genetic disorders. Based in Virginia, but providing support to moms in all states.

The Caregiver Compass: The all-in-one system to care for your medically complex child and yourself.

The Connected Parent: Our comprehensive database and easy-to-use filters help you connect with the local & online businesses you need, reviewed by families like yours. You're overconnected but underserved - we were too. Built by families just like yours, we understand that the most valuable insights you can receive are often based on the advice and experiences of other families going through challenges similar to your own.

The National Caregivers Library : The National Caregivers Library is one of the largest single sources of information and tools for caregivers and seniors in the country. It makes it resources available to caregivers for free through alliances with professionals, businesses and other organizations who serve seniors and their caregivers with a variety of products and services.

Advocate Like A Mama (mamasystems.net): I know personally how hard it can be to wade through the internet searching for something that will actually help support you and your kiddos. Navigating this journey can be a nightmare. That is exactly why I created Advocate Like a Mama. I want you to have FREE access to the training, resources, and encouragement YOU need.

Bringing peace to your home through systems (mamasystems.net): I know you are overwhelmed and anxious but there is hope, please don't give up. I have been where you are and even though there are so very many resources out in the world for you, I have found that no one graciously hands them to you! Instead, it almost feels as if you are supposed to magically know where they are and how to get the help you need. This is absurd! There's just no other way to say it. With your permission, I would love to share with you how to find the resources you need and how to implement them. It is a game-changer.

Sleuth: Where parents share hard-fought lessons and specific data about kids' health.

Wellthy: Wellthy provides personalized support to help you tackle the logistical and administrative tasks of caring for the ones you love, including yourself.

BLOGS, PODCASTS, MOVIES, & MEDIA:

Child Life On Call: Katie Taylor, a child life specialist, interviews parents of children with an illness or medical condition to help other parents feel less isolated on their parenting journey. The Child Life On Call blog also includes tips, tools and free resources to help parents feel more empowered during healthcare experiences.

Complex Child: Welcome to Complex Child, your source for information on children who are medically complex or have disabilities! Complex Child includes content written by parents of children with healthcare needs and disabilities, as well as individuals with disabilities. It is intended to provide medical information, along with personal experiences, in simple language that other parents can understand. Complex Child is always free!

Climbing the Emotional Caregiving Mountain - Complex Child

Life With a Side of the Unexpected: My mission at Life with a Side of the Unexpected is to help you find balance in the chaos, experience joy in the messy moments and make the most of your unique parenthood journey. We special needs parents need to connect, provide each other with camaraderie and support. Hopefully you can relate to my posts and feel a sense of comfort that "I get it" and you are not alone.

Confessions of a Rare Disease Mama on Apple Podcasts: Join me every week as I navigate the ups and downs, and everything in between of the crazy stressful, but always beautiful life of being a rare disease parent.

DadVocate - Rare Disease, Blog, Advocacy (rarediseasedad.com): RARE DISEASE - altered my being. DAD - what I love being. ADVOCATE - what I aim to be. Rare Disease DadVocate.

Exceptional Parent Magazine: Exceptional Parent Magazine provides practical advice, emotional support, and the most up-to-date educational information for families of children and adults with disabilities and special healthcare needs.

Blog | Extra Lucky Moms

Healthcare Activist, Rare Disease Mom, Patient Advocate (dmsullivan.com): Healthcare Activist, Rare Disease Mom, Writer, Speaker, Film Producer, Patient Advocate, Journalist, Marketing Maven, Dog-lover, Humorist. I am committed to mental wellbeing and strive to help people find their "okay" even when their bodies are not. I elevate patients' voices and experiences to help healthcare stakeholders understand the faults in our medical system—and empower rare disease and chronic patients with the support and information to find healing after harm.

Happiness Is Blind – Navigating Marriage & Motherhood with a special needs child

Blog | We Are Brave Together: They are the keys to meaningful connections -- in life, in relationships, and in writing. You will find these here. In what is shared, expressed, and confessed on this blog may the stories resonate and bring hope and strength. (And may you find a little humor, too.)

A Very Rare Adventure: This blog is a way for me to be raw and honest about the highs and lows of this rare life in the hopes that someone somewhere might read this and think "hey, I feel exactly the same". I spent a long time grappling with my emotions in silence. I'd sob in the bath ashamed of my feelings or wait till everyone was asleep then cry until anxiety and insomnia took over. I never want anyone to feel that level of loneliness and shame again. As Matt Haig says in his book The Comfort Book: "Silence is pain. But it is a pain with an exit route. When we can't speak, we can write.

Created by: Sierra Phillips @mrs.phillijt

When we can't write, we can read. When we can't read, we can listen. Words are seeds. Language is a way back to life. And sometimes it is the most vital comfort we have". So, here I am ready to offer some comfort with my words and tell you: you are not alone.

Best Special | Blog: Best Special presents product options to accelerate your child's development as recommended by speech, occupational, and physical therapists – but also, from our own caregiving experience for a child with disabilities. We hope our experience helps you focus your time, simplify your life, and direct your resources to helping your child flourish.

Joyful, Brave & Awesome: I started my website – Joyful, Brave & Awesome – as a way to process parenting a disabled child. By sharing my experiences, I hope to encourage braver, deeper conversation about parenting, disability, inclusion and more!

Mama Bear for Rare: Hey all! I am Michelle – just your average Mama trying to make the world a more inclusive place by sharing stories about my experiences as a mother of two children: one who is "neurotypical" and one who is "neurodiverse."

Once Upon A Gene- Rare Disease Podcast: These are the stories of my family, and of families like ours. These are the stories of how we have persevered, bonded, and grown. These are the stories of children who have been told that they cannot, and that have proved the world wrong.

Rare Mamas by Nikki McIntosh: Hi, I'm Nikki, a rare-disease mom just like you. My son Miles was diagnosed with spinal muscular atrophy (SMA), a rare, neuromuscular disease at the age of eighteen months old. I was thrown into a match I never expected. My inner fighter was awoken. I believe that, like me, you have a brave fighter within you. I want to help you approach the rare-disease journey with bold courage, fearless faith, and unrelenting hope. I want to create a community of brave rare mamas supporting one another.

Rare Mom Life: Here I am addressing all the stuff that goes through my head as we progress on our rare disease journey. It's mostly the hard stuff. The fun stuff is in all the pictures on Instagram and stories and check-ins on Facebook. Here is where life gets real.

Special Needs Supermom: I'm Nadine. Special Needs Supermom and mentor, international copywriter, author, podcaster, digital planner girl and graphic designer. It's my mission to help fellow supermoms find and recharge their superpowers.

Parenting Special Needs Magazine – Online Magazine Serving the Special Needs Community. Providing practical tips, sharing life's lessons, tackling the challenges and celebrating the joys of one of life's greatest gifts.

https://www.adragonmomswords.com/

https://knowrare.com/blog-v2/tag/Rare+Resiliency

The Rare Life: THIS IS THE RAW, REAL, AND ALL THE FEELS OF MEDICALLY-COMPLEX PARENTING.

Unseen: Caregiver Documentary Film: Many parent caregivers for children or adults who are disabled or medically complex are exhausted and isolated. Their mental and physical struggle is a public health crisis that costs us all. The "Unseen" documentary gives an unfiltered, honest glimpse into their lives to enable a change for millions of caregivers and their families.

RETREATS:

Apricity Hope Autumn Beach Retreat: This retreat is for moms who are the primary caregivers of medically complex and/or disabled children with life limiting conditions.

Care for the Caregiver Retreat: This event will be focused on you, the caregiver and helping you learn, make a friend, feel seen, and more. Whether you come for one day or the whole weekend, you won't want to miss this life changing event.

Labeled and Loved Retreat: Labeled & Loved presents a 3-day retreat for mothers of children with any disability or special need. As primary caretakers, we are at serious risk of burnout. Nineteen research studies have identified parents of children with disabilities to have an increased risk for depression (95%) and anxiety (90%). The divorce rate is over 85% for parents of children with a disability. At this retreat, every moment is carefully curated to empower you to combat these statistics all while relaxing, having fun, finding community, and equipping you to return home with the tools to best care for your child—and yourself. You will also meet other moms who will become your lifelines and keep you from feeling alone in this unexpected version of motherhood.

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The Lucky Mamas Retreat: The Lucky Mamas Retreat is held on a ranch just west of Austin, Texas. The retreat runs from a Thursday through Sunday in October, and caterers and private chefs nurture us with delicious meals while we relax and connect for three amazing days. We also do yoga by the creek as well as mindfulness sessions, S'mores by the campfire, live music under the stars, and lots of other fun and relaxing activities. You will leave the ranch feeling connected and loved, and with a new tribe of mamas to call friends!

Retreats | We Are Brave Together: A retreat is an opportunity for respite, rest and relaxation away from home, and away from the everyday world of intense caregiving. A time to connect with other brave moms and share stories, tears, laughter, and resources for self-care, family-care, and the altered motherhood journey. We Are Brave Together aims to provide these retreats at a reasonable rate, making them accessible for moms to have this much needed break. Our retreat fee covers housing, food, speaker sessions and goodie bags. We are excited to be able to offer Retreat Scholarships for each retreat.

SELF-CARE:

Care(giver) Packages | Apricity Hope: The Apricity Hope Project is excited to offer seasonal gifts of love and hope for caregivers. Our Care(Giver) Packages are care packages created specifically for individual caregivers. Whether they are in the hospital or simply need an extra boost of hope.

Caring for the Caregivers: 3 Tools for Self-Care | Cristol Barrett O'Loughlin | TEDxLuxembourgCity - YouTube

Special Needs Archives - 5 Minutes for Mom:

Rethink-Self-Care.pdf (vmware.com)

The Pampered Parent: The Pampered Parent is the only subscription box & online community catered specifically to special needs moms. You do so much for everyone else. It's time to do a little something for you. Our mission is to give you the self-care, support, and encouragement you deserve in a convenient, simple, exciting way.

SIBLING RESOURCES:

Activities for Siblings | Courtesy of PPCC: PPCC has assembled a number of activities designed to engage children and teens in thought-provoking, imaginative, playful and expressive activities. The activities selected are generally appropriate for all ages and can be done individually or in a group. They are designed to promote fun and togetherness, offer an opportunity to express feelings and emotions, inject humor and provide a welcome respite to daily stresses. Most of these activities can be modified as needed. Each activity has a suggested materials list including everyday items commonly found around the house.

Child Life On Call: Sibling support resources to help brothers and sisters navigate the hospital, lenses and disease.

Down Syndrome Workshops for Siblings: Workshops provide the opportunity for a lot of concerns to be addressed and feelings to be validated. Brothers and sisters will learn they are not alone in their experiences, while gathering some good strategies for how to cope with some difficult times with their brother or sister. It's a time to learn, grow, and celebrate our community of brothers and sisters!

For Siblings - SUDC Foundation: The SUDC Foundation offers you resources and referrals in helping your child cope with the death of his or her sibling at no cost.

Just Sibs: A place just for teens who have a sibling with an illness or injury, because let's be real – it can be tough!

Living with a rare disease: A story of two siblings: Jana and Tom Monaco have four children and two, Stephen and Caroline, were born with isovaleric acidemia (IVA), a rare disease that is potentially fatal if undetected. A crisis with Stephen at age 3 led to earlier detection of IVA for his little sister, Caroline. The Rare Disease Institute at Children's National Hospital is dedicated to supporting families, like Monaco's, in navigating the world of rare diseases to give every child diagnosed with one the opportunity to live a long, healthy life.

Hope For HIE - Super Sibs | Facebook

Lock In Hope: Lock Boxes of Love want the siblings of pediatric cancer patients to feel special, and feel the love and hope we send in each special box. Lock Boxes of Love are gift boxes that are tailored to the age and gender of each child and are filled with things such as books, blankets, toys and stuffed animals. We hope to make the siblings of pediatric cancer patient's, who often feel unnoticed, feel loved and special. We call these special sibling "sibling warriors."

What Siblings Need | We Are Brave Together: Just as parent caregivers feel unseen in our world, the siblings in a disability family often feel unseen. So much time, attention, and energy is directed towards the child overtly requiring so much care.

Siblings of People With Intellectual & Developmental Disabilities (thearc.org)

Sign Up for The Arc's Sibling Scene Newsletter: You'll receive news, personal stories, opportunities specifically for siblings of people with IDD, and more!

Pieces of Me: If you are new around here, let me introduce myself. My name is Amanda Owen and through Pieces of Me, I share my journey of being a sibling to someone with a rare disability, a founder and director of a nonprofit serving those with intellectual disabilities, and finding balance as a working mom, wife, and business leader.

Rare Sibling Stories: Highlighting the stories of rare siblings and their family members living with a rare disease.

Rare Sibling Story - Ultragenyx: "Nobody has the same story, but I hope siblings of those with rare conditions will take comfort in knowing that they are not alone."

Rare Siblings Project: Each sibling story, perspective and experience is different yet common themes emerge, issues of identity, privacy, communication, meaning of life, mortality, challenges of living a full life in parallel with loss and grief.

Sibling Leadership Network: WE ARE A NATIONAL NONPROFIT WHOSE MISSION IS TO PROVIDE SIBLINGS OF INDIVIDUALS WITH DISABILITIES THE INFORMATION, SUPPORT AND TOOLS TO ADVOCATE WITH THEIR BROTHERS AND SISTERS AND TO PROMOTE THE ISSUES IMPORTANT TO THEM AND THEIR ENTIRE FAMILIES.

Sibling Support Project: Founded in 1990, the Sibling Support Project is the first national program dedicated to recognizing, promoting and addressing the life-long and ever-changing concerns of millions of siblings of people with developmental, health, and mental health concerns. We are proud to be a program of Kindering.

Sibling Transformation Project: The Sibling Transformation Project is an anti-ableist organization of siblings of disabled people, grounded in anti-oppression and collective liberation. We support transformation in families with disabilities toward an interdependent world where all our access needs are met and our communities thrive.

Siblings with a Mission : Siblings with a Mission is an international organization where siblings of individuals with special needs can receive support and exchange stories with others. We serve both siblings and sibling supporters (parents, grandparents, friends, health care providers, professionals, etc.) of all ages and all backgrounds.

Siblings: The Unsung Heroes of Rare Disease Families - Patient Worthy

SIBNET: SibNet is the Internet's first and largest online community for adult brothers and sisters of people with disabilities. Created in 1996 as a listserv, SibNet became an email-based Yahoo group in 1998. SibNet is a "closed" group. Only adult siblings of people with special needs may be members. To join SibNet on Facebook, click here.

SIBSHOPS: Sibshops provide young brothers and sisters with peer support and information in a lively, recreational setting.

SuperSibs SibSpot | Alex's Lemonade Stand Foundation: Alex's Lemonade Stand Foundation (ALSF) recognizes that childhood cancer affects the whole family, not only the child who receives the diagnosis. SuperSibs is dedicated to comforting, encouraging and empowering siblings of children with cancer, so they can face the future with courage and hope. Our Comfort and Care mailing program sends age-appropriate mailings over a two-year period that include coping skills and encouragement for siblings as their brother or sister fights cancer. This program can go a long way towards helping siblings find their footing in a new normal and thrive in the future.

The Center for Siblings of People with Disabilities: Our mission is to help siblings of people with disabilities feel seen, supported, and empowered -- with a focus on providing early intervention for young siblings. Our work focuses on 1) providing multimedia resources and education for parents, relatives, service providers, and siblings themselves, 2) spreading awareness of sibling issues throughout the general population, and 3) providing programming to support young siblings, particularly through a lens of artistic expression.

The Healthy Sibling: A 5-minute read about a personal perspective of a mother raising both well and medically-complex young children. You will learn about the impact a medically-complex sibling can have on the family dynamic and resources that may support the well child in exploring their emotions.

The impact on RARE disease on siblings PDF: We hope the insights within this report will be a launch pad for greater conversation and action around supporting young siblings and carers, and we feel sure that the legacy of their contribution will shape the landscape for future generations of rare siblings.

VIP Siblings - SLC6A1 Connect: In the rare disease world, siblings may experience just as much difficulty as their afflicted brothers or sisters. Parents and guardians expend an incredible amount of time and energy on ensuring their rare disease child attends therapies and doctor's appointments, all while researching the specific disease and maintaining the household. As expected, these non-SLC6A1 siblings might be confused, scared for their brother/sister, and shuffled around between numerous medical obligations. We at SLC6A1 Connect understand just how important it is for these SLC6A1 siblings to obtain the resources and tools they need to navigate this uniquely difficult situation.

What is it like to have a sibling with a rare disease? | Share4Rare: Siblings of children with rare disorders are also caregivers and must often deal with responsibilities that are not usually attributed to people their age. In this article, we review the struggles these children must face.

BOOKS FOR SIBLINGS:

The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs

10 Great Books if You Have a Sibling with Special Needs

Getting to Know You (Sibling Stories)

Genetic Gems

Thicker Than Water: Essays by Adult Siblings of People with Disabilities

PODCASTS FOR SIBLINGS:

The Special Siblings Podcast: We focus exclusively on supporting siblings of kids with disabilities—a too-often overlooked population—and the unique issues they face. Hear from psychologists, researchers, and sibs of all ages on how to best support the sib in your life. For parents, healthcare providers, and sibs themselves.

Once Upon A Gene: Rare Disease Siblings, The Glass House Children - Bulletproof and Shattered - With SMA Sibling Cara Freedman on Apple Podcasts

TEEN AND YOUNG ADULT RESOURCES:

1 of 20 Podcast • A podcast on Spotify for Podcasters: Jonathan Cappiello was diagnosed with a rare genetic disorder that only 20 people in the world have. The condition is called 3 hydroxyacyl coa synthase deficiency, which in short compromises his immune system and his body cannot

process fats. Each week, he will discuss his lifestyle, his diet, and how he adapted to his condition. Additionally, he has a variety of guests to talk about their conditions. If you're interested in genetics, rare disorders, medicine, and healthy living-- this is the podcast for you!

AUCD Emerging Leaders Community: AUCD Emerging Leaders are a part of a community that includes current trainees from AUCD member sites; former (i.e. alumni) trainees; early career professionals from all health and related disciplines, including self-advocates and family members; and others that are relatively new to the disability field. This group of passionate individuals from every U.S. state and territory grows by the thousands each year. Together, this Emerging Leaders Community shares a passion to serve, research, and educate to make positive changes with and for people with disabilities and their families.

Autism After 21 | Madison House Autism Foundation: Autism After 21 is a growing movement that champions the expansion of attention, care and support that serves to maximize the wellbeing of those with autism throughout their lifespan. Neurotypical adults must make the same commitment to diversity and inclusion in our places of work, in our neighborhoods, and in our communities as we have long expected school children to do in the classroom.

TSLP | Apps to Support Transition

Parallel: Parallel partners with individuals and stakeholders worldwide to build pipelines that create inclusive opportunities, architect support ecosystems, and develop sustainable strategies for communities and businesses where Neurodiversity thrives. Our philosophy is prepare, educate, inspire, change, and create. We build opportunity on the post-secondary pipeline by preparing pathways to inclusive settings, educating for inclusion, inspiring meaningful corporate change, and creating supportive ecosystems. Together, we can make the world a more inclusive place.

Bloomfield | The Episcopal Diocese of Virginia: Bloomfield's mission is to provide grants that assist physically disabled children and young adults with the unique demands of their daily lives. Additional grants provide attendance at various camps programmed for these individuals. Grants are not limited to the Commonwealth of Virginia. However, preference is given to support projects and individual requests within the geographic area from which Bloomfield receives its financial support.

Carly's Cafe

Digging Deep: At the Digging Deep Project, we envision a world where every young person has access to the tools he or she needs to build emotional resilience. With support from philanthropist and survivor of young adult brain cancer, Sheri Sobrato, we built Shadow's Edge, the first FREE self-help mobile game designed for teens and young adults to tap into their healing power of self-expression.

Eye to Eye: Eye to Eye's mission is to improve the educational experience and outcomes of neurodiverse young people, while engaging them and their allies in the movement for a more equitable and inclusive society.

Financial Advocacy in RARE: Navigating the U.S. Health System for Young Adults - Global Genes - powered by HappyFox

Finding Jobs And Talent Just Got Easier - Hire Autism: Hire Autism is a free program led and run by the Organization for Autism Research (OAR). With an active jobs board and by offering resources for employers and job seekers alike, Hire Autism aims to expand opportunities for autistic individuals and serve as a continuing resource for them in their workplaces.

Friendship Circle International: The Friendship Circle exists to bring happiness and companionship to children and young adults with special needs by celebrating their individuality, as well as bringing energy, support, and peace of mind to their families.

Future Planning (thearc.org): Planning for the future is important for all families. You can't do it just once. It's an ongoing process.The Build Your Plan ® tool helps people with intellectual and developmental disabilities (I/DD) think about and plan for their future. The interests, preferences, and skills of the person with I/DD are the main focus.

InvisiYouth Charity: INVISIYOUTH CHARITY is a 501(c)3 nonprofit organization that helps teens and young adults around the world with various chronic illnesses and disabilities gain the right lifestyle programs, empowerment tools and fun resources to keep living life with any health struggles. With InvisiYouth, older youth (or our "medically adult-ish™" youth as we call them) are motivated in all the non-medical aspects of life with any illness, visible or invisible, and have access to resources and platforms so they can have joy, success and thrive in their diverse lives.

Learning Disabilities | Friends Of Quinn: Discover How To Thrive With Learning Differences.

LUKE'S FASTBREAKS: Luke's FastBreaks supports children, adolescents and young adults diagnosed with cancer or chronic/extended illnesses. We strive to promote normalcy and restore dignity during treatment by replacing the hospital

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gown with our unique medical shirts. #BeStrong #NoMoreHospitalGowns

LYNZEBRA – A Rare Disease Patient and Advocate: After spending most of my life in and out of hospitals, I've gained a ton of wisdom a long the way about living with a rare disease. Now I help people across the world, especially teenagers, to help them learn the skills they need to not only survive, but thrive.

National Center for Learning Disabilities | NCLD: The mission of NCLD is to improve the lives of the 1 in 5 children and adults nationwide with learning and attention issues—by empowering parents and young adults, transforming schools and advocating for equal rights and opportunities. We're working to create a society in which every individual possesses the academic, social, and emotional skills needed to succeed in school, at work, and in life.

One Rare - Young Adults Living With Rare Disease: opportunities that would improve the lives and futures of young adults, aged 18-35, living with rare disease, through education, mentoring, recreation and peer support.

Our Odyssey: Connecting young adults impacted by a rare or chronic condition with social and emotional support in the hope of improving their quality of life.

PACER Center - Champions for Children with Disabilities: PACER Center enhances the quality of life and expands opportunities for children, youth, and young adults with all disabilities and their families so each person can reach his or her highest potential. PACER operates on the principles of parents helping parents, supporting families, promoting a safe environment for all children, and working in collaboration with others. With assistance to individual families, workshops, materials for parents and professionals, and leadership in securing a free and appropriate public education for all children, PACER's work affects and encourages families in Minnesota and across the nation.

Supported Decision-Making | National Resource Center: Helping people with disabilities lead amazing lives through supported decision making.

Team Joseph | Duchenne Family Assistance Program: Every child and young adult battling Duchenne deserves the resources, the equipment, access to approved treatments and the best care that they need. Every family deserves support and partnership so they don't have to navigate a complex medical system alone. The Duchenne Family Assistance Program is a collaboration between Team Joseph and Little Hercules Foundation, and provides personalized assistance to individuals and families affected by Duchenne Muscular Dystrophy.

The Cooper Foundation Cleveland: Our mission is to assist children and young adults with disabilities get the help they need. The assistance may be funding for therapy, a summer camp, or devices/equipment to help with everyday living. We want to provide the "extra help" these individuals need to reach their full potential.

The National Collaborative on Workforce and Disability for Youth: The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) assists state and local workforce development systems to better serve all youth, including youth with disabilities and other disconnected youth. The NCWD/Youth, created in 2001, is composed of partners with expertise in education, youth development, disability, employment, workforce development and family issues. Funded by a grant from the U.S. Department of Labor's Office of Disability Employment Policy (ODEP), NCWD/Youth is managed by the Institute for Educational Leadership in Washington, D.C. NCWD/Youth offers a range of technical assistance services to state and local workforce investment boards, youth councils and other workforce development system youth programs.

The Orange Effect Foundation: foundation that empowers children and young adults with speech disorders to effectively communicate through technology and speech therapy.

Think College: Think College provides resources, technical assistance and training related to college options for students with intellectual disability, and manages the only national listing of college programs for students with intellectual disability in the United States.

What's Happening in Your State | Think College:Click any state on the map to see available information on activities related to postsecondary education for students with intellectual disability (ID) in that state.

Young Adult Guiding Coalition | Eye to Eye: The Young Adult Guiding Coalition (YAGC) is a 10-month long volunteer opportunity for young people aged 16-25 who identify as neurodivergent. YAGC members are primarily responsible for providing insight and input into Eye to Eye programs and services; co-creating opportunities for our Eye to Eye community; and serving as ambassadors for the movement to combat stigma and engage in anti-ableist practices as we work towards a world that celebrates neurodiversity. Our YAGC works together virtually as a singular advisory group in addition to 4 committees that work directly with specific internal teams here at Eye to Eye. Each Committee has a YAGC Committee Chair that works directly with an Eye to Eye Staff Liaison as collaborators throughout the year.

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Young Adult Programs | Muscular Dystrophy Association: We are committed to supporting you, a young adult, with resources, programming, and community connection as you move through high school, higher education, employment and independent living. MDA's peer-led initiatives create solutions for you to exceed limits and unleash your fullest potential.

Young Adult Rare Representatives: Young Adult Rare Representatives (YARR) are highly motivated rare disease community members between 16 and 30 years old. The main purpose of YARR is to instill confidence in the next generation of rare disease advocates. We want to ensure that young adults have a growing, diverse impact on public policy in the rare space and offer skill-building opportunities to foster growth in each individual's advocacy journey.

Youth Committee Finder | CareerOneStop: Youth Committees work under local Workforce Development Boards to guide youth programs and policy in their area.

SPORTS, CAMPS, AND ACTIVITY RESOURCES:

The Hole in the Wall Gang Camp: Dedicated to providing "a different kind of healing" to seriously ill children and their families, free of charge. We are a community that celebrates the spirit of childhood, the sound of laughter and the feeling of endless possibility.

Camp Twitch and Shout: Camp Twitch & Shout is a one week overnight camp for children 8 to 17 years of age who have been diagnosed with Tourette syndrome or Tic Disorder. Our Leader In Training program is available to 17 year olds with tics who are interested in eventually becoming a counselor. Camp is organized and managed by Tourette Information Center and Support (TICS), in partnership with Camp Twin Lakes, and is located at Camp Will-A-Way in Winder, Georgia.

Camp Trach Me Away: Just because a child is dependent upon a ventilator and or other equipment does not mean he or she can't experience all the fun of summer camp. Camp Trach Me Away, offers children with tracheostomies the chance of a lifetime to be a kid at a summer camp with other children who also have tracheostomies. Our summer camp provides a chance to make fond memories and lifelong friendships in a medically safe environment. The weeklong overnight camp is held in Rutledge, Georgia under the attentive supervision of medical professionals. Through generous donations Camp Trach Me Away is free to children ages 7-18.

Camp Red Cedar: Camp Red Cedar's mission is to encourage children and adults of all abilities to move beyond their boundaries through recreational activities, outdoor education, creative arts and interaction with horses, in an integrated environment, serving people of all abilities. Located in Fort Wayne, Indiana.

Paralympic Sport Development: The United States Olympic & Paralympic Committee (USOPC) is based in Colorado Springs, Colorado. U.S. Paralympics, a division of the nonprofit USOPC, is dedicated to becoming the world leader in the Paralympic Movement and promoting excellence in the lives of people with disabilities, including physical disabilities and visual impairments.

BaseABLE: BaseABLE's mission is to provide and encourage an inclusive environment for individuals with mental or physical disabilities to play baseball.

Special Needs Camps: Dedicated exclusively to camps that serve individuals with one or more of a wide range of special needs.

Inclusive Skating: Inclusive Skating is a World-recognized Charity that provides events, activities, education & training for skaters with additional needs. Inclusive Skating helps all skaters "Live the Dream" and learn to skate with their families and carers in a supportive environment. Ice Skating and Inclusive Skating competitions for skaters with additional challenges are open to all, come and join the community.

The Center for Courageous Kids: The Center for Courageous Kids provides a camp experience for children with life-threatening illnesses and their families. We offer nine separate week-long summer camps where we can serve up to 128 kids per week. Each week is designated for a different illness. We have a program and medical staff who are trained and experienced in all aspects of medical camping.

Special Olympics Programs by State: Get in touch with us to volunteer, become an athlete, join a Unified Sports team, work as a coach and to learn about upcoming events. Choose your location below to get connected with your local Special Olympics program.

Camp Simcha & Camp Simcha Special: Every summer, Camp Simcha Special welcomes 230 children and teens with a wide range of multiple diagnoses for two weeks of fun, friendship, and personal growth. Non-stop activities, bunk spirit, singing and dancing encourage independence and build self-confidence. It is a unique opportunity for children fighting chronic illness to build a community of people with whom to share hopes and dreams as they grow. Camp is totally free. When we say free, we mean it. Even our well-stocked canteen is free. We even pay for transportation from your home city. However, you are responsible for baggage and any other fees (including oxygen) levied by the airlines.

Move United: Move United uses sports to push what's possible so everyone, regardless of ability, has equal access to sports and recreation in their community. Established in 1956, Move United is proud to serve wounded warfighters, youth and adults with disabilities.

Locations - Move United: Join the movement by finding a Move United location near you.

Camp Alsing: Camp Alsing is a traditional, co-ed, sleepaway summer camp in Maine for young people who might struggle socially. We embrace the unique personality of each of our campers and help them build the social and community connections they seek. We spend our days engaged in all the typical camp activities and optimize the organic situations that happen every day in a camp environment to build confidence and understanding in our amazing campers. Alsing campers might not have a specific diagnosis or come to us with diagnoses like Autism, ADHD, NVLD, and/or anxiety. All our campers want to make friends and build connections – and of course, have an awesome summer!

The Hole in the Wall Gang Camp: Through one-on-one interactions and group activities, HOP brings Camp's unique summer programming and spirit to hospitals and clinics. Whether working bedside, in playrooms or outpatient clinic settings, our interactions and activities with children and families include arts & crafts projects, and interactive games specifically adapted for use in the medical setting, as well as other Camp-inspired programming and events. Our Hospital Outreach Program can be found in partner locations across the Northeast and Mid-Atlantic.

The Painted Turtle: The mission of The Painted Turtle is to provide a year-round, life-changing environment and authentic camp experience for children with chronic and life-threatening illnesses. The Painted Turtle supports children's medical needs, inspires them to reach beyond their illnesses, and provides care, education, and respite for their families. All campers and families attend completely free of charge.

Experience Camps: Experience Camps is an award-winning national nonprofit that transforms the lives of grieving children through summer camp programs and innovative, year-round initiatives. Through compassion, connection, and play, we allow grieving children to embody a life full of hope and possibility. By amplifying their voices, we are creating a more grief-sensitive culture.

Horse Boy Method Practitioners: find a Horse Boy Certified Program near you. Horse Boy Method is the only equine intervention, specifically designed for the nervous system and the brain. More than that, it was developed under the mentorship of adult autists such as Dr. Temple Grandin and neuro-scientists such as Dr. Robert Naviaux of UC San Diego. The brain child of autism Dad Rupert Isaacson, who stumbled upon an approach with his own son and a horse and then developed and refined this approach over a decade, Horse Boy Method is now used in about 30 countries worldwide and provides an effective program for cognitive, behavioral and even academic development in a way that feels joyful and easy, thus insuring buy-in from the client.

Disabled Hunters Services: Disabled Hunters Services uses its combined resources to locate, organize and cooperate in opportunities for people with disabilities.

Flying Horse Farms: Flying Horse Farms makes it possible for children with serious illnesses to heal, grow, and thrive.

Dive Pirates Foundation: Our team of Dive Pirates is group of volunteers who believes in supporting our community with our passion of scuba diving through the Dive Pirates Foundation, a 501(c)(3) not-for-profit public charity

Morgan's Wonderland - The World's First Ultra-Accessible™ Theme Park: Morgan's Wonderland offers 25 Ultra-Accessible™ attractions, sprawled across a 25-acre oasis of inclusion. From a wheelchair-accessible Ferris wheel to catch-and-release fishing, there is truly something for everyone to enjoy!

Autism Support, Planned Recreational Activities - Share A Vision: To enrich the lives of persons with autism spectrum disorder and other disabilities by providing professionally planned and supervised recreational leisure opportunities, such as: Vacations, Family Outings, and Social Groups.

Adaptive Climbing Coalition: We create a community through education, advocacy, and outreach to make climbing more accessible to everyone.

SeriousFun Network: We provide children living with serious illnesses with a spectacular camp experience and high-quality medical care, all in the safest and most supportive environment. And for the kids, it's high-flying, friendship-building, memory-making fun. Camp locations in the US and Internationally.

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Camp Odayin: At Camp Odayin, our mission is to provide fun, safe and supportive camp experiences and community building opportunities for young people with heart disease and their families.

Team IMPACT: Team IMPACT matches children facing serious illness and disability with college sports teams, creating a long-term, life-changing experience for everyone involved.

Summer Camps for Kids With Disabilities You May Want to Check Out (themighty.com)

Virtual Activities | Autism Speaks: looking for at-home ideas to keep busy? Browse activities by area of interest by clicking on a link below. While many of these resources offer courses for those with special needs, this is not a list of exclusively autism-friendly programming. Thanks to Autism Behavior Consultants and Los Angeles Unified School District, which together curated many of the activities listed. Thanks also to New England Center for Children, Gateway Learning Group, Helping Hands Family, Kadiant, Neurabilities and Early Autism Services for contributing resources.

Victory Junction: Victory Junction enriches the lives of children with serious illnesses by providing life-changing camping experiences that are exciting, fun and empowering, at no cost to children or their families. Located in North Carolina.

Camp Sunshine: Camp Sunshine inspires hope in families affected by life-threatening childhood illness through our unique, supportive program at its beautiful campus on Maine's Sebago Lake.

STARS of the Spectrum Golf: The Flutie Foundation's national golf league is for talented and elite autistic golfers from across the country. The league will promote golf as a positive activity and potential passion and career path for people with autism.

Victory Junction: Free from the confines of disease, illness or disability, children discover that they can just be kids! How does this happen? Victory Junction is a medically safe, yet exhilarating camp, that challenges children who have a serious medical condition to try things they never imagined possible. As they conquer activities like zip lining and archery or experience bowling, fishing or swimming, children build confidence that will shape how they view the rest of their lives.

Flutie Watersports Program: The Flutie Foundation is proud to sponsor AccesSportAmerica's adaptive program, the Flutie Watersports Program, for individuals on the autism spectrum taking place starting at the end of June 2022 - August 2022 at Malibu Beach in Boston, MA. This location is a flat-water lagoon, ideal for teaching water sports.

WISH GRANTING RESOURCES:

Bianca's Kids: Established in 2010, Bianca's Kids ("BK") is a 501(c)3 approved, New Jersey based, award-winning nonprofit organization that grants wishes to foster, sick and needy children. The organization was established by Debbie Savigliano in memory of her niece Bianca Yodice, who passed away in a car accident in 2010 at the age of 21. It was Bianca's work and passion for children that inspired her aunt to create a foundation in her name and memory. To date, BK has granted wishes for over 25,000 children in every state in the U.S. and even internationally in Australian, Italy, and the United Kingdom.

W15H Program: Since the inception of the W15H program in 2011, close to 100 children and teenagers with life-threatening illnesses have received an official W15H experience. During these all-inclusive experiences, travel, accommodations, dining reservations, customized daily activities, and gifts are provided, in addition to the opportunity to spend significant time with Tim. Though the W15H weekend eventually comes to a close, the relationship with TTF does not; through annual reunions, prayer and ongoing connection, recipients (and their families) remain permanent members of the TTF family.

Hunt Of A Lifetime: "Hunt Of A Lifetime" is a nonprofit organization with a mission to grant hunting & fishing dreams for children age 21 and under, who have been diagnosed with life threatening illnesses or life threatening disabilities. We are doing what we can to make a difference in their life, a dream come true. But we need your help, we are looking for people interested in helping the kids live their dreams, without you, we can't give them the dreams they so desire.

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Project Angel Fares: Project Angel Fares is a 501c3 nonprofit created in 2012 with the goal of "Providing Special Friends with Special Dreams". Project Angel Fares serves families who have a child with a disability or special needs and otherwise would not be able to afford the opportunity to visit San Antonio, Morgan's Wonderland & Inspiration Island with a 4 day, 3 night trip of a lifetime, with paid travel expenses.

Merlin's Magic Wand Children Charity: We're Merlin's Magic Wand, an international children's charity dedicated to creating magical experiences for children who need them most.

Making Adventure Dreams Come True | Outdoor Dream Foundation: Our goal is to connect kids and families suffering from chronic or terminal illness with the outdoors. Outdoor Dream Foundation grants outdoor adventures to children and youth under 21 years of age who have been diagnosed with terminal or life-threatening illnesses.

Catch-A-Dream Foundation: Catch-A-Dream grants once-in-a-lifetime hunting and fishing experiences to children 18 years old or younger who have a life-threatening illness. Catch-A-Dream's singular purpose is to provide consumptive use outdoor experiences to fill the "gap" created when the Make-A-Wish Foundation established national policy that precludes granting a child a wish that involves hunting or use of "…firearms, hunting bows, or other hunting or sport-shooting equipment."

A MOMENT OF MAGIC: A Moment of Magic Foundation is a national 501(c)(3) nonprofit organization with a mission to improve the quality of life of vulnerable and underserved children and inspire them to be brave, strong, and fearless through fun and engaging social wellness activities.

WGO Search | Wish-Granting Organizations | Give Kids The World Village (gktw.org): The process to be granted a vacation to Give Kids The World Village begins with a wish granting organization. Families that visit Give Kids The World must be referred by one of these wish-granting organizations or foundations. Children ages 3-18, battling a life-threatening illness as deemed by a medical doctor are eligible, regardless of income.

Wishes & Smiles - The Coalition Against Pediatric Pain (tcapp.org)

Sunshine Foundation – See What A Dream Can Do…: answers the dreams of children, ages three through eighteen, who have severe or profound physical/developmental/intellectual challenges or trauma from physical/sexual abuse, and whose families have limited income.

Dream Factory, Inc. (dreamfactoryinc.org): The Dream Factory is the largest all-volunteer driven children's wish-granting organization that does not limit its mission to children who have life-threatening illness. The organization believes children with chronic illnesses and disorders also suffer from substantial emotional and physical pain.

A Kid Again - Serving Children with a Life-Threatening Condition: We make life for families caring for a child with a life-threatening condition "normal" again by helping them gain back moments of positive, family-shared experiences and memories.

Ohr Meir Foundation: OHR MEIR is dedicated to bringing a feeling of joy and hope to the hearts of sick children by giving them a break from their rigorous treatment schedules. OHR MEIR through a variety of programs, coordinates and sponsors various trips throughout the year ranging from a night out on the town, out of state teen trips, to our annual trip to Disney World and other theme parks in Orlando.

"Live Life in The Front Row™" | Front Row Foundation: Lifts the spirits of people facing critical health challenges with memorable VIP experiences from the front row of their favorite sporting, music, or performance events.

Rare Wish Program® – Rare STRIDES®:Grant wishes for children and adults diagnosed with rare or undiagnosed complex medical conditions, disorders, and diseases.

Make-A-Wish America

Wish Granting Organizations -pg1 (itaalk.org)

TRAVEL RESOURCES:

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SATH – Society for the Accessible Travel & Hospitality: We bring together national and international organizations of and for persons with disabilities and those organizations providing services to travelers with disabilities and seniors to work on the issues affecting the quality of their life.

All-Inclusive Vacation Tours for Adults with Intellectual & Developmental Disabilities - Trips, Inc. (tripsinc.com): Trips, Inc.™ provides all-inclusive vacation packages for travelers 18 and older with intellectual and developmental disabilities. Our goal is to give the best life experience to our consumers by promoting independence and inclusion through travel. From theme parks to national parks, Alaska to Hawaii, cruises and international destinations-our excursions take you all over the world!

Curaçao Dolphin Therapy & Research Center: Welcome to the Curaçao Dolphin Therapy & Research Center, (CDTC), the leading dolphin assisted therapy center in the world that offers a unique and effective therapy program in a beautiful inspiring and relaxing Caribbean destination. Dolphin Assisted therapy has long been regarded as an effective form of therapy that has helped to improve levels of cognition and mobility for people with a wide range of developmental, physical and emotional conditions. Gentle by nature, the dolphins display an extraordinarily high level of intelligence and intuition that enables them to create, what many would describe as, a 'magical' connection with special-needs patients. These therapy dolphins work together with a team of qualified therapists and trainers under supervision of a scientific advisory board, to help improve the patient's overall wellbeing.

Handiscover | Accessible Travel Company: Handiscover gathers great hosts, disabled friendly accommodations and hotels that we select carefully for their quality and value. We offer a mix of accommodations adapted to different levels of mobility. Enjoy great disabled holidays!

Curb Free with Cory Lee | A Wheelchair Travel Blog: My name is Cory and I'm a travel addict and wheelchair user, hoping to inspire you to start rolling around the world.

Special Journeys: Special Journeys, LLC is a company dedicated to providing individuals with disabilities the opportunity to travel.

Project Angel Fares: Project Angel Fares is a 501c3 nonprofit created in 2012 with the goal of "Providing Special Friends with Special Dreams". Project Angel Fares serves families who have a child with a disability or special needs and otherwise would not be able to afford the opportunity to visit San Antonio, Morgan's Wonderland & Inspiration Island with a 4 day, 3 night trip of a lifetime, with paid travel expenses.

Cherry Blossom Vacations: to gift a vacation home stay to adoptive, foster, and families of children with a disability.

Disabled Accessible Travel - European Accessible Travel Services: Today, Disabled Accessible Travel is Europe's leading accessible travel agent. It offers a wide range of bespoke services to any type of traveler in need of adapted solutions.

Wheelchair Accessible Travel Blog by John Morris: Welcome to Wheelchair Travel — Accessible Travel Blog, a catalog of what I've learned while exploring the world with one hand, a passport and my power wheelchair.

Pamela and Craig Goldman River Retreat - Chai Lifeline: Family time is fun time at the Goldman River Retreat, a single-family home on several acres in the beautiful Ramapo Mountains. Outside, nature calls, and families can enjoy walks, fishing, or just watching the magnificent wildlife that surrounds the comfortable and spacious four-bedroom home. Close to restaurants and shopping, yet seemingly far from everything, the River Retreat offers families a chance to enjoy one another's company free from the distractions of everyday life.

Wonders Within Reach: We're so excited to share accessible adventures for all types of families. As a lover of travel, the number of countries I've traveled to matches my age (I don't have to say what that is, right?). Now my children can have the same boast. Exploring, expanding my world view, understanding different cultures, and learning through experience are all fuels to my personal fire, and now they shape the way I parent and teach my children. Age and disabilities change the way we explore, but they just make the journey that much more rewarding!

TSA Cares: TSA Cares is a helpline that provides travelers with disabilities, medical conditions and other special circumstances additional assistance during the security screening process.

Stella K. Abraham Family Center | Chai Lifeline: Located on the magnificent Jack and Moishe Horn Campus in Glen Spey, New York, home of Camp Simcha and Camp Simcha Special, the Stella K. Abraham Family Center offers a serene vacation option to individual families or groups who seek a restful vacation in the midst of beauty. Families have access to many of Camp Simcha's most requested facilities, including indoor gym, library, arcade center, and video room stocked with family-friendly DVDs. When the weather is warm, families enjoy boating on Camp Simcha's private lake as well as nature walks around the 150-acre facility. The Family Center is open from September to June when not in use for Chai Lifeline programs and retreats.

Tiff's Place | ADA Vacation Rental: Our property is located on a 5-acre lot surrounded by open fields and trees. The home has a spacious family area and a fully furnished kitchen with height-adjustable appliances. We offer our guests a large deck for grill-outs and a wheelchair-accessible swimming pool for warmer days in the backyard.

http://www.dawnbarclayink.com/traveling-different---the-book.html

Autism On The Seas: Autism on the Seas, an international organization, has been in collaboration with Royal Caribbean International since 2007 in developing cruise vacation services to accommodate adults and families living with children with Special Needs, including, but not limited to, Autism, Asperger Syndrome, Down Syndrome, Tourette Syndrome, Cerebral Palsy and all Cognitive, Intellectual and Developmental Disabilities. These services quickly expanded to other cruise lines.

PODCASTS:

1 of 20 Podcast • A podcast on Spotify for Podcasters: Jonathan Cappiello was diagnosed with a rare genetic disorder that only 20 people in the world have. The condition is called 3 hydroxyacyl coa synthase deficiency, which in short compromises his immune system and his body cannot process fats. Each week, he will discuss his lifestyle, his diet, and how he adapted to his condition. Additionally, he has a variety of guests to talk about their conditions. If you're interested in genetics, rare disorders, medicine, and healthy living-- this is the podcast for you!

20 Best Disability Podcasts You Must Follow in 2023 (feedspot.com)

A Little Something Extra on Apple Podcasts: A Little Something Extra, with Nancy Gianni and The GiGi is the first video podcast hosted by an individual with Down syndrome!

Advocate Like a Mother: Welcome to the official Advocate Like a Mother™ Podcast with Michelle Sullivan, Illeana De Sosa, and Andy Lara. We're here to empower and motivate you to use your voice.

All About Audiology Podcast: Dr. Saperstein loves sharing her passion for audiology. Her specialty is helping parents of children with hearing loss, explaining test results and providing information, support and guidance. Dr. Saperstein obtained her doctorate of audiology (AuD) at The CUNY Graduate Center in New York. She has experience working with patients of all ages and has worked as both a clinical audiologist and an educational audiologist. She is the producer and host of the All About Audiology Podcast.

Behind the Mystery: Rare and Genetic Diseases | Podcast on Spotify: Welcome to "Behind the Mystery," a podcast dedicated to rare and genetic diseases and the emotional, scientific and medical aspects associated with them.

BEING RARE PODCAST – The E.WE Foundation: conversations platform. We have intimate and sometimes difficult conversations about living with rare diseases, disability, medical complexities, and special health needs. Popular for our 1-minute episodes, Being Rare offers insight, perspective, and positive reinforcement. Join the conversation by following Being Rare wherever you listen to your podcasts!

Being Rare Podcast • A podcast on Spotify for Podcasters: Being Rare is an online resource hub and community conversations platform. We'll have intimate and sometimes difficult conversations about living with rare disease, disability, medical complexities, and special health needs. Popular for our 1 minute episodes, Being Rare offers insight, perspective, and positive reinforcement. Hosted by Sarita Edwards, a world's top patient expert, award winning advocate, global speaker, and CEO.

Beyond Awareness: Disability Awareness That Matters on Apple Podcasts: This is a forum for special education and general education teachers, parents, and community members who want to promote disability awareness from a progressive, dignifying, social justice, and diversity appreciation perspective.

Brave Together | Podcast on Spotify: We Are Brave Together is a non-profit organization that provides a supportive community for moms of children with special healthcare needs. The heart of We Are Brave Together is to strengthen, inspire, educate and validate all Special Needs Moms in their unique and difficult journeys. On Brave Together, founder

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Jessica Patay, along with the Brave community, will share interviews, celebrate stories, explore challenges, and rally hope for the motherhood journey. You are not alone.

Confessions of a Rare Disease Mama on Apple Podcasts: Join me every week as I navigate the ups and downs, and everything in between of the crazy stressful, but always beautiful life of being a rare disease parent.

Deliver the Dream | We help families with serious illness, crisis or disability: Deliver the Dream provides therapeutic programs to special populations including families facing a serious illness, crisis or disability. Most of our participants live in the state of Florida, however, we serve families throughout the United States. Our programs restore hope, strengthen relationships and change perspectives to provide inspiration for the future.

DNA Today: DNA Today is a multi-award winning podcast and radio show exploring how genetics impacts our health. Host/Producer Kira Dineen interviews leaders in genetics including genetic counselors, researchers, physicians and patient advocates.

Giants of Gene Therapy Podcast | ASGCT - American Society of Gene & Cell Therapy: ASGCT's first podcast, Giants of Gene Therapy, is available on the ASGCT Podcast Network. Society President Hans-Peter Kiem, MD, PhD, regularly interviews luminaries in the worlds of cell and gene therapy.

Health Unmuted: Health Unmuted is an audio library of podcasts created to promote health, wellness and care. Each series shares insights from health experts and people with firsthand experience as a patient or caregiver.

Joe Sooch - YouTube: Have an extremely rare disease called FOP where my muscles turn into bones. I lost 95% of my movement. Living my life one day at a time. Subscribe to follow my journey!

Just Say HIE Podcast - Hope for HIE - Hypoxic Ischemic Encephalopathy: Just Say HIE is the official podcast of the Hope for HIE foundation, a nonprofit serving the worldwide community of HIE families, whose children have been diagnosed with hypoxic ischemic encephalopathy.

Living a Sensory Life • A podcast on Spotify for Podcasters: Join Becky as she chats to other professionals to share knowledge about SPD, as well as insights from adults and children with SPD themselves.

Love That Surpasses Podcast • A podcast on Spotify for Podcasters: Take a seat and join the Love That Surpasses Podcast, where we share our hearts and experiences surrounding parenthood, disabilities, and God's calling on our lives to live victoriously, fearlessly, and free. You'll hear conversations about expectations, grief, jealousy, but also surrendering our lives and stepping into our God-given purpose with courage.

Mama Bear Podcast on Apple Podcasts: The Mama Bear Podcast is a place for women raising children with special needs to get together and chat about life. Mary Susan McConnell and her guests discuss the beautiful highs and the extreme lows that can come with parenting on such unique journeys. Conversations are fun, candid, and you may want headphones (adult language warning)

Moments of Joy: My goal is to serve: 1) the parent raising a child with a disability looking for a podcast that speaks directly to YOU. 2) the entrepreneurs or influencers looking to start their podcast and pursue their dreams at the same time. Whether you are passing through or stopping by again, my heart's desire for you is that you are inspired to choose joy today!

NASDDDS Podcasts - Nasddds

Never Give Up: A Rare Disease Podcast on Apple Podcasts: Life. Mental Health. Rare Disease. That's what Never Give Up is all about. This podcast is a companion to my blog, PKUJournal.com. I've Kevin Alexander, and I've been a professional storyteller for over 20 years. I'm also an adult living with the rare disease Phenylketonuria, or PKU. Since 2012 I've been traveling the world advocating for PKU, newborn screening, and rare disease awareness. Living with a rare disease can be a heavy burden, so on this podcast, I share thoughts, reflections, and stories to motivate you on your journey.

On Disabilities : NPR: Sickle cell patient's success with gene editing raises hopes and questions.

Once Upon A Gene- Rare Disease Podcast : mission is to learn, lift voices of the community, connect people to resources and to leave this world better than she found it for others in the rare disease world.

Patients Rising Podcast: Patients Rising brings its unique and established brand of patient advocacy to a weekly podcast, featuring honest and helpful discussion about issues impacting those with chronic illness. CEO Terry Wilcox hosts the show, with Robert "Dr. Bob" Goldberg, Co-Founder and Vice President of the Center for Medicine in the Public Interest.

Podcast | Labeled and Loved: We all have things that define us—whether it be a diagnosis or a dream. Host Stephanie Hanrahan and her guests invite you to take a look at life beyond their label. You'll get to know a real person, not a highlight reel, and in turn leave feeling a little less alone.

Podcasts We Love - Functional Formularies

pRETTy happy: Bringing families and friends together from the Rett syndrome community to discuss life, research, and just have fun. New episodes are released every other Monday morning!

R is for Rare | Podcast on Spotify: Annie Watson is a young adult who has lived with narcolepsy, a rare sleep disorder, for almost her entire life. Curious about other rare diseases, Annie will interview someone who has been affected (either directly or indirectly) by these diseases and disabilities. She will be discussing the ins and outs of some of the most captivating rare diseases with the patients, doctors, and loved ones who know what it's like to be rare. New episodes of R is for Rare are released every Tuesday.

Raising Rare Podcast: Imagine the excitement of becoming a new parent and then within hours finding out your child has a serious developmental disorder. That is exactly where Sanath Kumar Ramesh found himself in the summer of 2018. One year later, on his son's first birthday, they found out that their son, Raghav, had an extremely rare mutation of the GPX4 gene. At the time, doctors told them that Raghav may be the only one on the planet with this genetic variant who had lived beyond one month of life. The prognosis is completely unknown. They were alone. They were scared. And then they went into action. And now they want to share their story. Every couple of weeks Raising Rare will give you an update on baby Raghav as he grows up. We will also share how Sanath and his wife Ramya are driving toward a treatment for their son. We will explore the science that Sanath is initiating, their efforts to fund that research, and the people they meet along the way. We will also hear how the family adjusts to challenges and changes that they are faced with. Most importantly, we will share the wisdom they gain along the way so that other Rare Parents can learn from their steps and missteps. We don't know where this story will go. We do know we want you to join us for the journey.

Rare In Common — Many Voices. One Mission.: The 2017 Emmy-nominated Rare in Common documentary gave people from the rare disease community an opportunity to tell their stories. Today, the storytelling has expanded to the world of audio with the Rare in Common podcast.

RARECast: RARECast is a Global Genes podcast hosted by award-winning journalist Daniel Levine. It focuses on the intersection of rare disease with business, science, and policy.

RARING on Apple Podcasts: Welcome to RARING, the voice of the rare disease community and a no-BS forum for patients and their families, rare disease patient organizations, and medical professionals. If you live with a rare disease or love someone who does, RARING is the podcast for you, by you, and with you every day. Tune in to hear leading experts discussing next-generation diagnostics and treatments. Learn from passionate nonprofit leaders talking about their highs and lows fighting for their communities. And laugh and cry as real patients and caregivers like you share authentic and inspirational stories about their challenges and struggles to busy living. RARING: Because together, our voices are louder.

Safe Harbor: The Safe Harbor Podcast is for parents of children with disabilities. This show enables parents to come together as a community to share, learn and support each other on this complex path. Your host, Theresa Bartolotta, is mom to a young adult with Rett syndrome and has worked with hundreds of families as a pediatric speech pathologist.

Seizing Life Podcast – CURE Epilepsy: Seizing Life® is a CURE Epilepsy podcast and videocast aiming to inspire empathy, offer helpful stories, and give hope as we search for a cure for epilepsy. Listen as guests share stories and insights on living with and battling epilepsy.

Smile Strong | Podcast on Spotify: I'm Alyssa Messick, a wife and cleft mama x2. This podcast was created to help women who were made for more smile stronger every day.

Special Needs Supermom podcast | Podcast on Spotify: With stories about everyday life, tips to survive the holidays, how to prevent a supermom burnout, interviews with true experts and/or fellow special needs moms, and much more.

Strong & Rare Parenting • A podcast: Hi, Welcome to the Strong and Rare parenting podcast. My name is Victoria, and I am a special needs momma of two fun loving boys. In this podcast, we will speak about all things Autism, ADHD, and Rare Diseases. This podcast will bring awareness, acceptance, and knowledge on all things we want to learn as parents raising children with special and medical needs. When you join me, I hope that you will walk away with hope and be empowered to be a driver of change for our community.

The gwen effect podcast - episode 1 - Bing video

the lucky few podcast: WELCOME TO THE LUCKY FEW PODCAST WHERE WE ARE SHIFTING THE NARRATIVE BY SHOUTING THE WORTH OF PEOPLE WITH DOWN SYNDROME. WITH YOUR HOSTS, HEATHER AVIS, MICHA BOYETT, AND MERCEDES LARA.

Created by: Sierra Phillips @mrs.phillijt

The Neurological Disorder Podcast on Apple Podcasts: The Neurological Disorder Podcast is a podcast created by Mridula Bharathi, a high school sophomore, young changemaker, and advocate for neurological disorders. In this podcast, I interview people who are affected by neurological diseases, and they share their incredible stories as a fighter of the disorder.

The One in a Million Baby (libsyn.com)

The Rare Disorder Podcast | Podcast on Spotify: The Rare Disorder Podcast is a podcast created by Shivani Vyas, a high school senior, young changemaker, and rare disease advocate, dedicated to spreading awareness for rare diseases. This podcast is divided into 2 main series. In the "Meet a Fighter," Shivani interviews patients and those affected by rare diseases allowing them to share their inspirational stories. In "Meet An Expert/Partner," Shivani interviews public health experts, rare disease organization leaders, rare advocacy leaders, and more!

The Rare Life: THIS IS THE RAW, REAL, AND ALL THE FEELS OF MEDICALLY COMPLEX PARENTING.

Tube to Table | Podcast on Spotify: Helping tube-fed kids become happy and healthy eaters.

When Autumn Comes | Podcast on Spotify: We are two special needs moms who like to talk. We call ourselves the 4am Mom Club because more nights than not, our kids are awake at 4am. We both have very medical, complicated, rare, beautiful children. This is a podcast for medical and special needs mamas and families who are facing a life they never expected.

OTHER RESOURCES:

RARE Bear Program: The RARE Bear Project is a community driven initiative and is supported by the ever-growing RARE Bear Army of volunteers that help make one of a kind bears for special one of a kind kids. Gifted RARE bears will have a serial number specifically made for a child in our program. Some RARE bears will also be made for gifts for those who donate a certain amount to our programs to support rare disease research!

The Equity, Diversity, and Inclusion Hub: The Equity, Diversity, and Inclusion Hub provides resources, examples, and action steps that help enhance diversity, equity, and inclusion and promote cultural humility and responsiveness. The hub brings together the variety of existing resources available in the AUCD network all in one place. It also shares stories of how network members are promoting equity, diversity, and inclusion at their centers and programs and how to engage with AUCD technical assistance initiatives.

A Girl with Baggage: I'm 23 years old and I have been living with a chronic medical condition since I was born. This blog is where I share how I deal with managing a chronic illness, and stumbling my way through life in my 20's.

Bandaids and Blackboards: Welcome! This is a site about growing up with medical problems ...any ole type. Its goal is to help people understand what it's like, from the perspective of the children and teens who are doing just that. These kids have become experts at coping with problems that most of you have never heard of. They'd like you to know how they do it, and they hope that you'll be glad you came to visit. I've divided the contents into three ponds; one for kids, one for teens, and one for adults. Figure out which you are, and jump in!

Request A Song (A Kid Again) - Songs of Love: The Songs of Love Foundation is a national nonprofit 501(c)(3) organization that creates free, personalized, original songs to uplift children (ages 1-21) facing tough medical, physical, or emotional challenges. Each 'song of love' is delivered on USB and/or digital format with professionally produced music and lyrics containing the child's name and references to all of his or her favorite things. Since 1996 the Songs of Love Foundation has reached out to over 38,000 children in over 600 hospitals and health care facilities in all 50 states and the world.

COMFORT CUDDLES BY ERIN: Comfort Cuddles by Erin was created in July of 2019. We strive to bring comfort and smiles to those facing hardships. Contact us to request a blanket for your child or yourself. We have sent over 650 packages both in the US and internationally.

How to Get Started With the Ketogenic Diet (charliefoundation.org): The Charlie Foundation for Ketogenic Therapies was founded in 1994 to provide information about diet therapies for people with epilepsy, other neurological disorders and select cancers. Charlie Abrahams, pictured above, continues to be the inspiration for the foundation, working as a pre-school teacher, and proving that Epilepsy can be cured through Ketogenic Therapy.

Created by: Sierra Phillips @mrs.phillijt

Magic Wheelchair: Magic Wheelchair is a nonprofit organization that builds epic costumes for kiddos in wheelchairs — at no cost to families.

Santa's Little Hackers (santaslittlehackers.com): Santa's Little Hackers is a seasonal toy drive to adapt toys. We make simple modifications to the electronics of toys and give them away. These adaptations make the toys accessible to individuals with disabilities so they can play independently. Santa's Little Hackers is an annual event put on by MaxMods. MaxMods is a 501(c)3 not-for-profit corporation chartered to 'make the world accessible for all' by identifying adaptations and modifications to make the world work for individuals living with disabilities.

Positive Exposure | The spirit of difference: POSITIVE EXPOSURE promotes a more inclusive world through award-winning photography, films, exhibitions, lectures and educational programs

Down Syndrome Achievement Centers - GiGi's Playhouse (gigisplayhouse.org): We change lives through the consistent delivery of free educational, therapeutic-based, and career development programs for individuals with Down syndrome, their families, and the community, through a replicable playhouse model.

Donate A Car To Support A Nonprofit or Charity (careasy.org): CARS is a 501(c)(3) nonprofit that helps thousands of nonprofit organizations in the U.S. and Canada increase their fundraising and acquire new contributors through turn-key vehicle and real estate donation programs. Since 2003, CARS has returned more than $300 million to our partners. CARS also reinvests in our community by providing meals and transportation solutions to seniors each year through a program called On the Go.

About Us | Flutie Foundation: Our programs and activities improve the quality of everyday life for people and families affected by autism along seven key dimensions that are critical to living each day fully. We aim to provide a path for education and/or employment during the day; opportunities for physical and social activity outside of work/school; and the tools to be safe, supported, and informed at all times.

RODS Heroes – Helping hero children with special abilities come home to loving families.: RODS Heroes inspires families to answer the call to adopt a child with special abilities or difficult circumstances from children born with Down syndrome to children at risk of “aging out” of the system and never finding a family and home. We give voices to the voiceless children in foster homes and institutions in international countries.

HopeKidsHopeKids - Restoring Hope. Transforming Lives: HopeKids provides ongoing events, activities and a powerful, unique support community for families who have a child with cancer or some other life--threatening medical condition. We surround these remarkable children and their families with the message that hope is a powerful medicine.

iamvisABLE – can you see me now?: An inclusive platform aimed to cultivate connections, heighten awareness, and empower individuals of all ages living with an invisible, chronic illness through the concept of art and storytelling.

Home • The Butterfly Pig: Children's Boutique, Book, and Blog: We specialize in dolls and accessories that instill the values of self-love, respect for diversity, and inclusion of all. We have our own line of doll-sized medical devices, uniquely designed and created at The Butterfly Pig.

Personal Health Journals for Any Condition | CaringBridge: CaringBridge is your free online tool for sharing health updates. It is an easy and ad-free way to communicate health news to family and friends—all in one place.

Harmony 4 Hope – Music uniting people through rare disease: Welcome to Harmony 4 Hope! We are using music to fuel scientific discoveries in rare disease, educating medical students and uniting Rare Disease warriors!

Playground Grants | Landscape Structures, Inc. (playlsi.com): Although Landscape Structures does not directly provide playground grants, we have curated online grant resources with national, state and regional organizations that offer grant funding for commercial entities.

Go Shout Love: Go Shout Love is all about doing amazing things for amazing families with kids on rare medical journeys. We feature a different child each month and spend all month long shouting love and celebrating them in big ways. We believe in the power of being loud and we hope you will join us in making some noise for these families. Head over to our shop where you can apparel inspired by our featured families and other items where 85% of the net campaign funds during the month go directly to the family to help with items related to the care of the children.

Equipment for All Abilities - Inclusive Play: At Inclusive Play our vision is to design, develop and manufacture quality products that enable children – no matter what their ability – to play together.

Icing Smiles: Icing Smiles is a nonprofit organization that provides custom celebration cakes and other treats to families impacted by the critical illness of a child. We understand that the simple things, like a birthday cake, are luxuries to a family battling illness. Our goal is to create a custom cake for the ill child, or their sibling, that provides a temporary escape from worry and creates a positive memory during a difficult time.

Graham's Foundation: Preemie Parent Support: I created Graham's Foundation to educate and inform preemie parents, so they feel empowered and confident while they navigate the journey of prematurity. We at Graham's Foundation, are committed to a world where no parent goes through the experience of prematurity alone.

Team IMPACT: Team IMPACT matches children facing serious illness and disability with college sports teams, creating a long-term, life-changing experience for everyone involved.

United Cerebral Palsy: Mission is To be the indispensable resource for individuals with cerebral palsy and other disabilities, their families, and their communities.

HOME | A MOMENT OF MAGIC: We are on a mission to improve the quality of life of vulnerable and underserved children and inspire them to be brave, strong, and fearless through fun and engaging social wellness activities.

Designing 4 Hope : Designing 4 Hope is a local 501(c)(3) non-profit organization dedicated to helping critically ill children and their families by giving them dream bedroom makeovers. Our goal is to design and decorate their rooms providing them with a special place to rest, recover, heal and dream. Our hope is to help them forget about hospitals, treatments and needles for just a little while.

Jonah & The Whale Foundation: J&TWF's mission is to support families educationally, medically, and resourcefully throughout the United States, Canada, and beyond. J&TWF supports families by helping them understand the tools to navigate the medical and educational community, the tools to be as informed about their child's disease or disability as possible, and the tools to embrace their family's differences as well as individual needs.

Kids & Art Foundation: Kids & Art uses the power of the arts and creativity to mitigate stress, anxiety, and trauma induced from diagnosis and treatment of pediatric cancer and other critical medical conditions.

Kids Helping Kids : Kids Helping Kids is a non-profit organization that encourages teens to help each other when faced with life altering illness or injury.

Lasagna Love: Lasagna Love is a global nonprofit and grassroots movement that aims to positively impact communities by connecting neighbors with neighbors through homemade meal delivery. We also seek to eliminate stigmas associated with asking for help when it is needed most. Our mission is simple: feed families, spread kindness, and strengthen communities.

Smart Toys - The ultimate guide to developmental toys (smart-toys.info): At Smart-Toys.Info, we pride ourselves on using our years of industry knowledge to recommend the best toys for developing minds. We strive to bring you expert opinions on play and child development.

The Christmas Tree Project: Our mission is to give away fully decorated Christmas trees to families in need. The focus and heart of this project remains the thousands of families who cannot afford a tree, want a good Christmas and are thrilled and touched when they receive a Christmas tree as a gift.

Dolly Parton's Imagination Library: A Free Book Gifting Program.

Cards2Warriors: Have you been searching for tangible ways that your company can show support for those in the ill and disabled community? Are you seeking to STAND OUT as an authentically inclusive brand? We can help! Every month, we send thousands of sponsored greeting cards to medically fragile consumers so that they feel LOVED… making YOUR brand their hero!

Heartsome Handmade | Facebook: Medically inclusive custom dolls.

Accessible & Inclusive Commercial Playground Equipment (miracle-recreation.com): At Miracle® Recreation, we believe that every kid deserves to play, feel exhilarated and experience new environments. That's why we offer a variety of playground solutions that provide accessibility and sensory benefits to create truly inclusive play spaces that are exciting, challenging and help kids of all ages and abilities enjoy playing together.

https://nickspecialneeds.com/about/

https://www.eyegazedesignsbyemily.com/shop-online

https://www.theresabartolotta.com/

Created by: Sierra Phillips @mrs.phillijt

BOOKS ABOUT RARE DISEASE, DISABILITY, AND INCLUSION:

Disability Book Week - Disability Book, Inclusive Books

BOOKS FOR PARENTS:

Genomics of Rare Diseases: Understanding Disease Genetics Using Genomic Approaches (Translational and Applied Genomics): 9780128201404: Medicine & Health Science Books @ Amazon.com: Genomics of Rare Diseases: Understanding Disease Genetics Using Genomic Approaches, a new volume in the Translational and Applied Genomics series, offers readers a broad understanding of current knowledge on rare diseases through a genomics lens. This clear understanding of the latest molecular and genomic technologies used to elucidate the molecular causes of more than 5,000 genetic disorders brings readers closer to unraveling many more that remain undefined and undiscovered. The challenges associated with performing rare disease research are also discussed, as well as the opportunities that the study of these disorders provides for improving our understanding of disease architecture and pathophysiology.

A Zebra in a Field of Horses: One Parent's Candid Truth About Raising a Child with Special Needs: Miltimore, BSN, RN, Kelly C.: 9781502524621: Amazon.com: Books

Amazon.com: Ain't That a Mother: Postpartum, Palsy, and Everything in Between (Audible Audio Edition): Adiba Nelson, Adiba Nelson, Blackstone Publishing: Audible Books & Originals

Amazon.com: Confessions of a Special Needs Mom: Reece & Me eBook : Nicole, Trina, Perryman, Reece: Kindle Store

DEAR LOVED ONES: An Honest Guide to Helping the Special Needs Family You Love: Falcone, Julie: 9781736133507: Amazon.com: Books

Diagnosis: Rare Disease: Crompton, Denise, Michaud, Shaunee: 9798373403832: Amazon.com: Books

Amazon.com: Down Right Joy: Joyful stories of raising a child with special needs. eBook : D'Orazio, Tony: Kindle Store

Amazon.com: Loving Lindsey: Raising a Daughter with Special Needs eBook : Atwell, Linda: Kindle Store

Amazon.com: Rare Like Us: From Losing My Dad to Finding Myself in a Family Plagued By Genetic Disease eBook : Kane, Taylor: Books

Amazon.com: Saving Katie: A Father's Story eBook : Trebing, Steve: Kindle Store

Amazon.com: Stronger Every Day: Special-needs kid, stay-at-home dad eBook : Bigelow, Bo: Kindle Store

Amazon.com: The Other Side of Special: Navigating the Messy, Emotional, Joy-Filled Life of a Special Needs Mom eBook : Brown, Amy J, Clime, Sara, Holt, Carrie M: Kindle Store

Becoming a Seriously Happy Special Needs Mom: 21 Steps to Finding Your Happy Place: Bennett, Linda James: 9781535538442: Amazon.com: Books

Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs: Strohm, Kate: 9781590301500: Amazon.com: Books

Best Special Needs Parenting Books - Top Recommendations and Special Needs Parenting Book Reviews (childrensdisabilities.info)

For The Mom Who...Has a Child With Special Needs: Nicole, Kendra: Amazon.com: Books

Created by: Sierra Phillips @mrs.phillijt

Forever Boy: A Mother's Memoir of Autism and Finding Joy: Swenson, Kate: 9780778311997: Amazon.com: Books

Freefall: One Mother's Journey Raising a Child With Special Needs: Kaplan, Cindy: 9798985024289: Amazon.com: Books

From the Heart: On Being the Mother of a Child With Special Needs: Jayne D. B. Marsh: 9780933149793: Amazon.com: Books

Half A Brain: Confessions of a Special Needs Mom: Basch, Jenni: 9781734678604: Amazon.com: Books

I'm Not Ok (imnotok-ky.com)

Just Believe: Jack's Inspirational True Story Told Through His Mothers Eyes - Kindle edition by Marcinkowski, Tarina. Religion & Spirituality Kindle eBooks @ Amazon.com.

Love Is Not Enough: A Mother's Memoir of Autism, Madness, and Hope: Lexhed, Jenny, Hawkins, Jennifer: 9781628726060: Amazon.com: Books

Loving Tiara: Memoir - Kindle edition by Goff, Tiffani. Religion & Spirituality Kindle eBooks @ Amazon.com.

Making Toast: Rosenblatt, Roger: Amazon.com: Books

Special Journey Journal: Neckles, Nadine: 9798760396235: Amazon.com: Books

Special: Antidotes to the obsessions that comes with a child's disability: Dimmitt, Melanie: 9781925384680: Amazon.com: Books

The Boy Who Could Run But Not Walk: Understanding Neuroplasticity in the Child's Brain: Pape M.D., Karen: 9781988025056: Amazon.com: Books

This Boy We Made: A Memoir of Motherhood, Genetics, and Facing the Unknown: Harris, Taylor: 9781646221622: Amazon.com: Books

Two Small Footprints in Wet Sand: The Uplifting True Story of a Mother's Brave Quest to Save Her Daughter: Julliand,

Mom's Place 4 Grace: Five Keys to Thriving as a Parent with Your Special Needs Child: Vorel, Barbara Ann-Marie: 9798887591872: Amazon.com: Books

More of Everything: How I became a better parent to my child with extreme special needs by lifting my emotional burdens: Reade, Janie, Choi, Gyoung Soon, Page, Rhianon, DeGaetano, Gloria: 9798369610350: Amazon.com: Books

One in a Billion: The Story of Nic Volker and the Dawn of Genomic Medicine: Johnson, Mark, Gallagher, Kathleen: 9781451661323: Amazon.com: Books

One Small Starfish: A Mother's Everyday Advice, Survival Tactics & Wisdom for Raising a Special Needs Child: Addison, Anne: 9781885477873: Amazon.com: Books

Patients Rising Bookshop: Browse books mentioned or recommended by the team at Patients Rising.

Raising a Rare Girl: Lanier, Heather: 9780525559658: Amazon.com: Books

Sharing Love Abundantly in Special Needs Families: The 5 Love Languages® for Parents Raising Children with Disabilities: Chapman, Gary, Philo, Jolene: 9780802418623: Amazon.com: Books

Anne-Dauphine, Hunter, Adriana: 9781628724448: Amazon.com: Books

With Angel's Wings: Collins, Stephanie A., Erickson, Donna, Trahan, Nick, Davis, Charlie: 9780578179759: Amazon.com: Books

You Are Not Alone: An Encouraging Coloring Book for Mothers and Caregivers of Children with Special Needs: McIntosh, Kelli: 9798472699990: Amazon.com: Books

YOU WON'T BELIEVE IT (BUT IT'S TRUE): One family's journey into a rare genetic disease.: Martin, Donna A: 9780578273082: Amazon.com: Books

BOOKS FOR KIDS:

47 Strings. Tessa's Special Code: Carey, Becky: 9781942586074: Amazon.com: Books

Children's Books About Diversity and Inclusion | No Such Thing – No Such Thing As Normal

Created by: Sierra Phillips @mrs.phillijt

Eli, Included: Sullivan, Michelle: 9781089032045: Amazon.com: Books

Book | Wheellustrated Tales

Children's book AAC | Eddie the Elephant

Search results: 4 results for "book" – CureUp (cureupshop.com)

You're So Amazing : Catchpole, James, Catchpole, Lucy, George, Karen: Amazon.co.uk: Books

Margo and You – Mission:Inclusion (mission-inclusion.com)

The Zebra Alphabet Book - A Children's Book - Aditi Kantipuly (thezebrabook.com)

Communicative Disorder Adapted Books | Fastsnail Publisher

Elsie with the Great Smile: A First Look at Williams Syndrome: Kristen Cagadas, Brooke Vitale, Elisabeth Clover: 9798985764611: Amazon.com: Books

7 Books Featuring Kids with Rare Diseases (allstripes.com)

A Day at the Beach (Apert-fect Hero Adventures): Wynette, Letesha, H., Augustina: 9781735203959: Amazon.com: Books

A Friend for Henry: (Books About Making Friends, Children's Friendship Books, Autism Awareness Books for Kids): Bailey, Jenn, Song, Mika: 9781452167916: Amazon.com: Books

Acceptance is my Superpower: A children's Book about Diversity and Equality (My Superpower Books): Ortego, Alicia: 9798736040896: Amazon.com: Books

All Different and Beautiful: A Children's Book about Diversity, Kindness, and Friendships: Belrose, Belle: 9783949152009: Amazon.com: Books

All My Stripes: A Story for Children With Autism: Rudolph, Shaina, Royer, Danielle, Zivoin, Jennifer: 9781433819162: Amazon.com: Books

Amazon.com: Hannah's Down Syndrome Superpowers (One Three Nine Inspired): 9781732638129: Yarborough, Lori Leigh, Oslizlo, Roksana: Books

Amazon.com: I'm Basically A Unicorn: A Celebration Of What Makes Us Unique eBook : Hawkins, Melanie, Hawkins, Melanie: Kindle Store

Amazon.com: I'm Basically a Unicorn: 9781734165067: Hawkins, Melanie, Hawkins, Melanie: Books

Amazon.com: I'm So Glad You Were Born: Celebrating Who You Are: 9780310777021: Earhardt, Ainsley, Barnes, Kim: Books

Amazon.com: Katie Can: A Story About Special Needs—Children's Book About Down Syndrome and Different Abilities, K-2 (24 pgs) (Changes and Challenges In My Life): 9781641566247: Palmer, Erin, Joseph, John: Books

Amazon.com: The abilities in me: 22q deletion: 9781793163493: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The abilities in me: Cerebral Palsy: 9798421733850: Keir, Gemma, Lisovaya, Yevheniia: Books

Amazon.com: The abilities in me: Congenital heart defect: 9781092337625: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The abilities in me: Down Syndrome: 9798699497447: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The abilities in me: Down Syndrome: 9798699497447: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The abilities in me: Duchenne Musuclar Dystrophy: 9798767770656: Keir, Gemma: Books

Amazon.com: The abilities in me: Juvenile Idiopathic Arthritis: 9798691418242: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The abilities in me: Superstar Siblings: 9798767766550: Keir, Gemma: Books

Amazon.com: The abilities in me: Tracheostomy: 9798674992721: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The abilities in me: Tube Feeding: 9798674990642: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The abilities in me: Type 1 Diabetes: 9781696850612: Keir, Gemma, Walker-Parker, Adam: Books

Amazon.com: The Same but a Little Different: 9798668718658: Murray, Grace Yvonne, Murray, Grace: Books

An Ordinary Day: Kids with Rare Genetic Conditions: Haberberg, Karen, MacArthur, Daniel: 9781576878613: Amazon.com: Books

Anna's Big Week: A Story About Living with Noonan Syndrome: Pierpont PhD, Rene, Daswani, Saakshi: 9781981346561: Amazon.com: Books

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Awesomely Emma: A Charley and Emma Story (Charley and Emma Stories, 2): Webb, Amy, Liddiard, Merrilee: 9781506464954: Amazon.com: Books

Best Day Ever!: Singer, Marilyn, Nixon, Leah: 9781328987839: Amazon.com: Books

Billy's Sister: Life when your sibling has a disability (A Project of The Center for Siblings of People with Disabilities): Leving, Jessica, Sfar, Wiem: 9798618220682: Amazon.com: Books

Chicken Soup for the Soul: Children with Special Needs: Stories of Love and Understanding for Those Who Care for Children with Disabilities: Canfield, Jack, Hansen, Mark Victor, McNamara, Heather: 9781623610616: Amazon.com: Books

Claude: The True Story of a White Alligator: Smith, Emma Bland, Potter, Jennifer M.: 9781632172693: Amazon.com: Books

Completely Emme: A Cerebral Palsy Story (Completely Me): Green, Dr. Justine, Silva, Ana Luísa: 9781735255828: Amazon.com: Books

D is for Down Syndrome: A Child's View (ABC's of Childhood Challenges): Sturkey PT, Amy E, Ronzkie, Ikos: 9780998156729: Amazon.com: Books

Dan & DMD: A Children's Book on Duchenne Muscular Dystrophy: Yasmeh, Joseph, Yasmeh, Liora: 9781533110640: Amazon.com: Books

Different--A Great Thing to Be!: Avis, Heather, Mensinga, Sarah: 9780593232651: Amazon.com: Books

Don't Hug Doug: (He Doesn't Like It): Finison, Carrie, Wiseman, Daniel: 9781984813022: Amazon.com: Books

Eddyto's Journey: Sharing our experience with Angelman Syndrome: Orellana, Ms Isabel: 9781723224041: Amazon.com: Books

Eli, Included: Sullivan, Michelle: 9781089032045: Amazon.com: Books

Evely's Sister: A Project of The Center for Siblings of People with Disabilities: Diaz, Luna, Diaz, Tameka, Leving, Jessica: 9798796987667: Amazon.com: Books

Every So Often A Zebra Has Spots: Fischer, Lauren Grabois, Hunt, Devin: 9781733302623: Amazon.com: Books

Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism: Fiona Bleach, AAPC Publishing: 9781931282062: Amazon.com: Books

Extraordinary! A Book for Children with Rare Diseases: Ayik, Evren and Kara, Dale, Ian: 9781736034408: Amazon.com: Books

Genetic Gems: Turnwald MS CGC, Abigail, Duis, Dr. Jessica: 9798752738180: Amazon.com: Books

Getting to Know You (Sibling Stories): Turnwald, Abigail, Duis, Dr. Jessica, Nori MS CGC, Kelly, Mckinney, Ronald, Causey, Whitney: 9798492047542: Amazon.com: Books

Hiya Moriah: Nelson, Victoria, Boddz: 9781633937857: Amazon.com: Books

I am Just as Special: How to be a Sibling of a Special Needs Child: Hanna, Lena: 9781736498835: Amazon.com: Books

I Think My Sister is a Superhero: When Special Needs Start to Look Like Super Powers: Eichelberger, Audrey J.: 9798407636427: Amazon.com: Books

I Will Dance: Flood, Nancy Bo, Swaney, Julianna: 9781534430617: Amazon.com: Books

It's OK to be Different: A Children's Picture Book About Diversity and Kindness: Purtill, Sharon, Saha, Sujata: 9780973410457: Amazon.com: Books

Joe Learns About Fabry Disease: Dawn Laney, Michael Johnson: 9781439245842: Amazon.com: Books

Just Ask!: Be Different, Be Brave, Be You: Sotomayor, Sonia, López, Rafael: 9780525514121: Amazon.com: Books

Kindness is my Superpower: A children's Book About Empathy, Kindness and Compassion (My Superpower Books): Ortego, Alicia: 9798669081621: Amazon.com: Books

Meeting Mimi: A Story About Different Abilities, Guided Reading Level F (Playing and Learning Together): Dolan, Francie, Leach, Wendy: 9781731604224: Amazon.com: Books

My Tubey: A Day in the Life of a Tube Fed Girl: Merritt-Rubadue, Rhiannon, Merritt-Rubadue, Rhiannon: 9781460923085: Amazon.com: Books

Nathan's Autism Spectrum Superpowers (One Three Nine Inspired): Yarborough, Lori Leigh, Merheb, Natalie: 9781732638105: Amazon.com: Books

Our Book & Mission | Mighty Mila - cochlear implants

PUBLICATIONS – Sibling Support Project

Rare Is Everywhere: Katz, Deborah R, Katz, Deborah R: 9780995826106: Amazon.com: Books

Created by: Sierra Phillips @mrs.phillijt

Shut Up About Your Perfect Kid: A Survival Guide for Ordinary Parents of Special Children: Gallagher, Gina, Konjoian, Patricia: 9780307587480: Amazon.com: Books

The Abilities in Me Save Christmas: Keir, Gemma, Walker-Parker, Adam: 9781527247611: Amazon.com: Books

The abilities in me: ADHD: Keir, Gemma, Walker-Parker, Adam: 9798699504817: Amazon.com: Books

The abilities in me: Epilepsy: Keir, Gemma, Walker-Parker, Adam: 9798674993728: Amazon.com: Books

The abilities in me: Hydrocephalus: Keir, Gemma, Walker-Parker, Adam: 9798674988557: Amazon.com: Books

The abilities in me: Limb Difference: Keir, Gemma, Lisovaya, Yevheniia: 9798351304717: Amazon.com: Books

The abilities in me: Sensory Processing Disorder: Keir, Gemma, Lisovaya, Yevheniia: 9798351305509: Amazon.com: Books

The abilities in me: Speech Delay: Keir, Gemma, Walker-Parker, Adam: 9798675047888: Amazon.com: Books

The abilities in me: Spina Bifida: Keir, Gemma, Walker-Parker, Adam: 9798699503148: Amazon.com: Books

The Cardinal's Gift: A True Story of Finding Hope in Grief: 9781736775509: Heaney, Carole, Garnsworthy, Marlo: Books

The Do-Over Day: a children's book about surviving the worst day ever - Kindle edition by Inserro, Julia, Tartan, Miro. Children Kindle eBooks @ Amazon.com.

The Elephant in the Playroom: Ordinary Parents Write Intimately and Honestly About Raising Kids with Special Needs: Brodey, Denise: 9780452289086: Amazon.com: Books

Xander's Cerebral Palsy Superpowers (One Three Nine Inspired): Yarborough, Lori Leigh, Freeland, Lori, Oslizlo, Roksana: 9781732638150: Amazon.com: Books

You Are Enough: A Book About Inclusion: O'Hair, Margaret, Sanchez, Sofia, Cardoso, Sofia: 9781338630749: Amazon.com: Books

The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs: Meyer, Don, Gallagher, David: 9781890627522: Amazon.com: Books

The World Needs Who You Were Made to Be: Gaines, Joanna, Swaney, Julianna: 9781400314232: Amazon.com: Books

This Is Ella: Ewert, Krista, Baker, Celia Marie: 9781525513619: Amazon.com: Books

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs: Donald Joseph Meyer, Donald Joseph Meyer, Cary Pillo: 9780933149984: Amazon.com: Books

We Move Together: Fritsch, Kelly, McGuire, Anne, Trejos, Eduardo: 9781849354042: Amazon.com: Books

What Happened to You?: 9780571358311: Amazon.com: Books

What's Inside You Is Inside Me, Too: My Chromosomes Make Me Unique: Quinby, Deslie Webb, Visootsak MD, Jeannie, Johnson, Michael: 9780692310380: Amazon.com: Books

When Charley Met Emma (Charley and Emma Stories, 1): Webb, Amy, Liddiard, Merrilee: 9781506448725: Amazon.com: Books

Who Do You See When You Look at Me? (Hardcover) – Inspirational Books for Kids, Teaches Lessons of Disability Awareness, Kindness and Acceptance, Perfect Gift for Birthdays, Holiday & More: Angela Ray Rodgers, Grace Anna: 9781424558360: Amazon.com: Books

Wonderfully Different, Wonderfully Me: Zingale, Becky, Dumitru, Laurentiu: 9781631956966: Amazon.com: Books

You Are So Much More: An Inspiration for Children Healing From Illness or Injury: Tejpar, Serena, Lalani, Anoosha, Tejpar, Iman: 9781615996322: Amazon.com: Books

You're All Kinds of Wonderful: Tillman, Nancy, Tillman, Nancy: 9781250815279: Amazon.com: Books

FAITH BASED BOOKS:

Created by: Sierra Phillips @mrs.phillijt

Amazon.com: Brave Mom Fragile Heart: Journal of Intentional Prayers for Special Needs Moms: 9798800579475: Harbor, Cece: Books

Amazon.com: He Gave Them Something Extra: 9781973654964: Larriba, Steffanie: Books

Amazon.com: Like Me: A Story About Disability and Discovering God's Image in Every Person: 9780736985758: Wifler, Laura, White, Skylar: Books

Beautifully Broken: A Journey Through the Bible for Parents of Children with Special Needs: McIntosh, Jen: 9781973604068: Amazon.com: Books

Better Than OK: Finding Joy as a Special Needs Parent: Kelly Mantoan: 9781681924168: Amazon.com: Books

Bible Promises for Parents of Children with Special Needs: Mason, Amy E.: 9781496417275: Amazon.com: Books

Cora Means Heart: Memoirs of a Special Needs Mom - Kindle edition by Busick, J.A.. Religion & Spirituality Kindle eBooks @ Amazon.com.

Embracing This Special Life: Learning To Flourish as a Mother of a Child with Special Needs: Soehnlin, Jenn: 9781723938184: Amazon.com: Books

Encouragement Gift - Endurance with Jan & Dave Dravecky

Faith, Family, and Children with Special Needs: How Catholic Parents and Their Kids with Special Needs Can Develop a Richer Spiritual Life: Rizzo, David: 9780829436518: Amazon.com: Books

Held: Learning to Live in God's Grip: A Bible Study for Special-Needs Parents: Peoples, Sandra, Peoples Jr, Lee: 9781492391968: Amazon.com: Books

Hope Wins: Overcoming Feelings Of Hopelessness In Special Needs Families - Kindle edition by Williams, Leisa. Religion & Spirituality Kindle eBooks @ Amazon.com.

I Have Down Syndrome and God Made Me JUUUUUST Right!: Douglas, Bethany: 9781952840128: Amazon.com: Books

Raising Special Stars: Sixteen Weeks of Empowerment for Moms Raising Children With Special Needs: Book, Mattie: 9781664206113: Amazon.com: Books

Raising Special Stars: Sixteen Weeks of Empowerment for Moms Raising Children With Special Needs: Book, Mattie: 9781664206113: Amazon.com: Books

Special Grace: Prayers and Reflections for Families with Special Needs: Evans, Elrena, Eareckson Tada, Joni: 9781514003510: Amazon.com: Books

Special Needs Parenting: From Coping To Thriving: Lorna Bradley: 9780990807322: Amazon.com: Books

The Life We Never Expected: Hopeful Reflections on the Challenges of Parenting Children with Special Needs: Wilson, Andrew, Wilson, Rachel, Moore, Russell: 9781433550997: Amazon.com: Books

The Presence of God in Autism: A Bible study guide for moms with children on the ASD spectrum - Kindle edition by Cawthorne, Krystyna, Coolidge, Karen, Lewis, K.. Religion & Spirituality Kindle eBooks @ Amazon.com.

Unbroken Faith: Spiritual Recovery for the Special Needs Parent: Kim, Diane Dokko: 9781683971344: Amazon.com: Books

Unexpected Blessings: The Joys & Possibilities of Life in a Special-Needs Family: Peoples, Sandra: 9780764231667: Amazon.com: Books

JAPAN RESOURCES:

Initiative on Rare and Undiagnosed Diseases (IRUD) | Japan Agency for Medical Research and Development (amed.go.jp): The Initiative on Rare and Undiagnosed Disease (IRUD) is a clinical research program for patients with a rare disease. Due to the complications of their symptoms many sufferers remain undiagnosed even when seen by a medical professional. Moreover, so little is known about the etiology of rare diseases that very few treatments can be administered due to lack of development.

AUSTRALIA RESOURCES:

Kindship - Meet Parents Who Just Get It: Connect with parents raising children with disabilities, delays, and neurodiversity.

Home - Operation Restore Hope Australia - Cleft Lip & Palate Charity

CANADA RESOURCES:

Rare Diseases: Models & Mechanisms Network (rare-diseases-catalyst-network.ca): The Rare Diseases: Models & Mechanisms Network has been established to catalyze connections between people discovering new genes in patients with rare diseases, and basic scientists who can analyze equivalent genes and pathways in model organisms/systems. Catalyst Grants fund projects that will allow rapid confirmation of potentially disease-causing genes, and fuel pilot studies to improve understanding of how specific gene mutations cause disease. It is intended that collaborations across the Canadian biomedical community will expedite the understanding of disorders, enabling the design of new therapies to the ultimate benefit of those affected by rare diseases.

Seasons Centre for Grieving Children – Healing Hearts with Hope: Seasons Centre for Grieving Children has been providing peer to peer support for children between the ages of 5 and 24 years who are grieving the death of an immediate family member. The Centre is founded on the belief that every child deserves the opportunity to grieve in a supportive and understanding environment. Through ongoing DEI trainings and education, we're committed to creating and maintaining an inclusive culture where every individual feels valued and respected.

Happiness Is Blind Blog: Navigating Marriage & Motherhood with a special needs child.

Darling Home for Kids: The Darling Home for Kids provides high quality respite, residential and hospice palliative care services for children who are medically complex, many of whom suffer from progressive illness.

GenCOUNSEL Project | BC Children's Hospital Research Institute (bcchr.ca): For patients and families with unexplained health conditions, genome-wide sequencing can provide much-needed answers, but it can also raise a lot of questions. We are trying to figure out the best ways to provide genetic counselling for genome-wide sequencing in Canada so that we can best support these families. We will be looking into different clinical, ethical, and economic methods to make sure there is equitable access to genetic counselling and testing for all Canadians.

Mindfully Inclusive: Let us help our children navigate through this life by nurturing their social skills and assist in raising an emotionally healthy world that embraces differences; a world where everyone succeeds no matter where their path leads. Let us practice mindfulness, both with ourselves and with others, practicing inclusion and promoting kindness for all.

Fascia Therapy Treatment for Babies, Kids & Cerebral Palsy | Mississauga, Canada (weflowtherapy.com): Over 20 years of experience in the Pediatric Rehabilitation field combined with the latest discoveries about Fascia, Biotensegrity and Movement Control Theories to help parents drastically improve the development of their children.

Canadian charity SUDEP Aware

The Recess Project - About (recessprojectcanada.com): mission is to ensure the world is full of healthy, inclusive schools and lush, sustainable schoolyards.

CARE4RARE Canada; Care4Rare aims to make improvements in clinical genetics to allow patients without answers to receive a diagnosis much faster. This ultimately allows patients to better know what to expect, receive tailored clinical care for their rare disease, and connect to others with the same diagnosis.

Children's Heart Society (childrensheart.ca): The Children's Heart Society is a non-profit, charitable organization committed to providing support, education, research and awareness for those children affected with congenital and acquired heart disease.

PowerHockey Durham: PowerHockey Durham provides the opportunity for powerchair users in Durham region to experience the many benefits the sport of powerhockey has to offer. Launching in the Spring of 2023, through an introductory program, participants will learn the basic skills of powerhockey through a fun, inclusive environment.

EUROPEAN RESOURCES:

A Friend Like Me: A Friend like Me is a cuddly toy adapted with medical devices to look just like you or someone special to you. We offer a wide range of medical devices including feeding tubes, ostomy bags, oxygen prongs and catheters and are always willing to try to create custom toys to match your needs.

Advocates and Angels: WE ARE HERE TO HELP PARENT CARERS NAVIGATE THE WORLD OF DISABILITIES, HOSPITAL ADMISSIONS - PALLIATIVE CARE AND BEREAVEMENT.

Sensory Rooms Soft Play Safe Sleep Surrounds: We manufacture soft sleep surrounds that are safe and comfortable.

Cohesinet: CohesiNet aims to train a team of 12 PhD students to use complementary experimental approaches to study the molecular and cellular functions of cohesin, the multi-protein complex responsible for shaping and maintaining the structure of chromosomes, and to unveil the molecular bases of the diseases due to cohesin malfunctioning (the so-called “cohesinopathies” and various cancer forms).

Merlin's Magic Wand Children Charity: We’re Merlin’s Magic Wand, an international children's charity dedicated to creating magical experiences for children who need them most.

ASK | All Special Kids: ASK is a one-stop resource for parents, schools, and specialists, helping to support children, teenagers and young adults with learning differences and special educational needs in Switzerland. Our vision is to enable children, teenagers and young adults with learning differences and special educational needs (SEN) to reach their full potential and inclusion into society, and to ensure that they receive the understanding and respect all individuals deserve. Through the generous donations of private donors and foundations all of our services and programs are partly subsidized.

Child Growth Foundation: UK charity focusing on the support, understanding and management of rare growth conditions to improve the lives of children, adults and families affected. Support includes condition specific Facebook peer support groups, a support phone line, a support email system, printed and digital booklets and video resources.

Beacon – The rare disease charity for patient groups: Beacon (formerly known as Findacure) is a UK-based charity that is building a united rare disease community with patient groups at its heart. We envision a world in which no one faces their rare journey alone. Our charity upskills rare disease patient groups through trainings, guided programmes, community projects and research initiatives. We help these groups maximise their impact and deliver change for the world’s often neglected rare disease patients.

Care for the Family: We are a national charity which aims to promote strong family life and to help those who face family difficulties.

Contact: Contact improves the lives of all families with disabled children. With them, we transform their lives, break down barriers and tackle disadvantage through ambitious, collaborative and innovative work.

Disabled Accessible Travel - European Accessible Travel Services: Today, Disabled Accessible Travel is Europe’s leading accessible travel agent. It offers a wide range of bespoke services to any type of traveler in need of adapted solution.

EURORDIS: EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1000 rare disease patient organisations from 74 countries that work together to improve the lives of over 300 million people living with a rare disease globally.

Genome-Phenome Analysis Platform – RD-Connect: The RD-Connect Genome-Phenome Analysis Platform is an online tool for diagnosis and gene discovery in rare disease research.

Genomics England: We partner with the NHS to provide whole genome sequencing diagnostics. We also equip researchers to find the causes of disease and develop new treatments – with patients and participants at the heart of it all.

Home | Erfelijkheid.nl

RD-Connect; The RD-Connect Project was a multidisciplinary project that united partners from the EU and beyond to create an integrated global infrastructure for Rare Disease research.

Share4Rare: Share4Rare is a European project which aims to improve the quality of life of those affected by a rare disease. By working together, we can build a community to transform rare diseases into known diseases by advancing research and sharing knowledge.

Solve-RD | Solving the Unsolved Rare Diseases: "Solve-RD - solving the unsolved rare diseases" is a research project funded by the European Commission for five years (2018-2022). It echoes the ambitious goals set out by the International Rare Diseases Research Consortium (IRDiRC) to deliver diagnostic tests for most rare diseases by 2020. The current diagnostic and subsequent therapeutic management of rare diseases is still highly unsatisfactory for a large proportion of rare disease patients – the unsolved RD cases. For these unsolved rare diseases, we are unable to explain the etiology responsible for the disease phenotype,

Tubie-Tums: I'm a art teacher and become a tubie mum in 2020 at the start of a global pandemic and now I enjoy making tubie supplies!

predict the individual disease risk and/or rate of disease progression, and/or quantitate the risk of relatives to develop the same disorder.

Tiny Tickers: We want to increase early detection rates of cardiac conditions because we know that spotting a defect early can improve a baby's chances of survival and long-term quality of life. Around 6,000 babies are born with a serious heart defect in the UK each year, and around 1,000 of these newborns head home with no one realising their lives are in danger. We are changing that.

Tubie Buddies: Tubie Buddies is a way of helping children, adults and families with feeding tubes. Based in the UK.

Tubie Fashion: accessible to anyone with a probe or other medical device to order things that make life with it a bit more fun and bearable!

Tubie Life: My products bring fasion together with self confidence growing designs and putting our own stamp on the equipment that keeps us alive. It all started when I was sent home with a bag from the home feeding company that was... well... boring, black and inpractical. I couldnt carry anything but my feed and pump and felt my medical needs were becoming my personality. I wanted to change this to help others in my position, so Tubie Life was created.

U.S. STATE SPECIFIC RESOURCES

2023 statutory disability insurance matrix by state

Accessible and Inclusive International Playground Directory | Accessible Playgrounds: This directory lists playgrounds that have inclusive and accessible features. Yes, we would all love to have the perfect inclusive playground in our neighborhood. But we know that is not reality. Here you can find the best of the best as well as playgrounds that have added accessible swing seats or other accessible feature.

Apply for State Lifespan Respite Voucher Programs | ARCH National Respite Network & Resource Center: Click on a marker to apply for your State's Respite Voucher Program. There may be other programs in the state that pay for respite through self-directed respite vouchers, stipends, reimbursement or grant programs for specific populations, such as the National Family Caregiver Support Program, Medicaid waivers, the Veteran Directed Care Program.

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AskEARN | State Vocational Rehabilitation Agencies: Find state-based resources for connecting with candidates with disabilities.

AUCD | State Directory: A network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities.

Best Buddies International | U.S. Programs: Best Buddies is active in each of the 50 United States. Access to the programs offered within our Friendship, Jobs, Leadership Development, and Inclusive Living mission pillars will vary based on region. For more information on regional programs, please select a State office from below.

Bridges4Kids State Resources and Information: We are a non-profit organization providing an internet-based system of information and referral for parents and professionals seeking help for children from birth through transition to adult life. Find your information for your state using the map on this page.

CARE Act Statewide Map: The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.

Catholic Charities USA | Find your Chapter: In need of help or services? Looking to get involved with your local agency? Explore the map to find your local Catholic Charities.

CDS Directory: Welcome to the Directory of Consumer-Driven Services (CDS), a project of the National Mental Health Consumers' Self-Help Clearinghouse. The purpose of the Directory is to provide consumers, researchers, administrators, service providers, and others with a comprehensive central resource for information on national and local consumer-driven programs. Such programs have a proven track record in helping people recover from mental illnesses.

Chartbook State Data (ciswh.org): The State Data Chartbook is designed to help visitors understand the multiple dimensions of care for Children and Youth with Special Health Care Needs (CYSHCN). It contains a selective list of health indicators for all 50 states as well as Puerto Rico and the District of Columbia. Drawing from a range of trusted sources and updated regularly, it provides data in areas that include demographics, economics, child health services, insurance availability, and factors impacting coverage for CYSHCN.

Comparative Chart of Paid Family and Medical Leave Laws in the United States - A Better Balance

Connect With Parent to Parent Near You for Support: There are 37 Parent to Parent Alliance Member organizations across the country. All offer information and one-to-one emotional support to parents of children who have disabilities or special health care needs. To find your local Parent to Parent organization, click on your state on the map. If your state does not have a Parent to Parent organization, please contact a neighboring state organization.

Contact Us | Autism Society: 57 years and counting, the Autism Society, including our nationwide network of affiliates, connects people to the resources they need through education, advocacy, support, information and referral, and community programming. Click on your state below for local chapter information.

Contact Your Region/ADA Center: he ADA National Network consists of 10 regional ADA Centers and an ADA Knowledge Translation Center. The regional ADA Centers are distributed throughout the United States to provide local assistance and foster implementation of the ADA. Find the ADA Center that serves your State by clicking on the map below.

Directory of Community-Based Organizations Serving People with Disabilities: This directory provides an overview of these organizations, the populations they serve and support, ways the organizations can complement LHD efforts, and links to websites that provide information about local affiliates/chapters in various jurisdictions. NACCHO selected the organizations listed within because they were nationally recognized disability organizations, had local chapters nationwide, and provided services to persons with various types of disabilities. While this directory is not exhaustive, it illustrates how LHDs can collaborate with community-based disability organizations.

Disability:IN | Affiliates: The Disability:IN local affiliates across the nation are the heartbeat of the organization, driving the mission of disability inclusion forward by working with partners on the ground. We encourage you to partner with Disability:IN Affiliates! Use the map to find the chapter closest to you.

Dynamic Movement Intervention Provider List: Find a DMI Therapist in your state!

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Easterseals | Connect Locally: Please click the name of an Easterseals affiliate or the corresponding map marker for more detailed affiliate information including local service centers.

Easterseals | Nationwide Directory of Child Development Centers: Use our nationwide directory to find an Easterseals Child Development Center in your community.

Easterseals | State Autism Profiles: Easterseals has prepared a state-of-the-state report of autism services in the 50 states and the District of Columbia. The profiles highlight the number of children with autism who have received the state's special education services; state insurance coverage for autism, if available; the status of autism coverage in the Essential Health Benefits under the state's healthcare exchange; Medicaid services specific for individuals with autism; educational programs provided to students with autism or training that focused on autism; special education criteria; other state-led resources; and sponsors of autism legislation.

ECTA Center: Part B, Section 619 State Programs and Coordinators: Part B, Section 619 of the Individuals with Disabilities Education Act (IDEA) authorizes preschool formula grants to states to provide special education services for children ages 3–5 with disabilities.

ECTA Center: Part C State Systems and Coordinators: Part C of Individuals with Disabilities Education Act (IDEA)—the Program for Infants and Toddlers with Disabilities—is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers ages birth–2 with disabilities, and their families.

Family Caregiver Alliance: Our Services by State tool helps family caregivers locate public, nonprofit, and private programs and services nearest their loved one—whether they are living at home or in a residential facility. Resources include government health and disability programs, legal resources, disease-specific organizations and more. Caregiving is challenging, but there are resources to help. Click on a state below for state-specific resources, or scroll to view national resources and organizations.

Family Voices: Find a Family-to-Family Health Information Center (F2F) or Family Voices Affiliate Organization (FVAO). Click on the map or select a state or territory.

Find a Chapter of The Arc: use this page to find your local Arc Chapter.

Find a Guide | AACcessible: Find an AAC guide in your state!

Find an Attorney | Special Needs Alliance: Hire an attorney who understands the intricacies of special needs law. Click on a State Where You'd Like to Find an Attorney.

Find Chapter | A Kid Again: Year-round fun-filled adventures that allow children with life-threatening conditions to feel like A Kid Again. A Kid Again works to create a communal and interactive environment. Our program establishes ongoing, nurturing experiences that complement but do not overtake their day-to-day living.

Find Your Act Early Ambassador | CDC: Act Early Ambassadors expand the reach of the "Learn the Signs. Act Early." program and support their respective state's work toward improving early identification of developmental delays and disabilities, including autism.

Find Your Parent Center | Center for Parent Information and Resources: There are nearly 100 Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) in the US and Territories. Find your Parent Center below listed alphabetically by state or U.S. Territory.

FMLA Laws by State : In addition to the federal FMLA law, most states have some laws that can affect your right family medical leave. And under FMLA, if your state provides you with more generous benefits that FMLA, then your employer is required to follow the state laws, Select your state to learn more.

Friendship Circle Locations: Find your local friendship circle chapter.

Horse Boy Method Practitioners: find a Horse Boy Certified Program near you. Horse Boy Method is the only equine intervention, specifically designed for the nervous system and the brain. More than that, it was developed under the mentorship of adult autists such as Dr. Temple Grandin and neuro-scientists such as Dr. Robert Naviaux of UC San Diego. The brain child of autism Dad Rupert Isaacson, who stumbled upon an approach with his own son and a horse and then developed and refined this approach over a decade, Horse Boy Method is now used in about 30 countries worldwide and provides an effective program for cognitive, behavioral and even academic development in a way that feels joyful and easy, thus insuring buy-in from the client.

Intellectual and Developmental Disability Research Center Directory: Established in 1963 by Congress as "centers of excellence" for research in intellectual and developmental disabilities, Intellectual and Developmental Disabilities Research Centers (IDDRCs) represent the nation's first and foremost sustained effort to prevent and treat disabilities through biomedical and behavioral research. IDDRCs also contribute to the development and implementation of evidence-based practices by evaluating the effectiveness of biological, biochemical, and behavioral interventions; developing assistive technologies; and advancing prenatal diagnosis and newborn screening.

Kids' Waivers | By State: Medicaid waivers and Katie Beckett programs for children are unfortunately quite confusing. Not only that, but it is impossible to find information about them. This project, coordinated by Complex Child Magazine, is intended to simplify the process as much as possible. Our first goal was to create a full list of current Medicaid waivers and other programs for children with disabilities. We then created separate pages for each state that provide additional information and links for each program. We hope to provide a comprehensive resource of all Medicaid waivers and programs for children, including 1915(c) HCBS waivers, 1115 demonstration waivers, TEFRA/Katie Beckett programs, and state-based programs.

Kinship Navigator Programs Around the United States: Kinship navigator programs are most helpful when they serve all kinship families, regardless of child welfare involvement. However, because the majority of kinship families have no involvement with the child welfare system, it is particularly important to serve those outside that system of supports. The list below, organized by state and territory, notes which families each program serves, in addition to providing basic service information and a website link. Some tribes also have their own kinship navigator programs, but they are not yet on this list. For jurisdictions that do not offer a kinship navigator program, other kinship supports may be identified and listed.

LEND Programs by State: 60 Leadership Education in Neurodevelopmental Disabilities (LEND) programs. LEND Programs are interdisciplinary leadership training programs federally funded through HRSA's Maternal Child Health Bureau.

Lending Libraries | AACcessible: We have composed a list of AT and AAC Lending Library programs across the country. We will make every effort to keep this listing up to date. If you know of a resource not listed here, please submit the listing to us and we'll add it to the directory.

Local Support | National Down Syndrome Society: NDSS works with more than 250 local Down syndrome organizations across the country to provide an array of benefits to help better service the Down syndrome community in their local area.

Locations - Move United: Join the movement by finding a Move United location near you.

NDRN Member Agencies - P&A - CAP | NDRN: NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). There is a P&A/CAP agency in every state and U.S. territory as well as one serving the Native American population in the four corners region. Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States. Select your state to connect with your local center.

NORD State Report Card | States Serving People with Rare Diseases: The latest edition of the State Report Card was compiled using data current as of November 2022. NORD hopes the State Report Card can serve as a tool for patients, advocates, and policymakers as they strive to advocate for state policies to best serve the needs of the rare disease community.

Resource Guide - United Cerebral Palsy: At UCP we know it's not always easy to find information about the disability services available in your community and state, so we've put together a list of organizations that can help guide you.

Sibling Leadership Network: SLN has chapters in many states. If there is not a chapter in your state and you are interested in developing one use our Contact Form to get in touch.

Special Olympics Programs by State: Get in touch with us to volunteer, become an athlete, join a Unified Sports team, work as a coach and to learn about upcoming events. Choose your location below to get connected with your local Special Olympics program.

State Agencies - Nasddds: To find a particular state's intellectual/developmental disabilities (I/DD) agency address and phone number, click on that state on the map or state name below. To visit that state's website, click on the state name link included with the address and phone number.

State by State Community-Based Resources for Families - Center for Innovation in Social Work & Health: The Catalyst Center works primarily at the system and policy levels, which means we collaborate with researchers, agencies, government and other national and state partners to promote strategies for improving the health care system. Many organizations provide direct services and assistance to Children and Youth with Special Health Care Needs and their families. This directory, which is organized by state, provides links to a wide range of direct service organizations, and to important information related to Title V Maternal and Child Health programs. Title V programs work to improve the health and well-being of women and children, including children with special health care needs.

Created by: Sierra Phillips @mrs.phillijt

State Chapters - Sibling Leadership Network: SLN has chapters in many states. If there is not a chapter in your state and you are interested in developing one use our Contact Form to get in touch.

State Funding | BraunAbility: Many states have programs or services to help aid residents in acquiring the mobility equipment they need. Some grants are condition-based, while others are community-based. You can begin your state-by-state search below.

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State Grants for Wheelchair Vans | The Mobility Resource: If you need assistance in buying a handicap van, you should know that states offer various grants and other assistance programs for those who qualify. These grants and other programs could help you finance a wheelchair van, scooter, wheelchair lift, adaptive driving equipment, or other mobility product.

State Health Insurance Marketplace Types, 2023 | KFF: These states are considered to have a State-based Marketplace, and are responsible for performing all marketplace functions for the individual market, except that the state will rely on the federal Healthcare.gov website for eligibility and enrollment functions. Consumers in these states apply for and enroll in coverage through Healthcare.gov.

State Insurance Guide by State : Courtesy of the Angelman Foundation, this ppt gives an overview of state insurance broken down by each state!

State Profiles | RareAction Network: NORD has increased its involvement in state-based policy matters in order to ensure that patients are able to access the treatments the rare community has fought so hard to get developed and approved. NORD recognizes that now more than ever, the cost and availability of health care services for patients with a rare disease is dependent upon state-based policy decisions.

State Profiles | RareAction Network: RAN is the nation's leading rare disease advocacy network working to improve the lives of the 30 million Americans impacted by rare disease. The goal of RAN is to ensure that the rare disease community is represented and supported in all 50 states. Please use this link to find your state's network.

State Rankings on Policy Alignments to Support Working Caregivers

State Resources - International Rett Syndrome Foundation: Your state has resources that your family may be able to access to provide support with medical attention, therapies, Medicaid and other funding, as well as educational support. Families like yours have helped curate your state's resources. Click on your state below to find your International Rett Syndrome Foundation Family Empowerment State Representative, available clinical trials or Rett syndrome clinics and many other resources.

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State Resources | National Parent Helpline: The National Parent Helpline® is here for you and is open to parents and caregivers of children and youth of all ages. Use this page to find local support.

State Resources | Rising Kites: Locate your state below to find helpful resources to assist you as you navigate this new journey of raising a child with Down syndrome.

State Work - National Center for Pyramid Model Innovations: find information on your state's Pyramid Model implementations.

Statewide Programs - RESNA Catalyst Program: Each state has a federally-mandated Assistive Technology program. These programs were set up to provide technology related assistance to people with disabilities. They will have information about low-cost computers, loan programs, AT evaluations and more.

Support in your area | March of Dimes: Find resources, programs, events, and initiatives to help you through every stage of pregnancy.

Supported Decision-Making State Information: Find information about your state's laws and programs that impact supported decision making for people with disabilities.

Technical Assistance: State TA Liaisons | DaSy Center: The individual technical assistance providers below have been identified as primary contacts for the respective states and territories.

UCEDD Programs by State: 67 University Centers for Excellence in Developmental Disabilities. Since 1963,

Created by: Sierra Phillips @mrs.phillijt
University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) have been working to accomplish a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision. Currently, sixty-seven UCEDDs in every state and territory are located in a university setting.

United Ways in the United States | United Way Worldwide: There are more than 1,100 local United Ways around the world. Find yours by clicking on your state below.

What's Happening in Your State | Think College:Click any state on the map to see available information on activities related to postsecondary education for students with intellectual disability (ID) in that state.

Wrightslaw Yellow Pages for Kids with Disabilities: Find educational consultants, psychologists, educational diagnosticians, health care providers, academic therapists, tutors, speech language therapists, occupational therapists, coaches, advocates, and attorneys for children with disabilities on the Yellow Pages for Kids for your state.

MILITARY FAMILY RESOURCES:

EFMP Quick Reference Guide: This guide provides staff with reference information and instructions to assist family members with special needs with enrollment into the EFMP, EFMP Family Support, and Family Member Travel Screening processes for the Army, Marine Corps, Navy, and Air Force. For your reference, search tools for contact information, Family Support contact information, and relevant forms can also be found in this guide.

Army Exceptional Family Member Program (EFMP) (armymwr.com): The Exceptional Family Member Program (EFMP) provides comprehensive support to Family members with special needs. An Exceptional Family Member is a Family member with any physical, emotional, developmental, or intellectual disorder that requires special treatment, therapy, education, training, or counseling, and meets the eligibility criteria. EFMP pertains to active-duty Soldiers, US Army Reserve Soldiers in the Active Guard Reserve (AGR) Program, and Army National Guard AGR personnel serving under authority of 10 USC or 32 USC.

Maps - Military Parent Technical Assistance Center (branchta.org): The maps help you find military installations in your state, along with contact information for Exceptional Family Member Program (EFMP) Family Support or School Liaison Office (SLO) staff in each location. For Coast Guard and National Guard locations, we have contacts for the Special Needs Program (SNP) and the Family Assistance Coordinators, respectively. Contacts who support Recruiter families are also included.

Military Families Resources for Young Children | Sesame Street (sesamestreetformilitaryfamilies.org)

Early Intervention Additional Resources | EFMP Directory (militaryonesource.mil)

Military Child Education Coalition | MCEC

Resources for Students, Parents and Educators | MCEC - Military Child Education Coalition

Parent Programs and Resources - Military Child Education Coalition

Our Military Kids

Our Military Kids Family Resources: Our Military Kids is proud to share the following resources with military families

Legal Support for Military Families with Special Needs | Military OneSource

Special Needs Program (SNP) | Office of Work-Life Programs (cg-111) (uscg.mil): The SNP provides a comprehensive, coordinated, multidisciplinary approach to community support, housing, medical, educational, and personnel services for Coast Guard families with special needs.

CGMA | The official relief society of the US Coast Guard (cgmahq.org)

CGMA | Special Needs Support (cgmahq.org): Special Needs Grants provide financial assistance to Active Duty CGMA clients who are faced with increased financial requirements because they have dependents with special needs. They are open to Regular Coast Guard active duty members and Coast Guard Reserve members on active duty for 181 days or more who have dependents registered in the Coast Guard Special Needs Program.

Exceptional Family Member Program (af.mil)

Created by: Sierra Phillips @mrs.phillijt
Army_DirectSTEP.pdf (armymwr.com):: DirectSTEP® eCourses are available for free to Soldiers and Family Members, Army EFMP staff, and Special Education staff associated with teaching military children. DirectSTEP® eCourses teach staff, parents, and educators how to handle critical education issues to obtain positive outcomes.

Autism Care Demonstration | TRICARE: The TRICARE Comprehensive Autism Care Demonstration (ACD) covers applied behavior analysis (ABA) services. Under the ACD, ABA services are authorized to target the core symptoms of autism spectrum disorder (ASD).

EFMP - Exceptional Family Member Program Benefits | Military OneSource: Benefits such as support services, programs and allowances are provided to the military community in addition to base salaries and wages. Browse EFMP - Exceptional Family Member Program-related benefits below and click for more details and to access information.

Finding Jobs And Talent Just Got Easier - Hire Autism

A Guide for Military Families | OAR (researchautism.org): This guide and its companion website are resources expressly for military families that have autistic children. Their purpose is to give each family the tools and access to information that it needs on its unique life journey through autism.

Operation Autism | A Resource Guide for Military Families: Operation Autism is a web-based resource specifically designed and created to support military families that have children with autism.

Resources Directory | Operation Autism: Operation Autism's Resource Directory allows you to search for local resources including schools, EFMP contact information, community services, and ABA providers accepting TRICARE. The directory is organized by base and can be searched by state, base name, or zip-code.

EFMP - Exceptional Family Member Program Resources | Military OneSource: There are many resources through Military OneSource and other Defense Department programs that support mission readiness and enhance quality of life for the military community. Browse EFMP - Exceptional Family Member Program-related resources below and click for more details including links and access information.

EFMP & Me: The Exceptional Family Member Program Resource (militaryonesource.mil): Navigating military and community resources during major life events can be challenging as a military family. The EFMP & Me tool provides checklists, resources and referrals to guide you through each process and find support from the Exceptional Family Member Program. Use this tool to maneuver through the Defense Department's network of services and supports for families with special needs. No sign-up is required for service members and family members, but you can choose to create an account to save your progress and preferences.

Special Needs Parent Tool Kit : Birth to 18: The Office of Community Support for Military Families with Special Needs is pleased to provide the Department of Defense Special Needs Parent Tool Kit — Birth to 18. This tool kit provides information and resources that will help you improve your quality of life and teaches you how to advocate for your child with special needs. Each of the six modules addresses issues you are likely to encounter throughout your child’s life. Whether your child has been recently diagnosed with a special need or if you are a parent for whom the diagnosis is not new, this tool kit has something for you.

Respite Care Overview.pdf

EFMP Exceptional Advocate eNewsletter | Military OneSource: The Exceptional Advocate is an eNewsletter for military families with special needs and those who support them. Published quarterly, The Exceptional Advocate focuses on updates and information from the Exceptional Family Member Program.

EFMP | Education Directory for Children with Special Needs (militaryonesource.mil): The Education Directory for Children With Special Needs provides military families who have children with special needs the resources they need to make informed assignment decisions and experience easier transitions.

EFMP Info for Exceptional Family Members | Military OneSource: EFMP is more than just one program or connection point, it's the work of three components: Family Support, Identification and Enrollment, and Assignment Coordination. The program assists by identifying and enrolling family members with special medical or educational needs; finding out what services are available at current or new duty stations; and supporting families with information, referrals when appropriate, and non-clinical case management to access services.

EFMP Reimbursement Process | Marines

EFMP, Exceptional Family Member Program | Military OneSource: Exceptional Family Member Program Family Support provides information, resources, skills and support to help military families with special needs navigate their systems of care. As families gain confidence, they become effective advocates for themselves and their family members, improving the quality of life.

Created by: Sierra Phillips @mrs.phillijt
Exceptional Family Member (navy.mil)

Exceptional Family Member Program (usmc-mccs.org)

Extended Care Health Option | TRICARE: The Extended Care Health Option (ECHO) provides financial assistance to beneficiaries with special needs for an integrated set of services and supplies.

Home - Military Parent Technical Assistance Center (branchta.org): To build the capacity of Parent Centers to provide effective services to military families of children and youth with disabilities.

Medicaid Waivers for Military Families With Special Needs | Military OneSource

Military Family Support Discussions - Military Parent Technical Assistance Center (branchta.org): We're an open group of parent center and military-connected professionals (EFMP & School Liaisons, FACs and FRS) who share with and support one another in their work serving military-connected families. Drop in during our monthly meeting hour or come early and stay-ask a question, share an insight—it's what we're all about, and you are cordially welcome!

National Resource Directory | Connecting our Service Members & Veterans (nrd.gov): The NRD is a database of validated resources that supports recovery, rehabilitation, and reintegration for service members, veterans, family members, and caregivers.

National Resource List 2022: Exceptional Family Member Program National Resources.

Navy App Locker: This interactive app provides guidance and support to Sailors whose family members have chronic medical, mental health and/or special education needs. The app includes essential EFMP information, frequently asked questions and handy resources including a Video and News section, allowing Sailors to have the information they need to help their family members thrive.

Navy CYP EFM Respite Care Parent Flyer_Final.pdf: Navy Child & Youth Programs is proud to offer 40 hours of free respite care a month to families with children identified as exceptional family members.

Post-High School Transition Resource for Military Families-with handout - Military Parent Technical Assistance Center (branchta.org)

Respite Care | TRICARE

San Diego County Resource list: Exceptional Family Member Program Local Resources for San Diego.

Special Needs Overview | Military OneSource

Support: Military Families w/ Special Needs | Military OneSource: Military OneSource provides enhanced support for military families with special needs. Special needs consultants are available by phone or video to help you navigate the medical and educational needs of your family, and connect you with military- and community-based support.

ALABAMA RESOURCES:

2-1-1 Database: You can search the 2-1-1 Database by clicking on the appropriate category below and select the service you are looking for. Enter your Zip Code in the "Serving" Box below.

Achievement Center: Our Mission is to provide vocational development services and extended employment programs for individuals with physical, mental and developmental disabilities and for persons without disabilities who are culturally, socially or economically disadvantaged; to assist them in obtaining competitive or extended employment; to help maximize their independent living skills; and to equip them to live at the highest possible level of independence within the community.

Family Guidance Center: Family Guidance Center of Alabama is dedicated to strengthening families through partnering with families, organizations, and communities and through the provision of an accessible comprehensive system of coordinated programs and services designed to enable people of all ages in Alabama to envision and achieve their goals.

iCanConnect: With five campuses in Talledega and eight statewide regional centers, AIDB assists clients from early intervention to senior citizens. The Institute now serves more than 20,000 people each year statewide with a wide array of programs.

Alabama At4all: STAR, Alabama's Assistive Technology Resource, is a special program through the Alabama Department of Rehabilitation Services. We provide services as part of a federal grant through the Assistive Technology Act. Services include alternative financing program, reutilization centers for durable medical equipment, an assistive technology lending library, and assistive technology training and demonstrations.

Alabama Council on Developmental Disabilities: We are dedicated to the vision that all Alabamians, regardless of disability, will live, learn, work, and play in inclusive communities. To that end, we work towards system changes in aspects of service/support to promote better lives for individuals with developmental disabilities and their families.

Alabama Council on Developmental Disabilities | Community Support: The term "Community Supports" means supports that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life. They are designed to enable such individuals to control their environment; permit the most independent life possible; prevent placement into a more restrictive living arrangement than is necessary; and enable them to live, learn, work, and enjoy life in the community. Other supports may include early intervention services, respite care, personal assistance services, family support services, supported employment services, support services for families headed by aging caregivers of individuals with DD, provision of rehabilitation technology and assistive technology, and assistive technology services.

Alabama Lifespan Respite Resource Network:: To increase access to and availability of high quality respite resources for all caregivers in Alabama.

Alabama Parent Education Center: The Alabama Parent Education Center (APEC) is a non-profit 501c3, organized in 2002 by Alabama parents, educators, and professionals serving families. APEC provides services and supports to assist families particularly those underserved including minority, low-income, and those with children with disabilities.

Alabama Rare Disease Advisory Council: Alabama Governor Kay Ivey established the Alabama Rare Disease Advisory Council in 2017 to serve as an advisory body to the governor and the Alabama Legislature. Our focus is on research, diagnosis, treatment, and education regarding rare diseases and their economic impact on the state. Our Council comprises 17 members representing distinct areas of expertise in medicine, research, advocacy, and government policy. The governor nominates each member to fulfill a three-year term of service

Alabama Rare: Alabama Rare is a grassroots organization to unite Alabama around the rare disease population. It acts to bring support for individuals & families, educate the broader community, bring awareness to the population's needs, and advocate for necessary change to improve healthcare delivery. It aims to celebrate what we have in our backyard, and collaborate with stakeholders to move rare disease diagnostics, policy, delivery of care, and patient experience forward.

ALL Kids | Alabama Department of Public Health: ALL Kids is a low-cost, comprehensive healthcare coverage program for eligible children under age 19. Benefits include regular checkups and immunizations, sick child doctor visits, prescriptions, vision and dental care, hospitalization, mental health and substance abuse services, and much more.

Arc of Shelby County: The Arc of Shelby County is a 501(c)3 non-profit located in Pelham, Alabama. Through advocacy, coaching, and support, we empower individuals with developmental disabilities and delays and their families to achieve their goals.

Austin 1st Foundation | Rare Disease: Austin 1st Foundation, Champions for Rare Diseases by raising awareness and research dollars to provide support for families in Alabama and beyond.

Camp ASCCA: Providing camping experiences for children and adults with disabilities, Camp ASCCA is open year-round. Within its barrier-free environment, Camp ASCCA offers 230 wooded acres on the shores of beautiful Lake Martin in Alabama.

Caregiver Support & Information | Full Life Ahead: list of caregiver and respite resources for Alabama.

Caregiver Wellness Initiative: In addition to respite breaks and caregiver education, Alabama Lifespan Respite offers Care Chats (one-on-one support hours available by phone or video conferencing) with ALR social worker staff, monthly support groups, and caregiver mental health education opportunities to help increase overall caregiver wellness. To further support the total wellbeing of unpaid, full-time family caregivers statewide, Alabama Lifespan Respite has established the Caregiver Wellness Initiative (CWI) to increase available Emergency Respite reimbursement funds and designate funds specifically for mental health counseling to caregivers currently enrolled with any ALR reimbursement program.

Circle of Hope: Circle of Hope's mission is to offer support to families of children with life threatening and chronic conditions.

Created by: Sierra Phillips @mrs.phillijt
Community Respite by County

CORE Academy: CORE Academy offers intensive and individualized education programs for students with autism and other developmental and intellectual disabilities. Our goal is to provide quality educational services to as many children with special needs as possible, creating an environment where each student can learn in a manner that best suits his or her needs.

CORE Life: Because deficits do not just vanish when a certain age is met, CORE Life serves as a way to continue to provide much needed support to these individuals and their families, no matter their age. Through adult transitional services, CORE Life will focus on building vocational and community living skills for its participants, with the goal of moving towards independence and, if applicable, employment in the community.

CORE Respite: CORE Respite will soon provide quality care for these children and adults while presenting caregivers with a much-needed break to help promote a healthy home environment.

Easterseals Alabama | Financial: list of financial services through Easterseals.

Easterseals Alabama: Easterseals provides exceptional services to ensure that all people with disabilities have equal opportunities to live, learn, work and play.

Easterseals NWAL: The Easterseals Rehabilitation Center Northwest Alabama is committed to providing quality community services to enable children and adults with disabilities to achieve their maximum potential. To do this, we strive to be the most effective organization helping those we serve live with equality, dignity, and independence. The services provided include Vocational Rehabilitation, Physical Therapy, Speech Therapy and Occupational Therapy.

EASTERSEALS WEST ALABAMA: To change the way the world defines and views disability by making profound, positive differences in peoples' lives every day.

Family Support: To enhance the lives of Alabamians with disabilities and their families.

Family Voices of Alabama: Family Voices of Alabama (FV of AL) aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Field of Angels, Calera Alabama: was organized and developed to hold, promote, and support amateur youth sports and sporting events to promote sportsmanlike competition for individuals with mental or physical conditions that prohibit safe participation in other leagues in the state of Alabama.

First 5 Alabama: The mission of First 5 Alabama is to enhance healthy attachment relationships between children birth to age five and adults who care for them through promotion, prevention, and intervention supports throughout Alabama's early childhood system. First 5 Alabama Infant and Early Childhood Mental Health Consultant, in partnership with United Ability, is located at Hand in Hand Early Learning Program.

First Teacher Home Visiting Program: The First Teacher Home Visiting Program perfectly augments all other programs for children and families and provides free home-based services to families. It offers training and support in such areas as parent-child interaction, parenting skills, and child development. Families with children ages birth to five who may have a diagnosed disability, developmental delay or are just in need of extra support in the home are recipients of these home visiting services. Services can also start prenatally.

Full Life Ahead: The purpose of Full Life Ahead is to positively impact the lives of individuals with disabilities and their families by helping them create hope, encourage dreams, set expectations, and establish an action plan to achieve the fullest adult life.

Hand In Hand Early Learning Program | United Ability: Hand In Hand Early Learning Program is a program for children from 6 weeks to 4 years of age. The program's name reflects total environment rich in unique learning experiences. It is a place where children play, learn and grow together. Children of all abilities develop understanding, acceptance and compassion – a great foundation for future success.

Hearts Respite Program | United Ability: Hearts Respite provides reimbursement for childcare to those families of a child with a disability under the age of 19 years. Caring for a child with a disability is emotionally and physically demanding. The Hearts Respite program allows the parent to train a caregiver of their choice in how to care for their child. The monies provided through the Children's Trust Fund enable United Ability to reimburse those family members for their out-of-pocket child care expenses. This program is provided in collaboration with the Alabama Department of Child Abuse and Neglect Prevention Community-Based Child Abuse Prevention.

Aaron's Staff | Respite Care Ministries: Aaron's Staff is a nonprofit organization dedicated to providing respite for parents and guardians who have children with special needs. The ministry is made up of volunteers from area churches, schools and individuals who give of their time to provide quality care for the children and their siblings while the parents take some time for themselves.

Down Syndrome Alabama: We envision and strive for an Alabama where individuals with Down syndrome are accepted and included for who they are. We provide hope and support to each person and their families with educational resources and networking opportunities throughout all stages of life.

Montgomery Children's Specialty Center: We're committed to providing your loved one with a successful, comfortable recovery in a family-friendly environment. Whether you are here for a temporary living solution, or a permanent one, our children's nursing and rehabilitation community offers a safe and secure setting for as long as needed.

Southern Cross Home Care: We understand that no one care plan fits all. Daily services can include meal preparation, personal hygiene, light housekeeping, medication reminders, driving to appointments or running errands and companionship. We will take the time to get to know you and develop an individualized care plan that fits your specific needs.

Times Out, Inc: Times Out, Inc. is a not-for-profit social service organization that provides support services for persons 15 and older who have intellectual disabilities, mental illness, or pervasive developmental disabilities. The organization will provide companion services that will enable the person to participate in social and recreational activities within their local community such as eating out, going to movies, attending and participating in sporting events, etc.

Iron City OT: We provide mobile occupational services in Birmingham, Alabama. A licensed occupational therapist works with clients in their everyday environment to identify and achieve meaningful goals. We travel to homes, day cares, pre-schools, and school systems to provide client-centered sessions. DMI services offered with the only certified DMI therapist located in Alabama

Lakeshore Foundation: To provide opportunity for individuals with disability to live a healthy lifestyle through physical activity, research, advocacy and health promotion.

Opportunity Center: The mission of the Opportunity Center - Easter Seals community rehabilitation program is to provide vocational development and extended employment, primarily for individuals with mental, emotional, and physical disabilities, to maximize their employment potential.

Parents As Teachers - EASTERSEALS WEST ALABAMA: The Parents as Teachers Program (PAT) provides information, support, and encouragement to parents in need. PAT teaches parents the skills needed to help their children develop optimally during the critical, formative years of life. PAT is a champion for early intervention and parental involvement and serves as a unified voice for early childhood education and healthy child development. The program supports a parent's role in promoting school readiness and healthy development of children.

People First of Alabama: People First of Alabama is a group of people with developmental disabilities living in Alabama communities dedicated to making our dreams happen by having choices and control over our lives. This means having opportunities to make decisions and plans for ourselves instead of having others make them for us.

Respite Care Provider Grants: Alabama Lifespan Respite (ALR) is looking to fund direct respite care hours to underserved populations. The Respite Care Program Grants will be available once a year to increase direct respite care services to existing and start-up programs that provide services to underserved populations.

Anderson College of Nursing and Health Professions | Respite Program: The Anderson College of Nursing and Health Professions (ACONHP) continues to facilitate a monthly respite program in Florence, Alabama. Local families are invited to bring their child with special needs and their siblings to monthly respite program events from 5:00pm-8:00pm. The ACONHP respite program provides parents a "break" from the stress associated with caring for a child with special needs

SDF Alabama: The program is an Alternative Financing Program for individuals with disabilities and their families to borrow money at a low-interest or extended-terms for the purchase of assistive technology, adaptive equipment and related services. Alternative financing needs may include but will not be limited to a means of paying for devices not covered by public programs, as a means of providing a loan sooner than other public programs, and/or a means of having another funding source available

SouthSeq – HudsonAlpha Institute for Biotechnology: SouthSeq is a NIH-funded research study looking at how a new kind of genetic test, called whole genome sequencing, can be used to try to find the reason for medical problems among newborns in a neonatal intensive care unit (NICU).

Special Connections - Briarwood Presbyterian Church: Special Connections is a ministry to people of all abilities. Our desire is to see society and the Body of Christ show equal concern for people with disabilities and their families as is shown for others. Therefore, our focus is ministering, in word and deed, both to and alongside people touched by disability. We seek to enable people with disabilities and their families to hear the gospel of God's grace, fully participate in the Body of Christ, and fully contribute in their churches and communities. Please see our organization's statements and core beliefs below.

Special Families Project: We provide prevention services to parents of children with disabilities to assist them in parenting their children. We help parents connect with other families and community resources, thereby reducing parental stress and isolation.

The Alabama Family Trust: Individuals with disabilities and their families can face significant challenges in planning for the future. Alabama Family Trust provides a multitude of resources for families looking for more information on supplemental needs trusts for loved ones with disabilities. Our team is dedicated to serving children and adults with physical, mental health or intellectual disabilities — and providing peace of mind to families.

The Alabama Institute for Deaf and Blind: The Alabama Institute for Deaf and Blind (AIDB) is the world's most comprehensive education, rehabilitation and service program serving individuals of all ages who are deaf, blind, deafblind and multi-disabled. Founded in 1858 by a young medical doctor who wanted to educate his deaf brother, AIDB now serves more than 31,000 infants, toddlers, children, adults and seniors with hearing and vision loss throughout Alabama each year.

The CORE Project, Inc.: We are a non-profit corporation that provides help and hope to individuals with special needs throughout their lifetimes. By providing opportunities for clinical care, education and family support under one roof, our team fosters independence and a sense of belonging for our clients—helping them move from labeled to living. Our goal is to make our community the best place to raise a child with special needs!

The E.WE Foundation: The E.WE (/ē/·/wē/) Foundation is an IRS approved 501(c)(3) healthcare advocacy organization established to provide resources and support to families affected by Edwards Syndrome, commonly known as Trisomy 18, and other rare diseases.

UCP of Alabama: UCP of Alabama serves children and adults with developmental disabilities across the state of Alabama. Our organization is comprised of six affiliates located throughout the state. Through a variety of programs offered by the different affiliates, we strive to provide opportunities that foster independence and productivity for every individual we serve.

UNA's Collaborative Special Education Program: The Collaborative Special Education program prepares undergraduate and graduate students to work in general and special education settings with children and young adults who have varying ranges of exceptionalities. Our students attend courses together, work on numerous collaborative assignments, host activities, and complete field experiences within their courses in local classrooms. Students are actively engaged in the surrounding schools and communities to assist in providing additional support and resources to individuals with exceptionalities.

Undiagnosed Diseases Program: The Undiagnosed Diseases Program (UDP) seeks to meet the needs of patients with severe chronic medical conditions in whom a diagnosis has not been made despite extensive efforts by the referring physician.

United Ability | Nonprofit Disability Services: United Ability provides innovative services connecting people with disabilities to their communities and empowering individuals to live full and meaningful lives.

United Way of Central Alabama: United Way of Central Alabama builds a great community and advances the common good by bringing people together to help others. By pooling our resources and working together, we pave the way for real, tangible change in health, education and financial stability. There's power in numbers, which means we accomplish much more when we come together as a whole. Our way — the United Way — is more powerful than any one entity or individual alone. By partnering with us through volunteering or donating, you're a part of something bigger than yourself, fulfilling your own life and the lives of others. If you're in need of assistance, United Way can connect you with an organization that can help meet your specific needs. By letting us help, you're joining a community that cares and forming meaningful relationships in the process.

ALASKA RESOURCES:

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Stone Soup Group – Supporting Alaskan Families who care for children with special needs.: Stone Soup Group is a statewide 501(c)3 non-profit that provides information, support, training and resources to assist families caring for children with special needs. We are staffed almost entirely by parents or family members of children with special needs, so we know the journey and work from a family centered philosophy. In short, we work to assist other families as they navigate through what is often an overwhelming and confusing process following a diagnosis or at times of transition later down the road.

Access Alaska: Access Alaska encourages and promotes the total integration of people who experience a disability and senior Alaskans to live independently in the community of their choice.

Northwest ADA Center | ADANW (nwadacenter.org): he Northwest ADA Center is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and is part of the ADA National Network(link is external). The ADA National Network Centers are a national platform of ten centers comprised of ADA professionals and experts charged with assisting businesses, state and local governments, and people with disabilities as they manage the process of changing our culture to be user friendly to disability and the effect the variety of health conditions can have on society. The regional advisory committee and our state partners are premier leaders in ADA compliance in each of the states served--Alaska, Idaho, Oregon, and Washington.

Alaska Infant Learning Program: The Alaska Infant Learning Program is a statewide system of professionals dedicated to serving all Alaskan families with children who are at risk for or experience developmental delay.

Aging and Disability Resource Centers (alaska.gov): Alaska's ADRCs connect seniors, people with disabilities, and caregivers with long-term services and supports of their choice. The ADRC network serves Alaskans statewide, regardless of age or income level, through regional sites. The State of Alaska administers the ADRC grant through, and in partnership with, the regional sites.

Developmental Disabilities Resource Connection (DDRC) (alaska.gov): The DDRC program assists individuals with developmental disabilities and their families wishing to access services through State of Alaska Developmental Disabilities Programs. The DDRC Program is often the “point of entry” for accessing services. Assistance may include: applying for eligibility; referral to a wide variety of resources in their home community; completing forms and gathering documentation for Medicaid, the Registration and Review, other public programs; and/or applying for Mini-Grants.

Home - WSRGN (westernstatesgenetics.org): The Western States Regional Genetics Network, formerly known as the Western States Genetic Services Collaborative, is a federally-funded, multi-state project that seeks to increase access to genetic services and education for medically underserved populations. The participating states and territory are Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. The Western States Regional Genetics Network, formally known as the Western States Genetic Services Collaborative, is a federally-funded project that seeks to improve access to genetic services and education for medically underserved populations. By working together as a region to increase access to and reduce disparities in clinical genetic and newborn screening services, the participating states/territory seek to improve the health of individuals with or at risk for heritable disorders.

Developmental Disabilities Resource Connection Roster (alaska.gov)

MAP Parent Mentor Program – Stone Soup Group: Stone Soup Group offers Mentor-Advocate-Partner Program (MAP), a volunteer peer support opportunity adapted from nationally recognized Parent-to-Parent USA programs, specifically for Alaskans. As parents ourselves, we know one of the best resources for families is connecting with other families who have had similar experiences caring for a child with special needs; who have already come to accept and understand their child’s unique needs.

Mini Grants - Alaska Mental Health Trust: The Trust mini grant program provides individuals within all Trust beneficiary groups up to $2,500 for a broad range of equipment, supplies and services to improve their quality of life, increase independent functioning, and help them attain and maintain healthy and productive lifestyles. A mini grant is based on need and is awarded to an agency on behalf of the beneficiary.

Neurodevelopmental Outreach Clinics (alaska.gov): Neurodevelopmental screenings and diagnoses are delivered by Pediatric Neurodevelopmental Specialists from the Children’s Hospital and Medical Center in Seattle and the University of Virginia Children’s Hospital. These specialists offer screenings, evaluations, diagnoses, follow up referrals, recommendations for treatment and care, and information on early intervention and education programs, as needed. Sponsored by the State of Alaska, the providers and their teams travel annually to communities across Alaska. They are able to evaluate children from 12 months to 12 years old, and support local providers in meeting the developmental special health needs of infants and children in rural Alaska.

Metabolic Clinics (alaska.gov): The Metabolic Clinic serves people from all over Alaska and occurs three times a year in Anchorage and Fairbanks. The clinic is staffed with a program manager, office assistant, a nutritionist, and a contracted out-of-state biochemical geneticist. The biochemical geneticist is a doctor who is specially trained in the area of metabolic genetics.

ARIZONA RESOURCES:

Special needs resources in Arizona - Raising Arizona Kids

Sunrise Care Boxes: Sunrise Care Boxes are customized care packages for teenagers in Arizona with chronic, life threatening, or terminal illnesses.

Pilot Parents of Southern Arizona: We are committed to providing encouragement and support to families who have children with special needs.

Adult Day Health Centers | Respite Brochure: Adult Day Health Centers (ADHC) provide a safe place where a person can be nurtured and stimulated. Centers are licensed by the Arizona Department of Health Services. Services are available Monday – Friday from morning to evening.

Maricopa County Caregiver Support Program (azcaregiver.org)

Respite Voucher Program Flyer: Eligible categories for reimbursement include: In-Home Respite Care, Outside of home Respite Care, Adult Day Health Centers, Educational Respite, and Emergency Respite.

Resources – Pilot Parents of Southern Arizona

PediaLabs - Mobile Phlebotomy Services: PediaLabs is a group of mobile phlebotomists based in Tempe, AZ. Our certified phlebotomists help children and others have an easier, more comfortable experience by providing mobile phlebotomy and lab services at home.

Caregiver Respite - Arizona Caregiver Coalition (azcaregiver.org): The Arizona Caregiver Coalition is a community-based, 501(c)3 tax exempt organization. It was founded to support and advocate for family caregivers in Arizona. We partner with the Arizona Department of Economic Security, Area Agencies on Aging, and other community based organizations.

Family Caregiver Reimbursement Program - Arizona Caregiver Coalition (azcaregiver.org): Family caregivers can be reimbursed 50% for home modifications and assistive care technology up to $1,000 each for one (1) or more qualified family member. Funding is limited and is distributed as first come first served. The Family Caregiver Reimbursement Program assists family caregivers with a partial reimbursement for home modifications and assistive care technology to enable their qualified family member to be mobile, safe, and independent to avoid institutional care.

Raising Special Kids – Help and Hope for Families: Raising Special Kids exists to improve the lives of children with the full range of disabilities, from birth to age 26, by providing support, training, information and individual assistance so families can become effective advocates for their children.

RPBF - Resilient Parenting for Bereaved Families (bereavedparenting.org): We provide information and practical tools to parents and caregivers, as well as providers who provide services to bereaved families.

Selah Carefarm | Animal Grief Therapy for Bereaved Families: The Selah Carefarm just outside of Sedona, AZ is the first carefarm for the traumatically bereaved in the U.S.vIt's a very special place on 10 acres of beautiful farmland where bereaved family members can come to both give and receive connection, compassion, and understanding. All the animals on the carefarm have been rescued from abuse, neglect, and torture. Our grieving families know what it means to suffer, and so do these animals.

Programs — amandahope.org: We bring Amanda's sunshine to some of the most difficult days through our Major Distractions events and Meals of Hope lunches. We host Spa Days, Craft Days, Family Events, Teen Nights, and many more! Our warriors love to know that we always have something fun in store! Our in-person events are in Arizona, but our virtual events are open to families anywhere with a child battling cancer or a life-threatening illness.

Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

Year 6 Genetic Navigator Outreach Presentation (canva.com)

Arizona Genetic Navigator

Genetic Ambassador Program - Mountain States GeneticsMountain States Genetics

Way to Grow Pediatric Therapy: Pediatric Occupational Therapists (OT), Physical Therapists (PT) and Speech Therapy (ST) help children to restore or develop their functional performance in a variety of areas. For children, some of the areas include play, self-help skills, functional mobility, school performance, and social skills. At Way to Grow, LLC, we provide individualized, play-based and child-centered OT, PT and ST services. Our treatment sessions are provided in a clinic setting with a sensory based gym, featuring a wide variety of equipment, toys and activities to motivate, encourage and provide each child with a "just right" challenge to foster maximum skill development. Your child will love to grow and learn with us in our fun, safe and supportive environment!

Disability Organizations and Agencies | Sonoran UCEDD (arizona.edu): The Sonoran UCEDD is committed to informing families, individuals with DD, state agencies, advocacy groups, national disability organizations, and state legislators about disability related programs, issues, and research utilizing a variety of formats and modalities. We strive to ensure that information disseminated by the Sonoran UCEDD is available in accessible formats including in Spanish, audio or close captioned, culturally relevant and at a wide range of literacy levels. Below are the resources available on our website.

Sonoran Center UCEDD: The goal of the Sonoran Center is to ensure full community participation by individuals with developmental disabilities. The Sonoran UCEDD has been hard at work to make its vision a reality – to ensure that individuals with intellectual and developmental disabilities have the supports they need to fully take part in the life of our community.

ARKANSAS RESOURCES:

The Heartland Genetics Services Network: The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

AIRS Live Streaming (aetn.org): Arkansas Information Reading Services for the Blind.

ARSILC - Arkansas State Independent Living Council: The mission of the Arkansas State Independent Living Council is to promote independence, including freedom of choice and full inclusion into the mainstream of society, for all Arkansans with disabilities.

Mainstream Center for Independent Living (mainstreamilrc.com): Mainstream is a non-profit, non-residential, consumer-driven Independent Living Resource Center for people with disabilities in central Arkansas. Consumers of Mainstream set their own goals and take the lead in developing plans to meet those goals and objectives. Mainstream, which has been in existence since the summer of 1987, offers services to consumers and other stakeholders free of charge.

Arkansas Access To Justice – Representing Hope (arkansasjustice.org): The Arkansas Access to Justice Commission works to ensure justice for all. That means that all Arkansans get the protections of the law. We research the unmet legal problems of Arkansans, encourage attorneys to do pro bono work for families who are priced out of the legal market, and recommend evidence-based solutions to policymakers.

Brochure rev 2020 Arkansas Disability Coalition Family 2 Family.pub:

102121_DDS_CHC_Infographic-final (arkansas.gov)

Arkansas Children's Medical Program

ACCESS: ACCESS® is located in Little Rock, Arkansas, and offers full-time education, therapy, training and activities for children and youths with learning disabilities. We serve families from Arkansas and surrounding states, including those families who have relocated to our state to enroll their children in our programs.

Arkansas Autism Resource & Outreach Center | AAROC: The Arkansas Autism Resource & Outreach Center (AAROC) is a registered 501(c)(3) charitable organization and all donations are tax deductible under section 170 of the Internal Revenue Code. Your generous contributions help us continue our current services to families in Arkansas, such as service coordination, training, and ongoing technical assistance. Donations like yours will also help the AAROC develop new programs, such as supports for children with autism to attend summer camps and after school programs.

The Center for Exceptional Families – Advocacy with heart.: Assist Arkansans with disabilities in attaining an exceptional quality of life by providing resources and support to individuals and families!

The Center for Exceptional Families | Resources: Here you can find a list of state and national resources.

Resource Partners – The Center for Exceptional Families

Arkansas Treasurer of State | ABLE Accounts: ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, were created as a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014, better known as the ABLE Act. The beneficiary of the account is the account owner, and income earned by the accounts will not be taxed. Contributions to the account made by any person (the account beneficiary, family and friends) will be made using post-tax dollars and will not be tax-deductible on the federal level. However, Arkansas law allows for state income tax deductions of up to $5,000 per individual for contributions made to an Arkansas ABLE account.

Community of Champions: Community of Champions is an advocacy program funded by the Arkansas Governor's Council on Developmental Disabilities. Our mission is to develop every Arkansan into an advocate for themselves or their peers. We envision communities full of champions, advocating for individuals with developmental disabilities. Community of Champions strives to educate, inspire, and empower peer advocates, self-advocates, and state leaders to understand the importance behind advocacy and how it brings our communities closer together, growing our state to its maximum potential.

Arkansas Autism Foundation: AAF helps individuals and families with autism across their lifespan and provides autism-friendly events and relevant workshops and training opportunities. We raise awareness about autism and provide important resources and support to families, and are committed to funding yearly grants for innovative or already existing programs that improve the lives of those affected by autism.

CoBALT Project: CoBALT's mission is to get the right child to the right services at the right time and place. CoBALT teams allow families quicker access to specialized developmental evaluations, which results in appropriate diagnosis and quicker referral for therapy services.

TEFRA - Arkansas Department of Human Services: The Tax Equity and Fiscal Responsibility Act (TEFRA) is a Medicaid program that can help families with children younger than 19 years old who have a disability receive care in their homes rather than an institution.

Schmieding Developmental Center: Schmieding Developmental Center strives to improve the diagnosis and treatment of children with neurodevelopmental and medical conditions that impact cognitive, emotional and behavioral function through direct care, teaching and training providers, and collaborating with other agencies to increase awareness and the creation of services.

Dennis Developmental Center | UAMS Department of Pediatrics: The Dennis Developmental Center specializes in the assessment of developmental conditions that result in delayed milestones, inability to communicate effectively, inattention, hyperactivity, impulsivity, learning problems, and poor or atypical social interactions. Evaluation and therapy are also provided for families coping with the stress of chronic developmental disorders or chronic medical illnesses, and with grief and loss concerns. The Dennis Developmental Center coordinates the expertise of developmental pediatricians, nurse practitioners, speech/language pathologists, clinical social workers, clinical psychologists, psychological examiners and when indicated, other clinical specialists.

Sources for Community Independent Living: SOURCES provides services, support, and advocacy for individuals with disabilities, their families and the Northwest Arkansas community.

United Way of Central Arkansas

Arkansas Hands and Voices: Our goal is to form a comprehensive group of parents and professionals that work together to benefit children and families with children who are deaf or hard of hearing.

Central Arkansas Disability Services: Empowering individuals through person-centered services focusing on home, community, and employment services that support full inclusion in the community.

Riley's Warriors, Inc.: A 501(c)(3), Non-Profit Ministry to the Families of Children with Special Needs.

Riley's Warriors, Inc. | The HOPE Notebook: The HOPE Notebook (Helping Organize and Prepare Effectively) is an organizational system to help parents, family members and caregivers of individuals with disabilities manage information associated with those individuals. In caring for an individual with special health care or educational needs, you receive paperwork and information from a wide array of sources. This system will help you organize all of that information in one location so that you can find it when you need it. And, by keeping the information in a central location, it becomes easier to share information with others who are part of the individual's educational or health care team.

Community Connections | Respite Care: Community Connections will be providing monthly Respite Care Events for kids in Bryant, Conway, & Little Rock! We want parents/guardians to have the opportunity to take a break, run errands, have a date, or even head home to sit in silence……whatever respite care means to you! Siblings are welcome, we just ask that you please fill out one form per child so we can plan activities and staffing accordingly!

Community Connections | Family to Family Mentoring: We know raising a child with special needs comes with its own unique challenges. Some of the best input and encouragement many of us receive comes from individuals who are one step ahead in the journey!

NAMI Arkansas: NAMI Arkansas is a private, non-profit organization whose mission is to help people living with mental illness, their families, and the community. NAMI Arkansas operates a statewide organization providing and coordinating a network of local support groups providing support, education, and advocacy throughout the state.

Arkansas | RareAction Network

Arkansas - EveryLife Foundation for Rare Diseases

Apply for Respite Voucher - Arkansas Department of Human Services: Through the federal Lifespan Respite Grant for Integrity & Sustainability (#90LRLI0045) awarded to Arkansas Department of Human Services- Division of Provider Services and Quality Assurance (DPSQA) by the Administration for Community Living (ACL), respite voucher are available for Arkansas caregivers. As of November 1, 2021, DPSQA will be accepting voucher applications through the Choices in Living Resource Center. Voucher funding is awarded on a first-come-first-serve basis or until funding runs out. An applicant may receive up to $300 quarterly, $1200 annually.

Lifespan Respite Voucher Brochure

Arkansas Advocates for Children and Families | AACF: Arkansas Advocates for Children and Families was founded in 1977 by a group of prominent Arkansans who believed that children needed an "independent force to provide information and education to parents and citizens about our state's policies toward children and families." For 45 years, AACF has provided leadership, research, and advocacy to promote wide-ranging reforms that have improved the lives of Arkansas children, and we have never been afraid to lead the way when the need arose.

Easterseals Arkansas: Easterseals Arkansas is empowering individuals with disabilities to live, learn, work and play in their communities. We are leading the way to full equity, inclusion, and access through life-changing disability and community services. For more than 75 years, we have worked tirelessly with our partners to enhance quality of life and expand local access to healthcare, education, and employment opportunities. From child development centers to physical rehabilitation and job training, Easterseals Arkansas is empowering people with disabilities, families and communities to be full and equal participants of society.

Special Education: The Special Education Unit in the Division of Learning Services collaborates with local school districts, educational service cooperatives, and other state agencies to ensure that all children with disabilities (ages 3 to 21) in Arkansas receive a Free Appropriate Public Education (FAPE) as outlined in the Individuals with Disabilities Education Act (IDEA). The Special Education Unit is committed to improving educational results for students with disabilities through statewide leadership, support, and service to schools, educators, students, families, and other stakeholders.

The Arc of River Valley: Our mission at The Arc is to provide advocacy, education, and recreation for those with intellectual and developmental disabilities. We currently serve more than 450 members who live in Sebastian, Crawford, Logan, and Franklin counties in Arkansas and LeFlore and Sequoyah counties in Oklahoma. The Arc offers weekly classes and activities for members. These include movies, outdoor activities, bowling, art, science classes, cooking classes and so much more. The Arc also holds quarterly advocacy meetings. These include guest speakers on various topics. The Arc also helps connect members with advocates and resources. This includes local legislators, Disability Rights Arkansas, Arkansas legal services, transportation, and medical services. Arc is open Monday through Friday from 10:00 AM to 4:00 PM. Membership is $25 a year and includes all activities at the Arc.

Mays Mission for the Handicapped: Mays Mission for the Handicapped has been providing opportunities to people with disabilities. We are a religious, charitable, nondenominational, nonprofit organization dedicated to assisting the physically and spiritually disabled and promoting awareness of the potential of individuals with disabilities. Being a 501(c)(3), we are supported through charitable contributions from our faithful and loyal supporters. Because of the generous nature of our donors, we are able to provide services like On-The-Job training, scholarships, camperships, referral services, emergency monetary assistance, awareness education, and goodwill.

Children and Youth with Sensory Impairments and Additional Disabilities | CAYSI: CAYSI serves Arkansas children with dual sensory impairments and additional disabilities, otherwise known as deaf-blindness. We strive to identify the children in the state, promote academic achievement, and improve lives for children with dual sensory impairments through the education and collaboration of special and regular educators, families, early intervention providers, specialists, paraprofessionals, as well as OT's, PT's, SLP's.

M-Pacting Youth and Families, Inc.: M-Pacting Youth and Families, Inc. is a 501(c)(3) non-profit organization with the goal of improving the lives of individuals and families living with developmental and physical disabilities by providing high quality services in the least restrictive appropriate setting.

Arkansas Lifespan Respite Coalition: Arkansas Lifespan Respite Coalition (ALRC) is comprised of family caregivers and staff from organizations with outreach across the state, representing all populations regardless of age, income, cultural or ethnic background, or need/disability of the care recipient.

Arkansas Lifespan Respite - Arkansas Department of Human Services

Arkansas Lifespan Respite Search Locator (Registry) - Arkansas Department of Human Services: Welcome to the Arkansas Lifespan Respite Search Locator. This FREE registry connects those needing respite care with respite care providers. Direct care professionals or providers can sign up to be found as a respite care provider and find meaningful caregiver jobs, and primary caregivers can search this database for in-home or agency-based respite care providers that most closely meet their needs.

Title V: Children with Chronic Health Conditions (CHC) - Arkansas Department of Human Services: DDS Children's Services provides case management/care coordination for children birth to 21 years of age. Title V Care Coordinators will provide individuals and their families with information about the array of services that are available in their community and assist with referrals and applications for those services.

Title V: Children with Chronic Health Conditions | Respite Program: This Title V Program is available to SSI and TEFRA recipients under age 18 on a first come first served basis based on need and financial eligibility. With approval of the application, families are eligible for up to $1,000.

ASN | Family Support Program: Arkansas Support Network's (ASN) Family Support Program helps support parents or guardians to advocate for their children with disabilities. While we specialize in helping parents or guardians navigate special education, we provide training and information for all types of families, including: foster families, marginalized communities, the parents of young people in the juvenile justice system, and self advocates. In addition, we also collaborate with professionals working with these groups.

ASN | Arkansas Disability Resources

First Connections | Early Intervention Services: First Connections collaborates with families to facilitate the child's participation in family and inclusive community activities through intervention linked to specific family-centered goals which support the family's enhancement of their child's development.

Blue Umbrella: The Blue Umbrella is an extension of the Department of Human Services/Division of Disabilities Services and is a unique gift shop that embraces inclusion for all. In our store, you will find one-of-a-kind, handmade items by Arkansans with developmental and intellectual disabilities. Our mission is to celebrate these individuals who want to work and contribute to their communities while providing them a sense of pride and source of income.

A PARENT'S GUIDE - CIVIL RIGHTS/ EDUCATION (wsimg.com)

Parent Advisory Council CMS Inc. (arkansaspac.org): The purpose of the Parent Advisory Council was to give parent input and to make Title V Children's with Special Health Care Needs family-friendly. We became a 501c (3) in 1995. The purpose of that was to seek funding to help in advocacy/education activities. We are a diverse group of parents and guardians of children with special health care needs and are committed to advocacy and educating other families, government agencies and health care professionals.

Care Coordinator by County Map

Transition Readiness Changing Roles for Families: This transition checklist is intended for youth with complex medical needs. Many youth with complex medical needs may need total assistance in self-care, decision making and expressing themselves.

Title_V_Health_Care_Transition_Protocol_2021_08_05.docx (live.com): The Maternal Child Health Title V definition of transition is the percentage of adolescents with special health care needs who receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. Arkansas has chosen Transition as a National Performance Measure (NPM) for the Title V Children and Youth with Special Health Care Needs (CYSHCN) Program. The NPM for Health Care Transition is the percentage of adolescents with and without special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care.

Division of Developmental Disabilities Services: The Division of Developmental Disabilities Services (DDS) believes clients with developmental disabilities and delays and their families should have choices when selecting services that will help them thrive. That's why we offer high-quality services in homes and communities as well as in 24-hour residential programs. We believe that clients should have access to services in the least restrictive settings to meet their needs and that they have the constitutional right to live and learn and experience life just like any other Arkansan. The DDS Intake and Referral unit is the best place to start if you, a loved one, or a person in your care needs services and support.

ICAN Tools for Life: iCAN is the Arkansas statewide Assistive Technology program designed to make technology available and accessible for everyone who needs it. Assistive technology (AT) is any kind of device or tool that helps people live, learn, work, and communicate more independently. AT can be very simple and inexpensive, like a modified knife and fork, or it can be very sophisticated and costly, like a computerized speech device.

Links | Governor's Council on Developmental Disabilities (arkansas.gov)

Partners for Inclusive Communities | (uark.edu): Partners for Inclusive Communities (Partners) is Arkansas' University Center on Disabilities. Administratively located within the University of Arkansas College of Education and Health Professions. Partners is a member of the nationwide Association of University Centers on Disabilities.

Resources | Governor's Council on Developmental Disabilities (arkansas.gov): On this page you will find downloadable copies of many of our publications.

Governor's Council on Developmental Disabilities: The Governor's Council on Developmental Disabilities (GCDD or Council) promotes integration, inclusion and independence for Arkansans with developmental disabilities (DD). We do so by identifying the most pressing needs of the DD community in our state and addressing those needs by conducting outreach, fostering change and supporting capacity-building efforts.

Telecommunication Access Program: The Telecommunication Access Program (TAP) provides specialized telecommunication equipment to eligible Arkansans who are deaf, hard of hearing, deaf-blind, or who have a speech, visual, mobility, or intellectual impairment. TAP strives to remove telecommunication barriers through the delivery of adaptive communication technology.

Coalition for Strong Arkansas Families: We envision an Arkansas where everyone, no matter their age, background, race, gender, disability, or status, has the opportunity to live meaningful, fulfilling lives in strong, thriving communities.

Transition Services - Disability Rights Arkansas: Transition services are available for students eligible for special education and 504 services. They are meant to create a smooth pathway for a young person to move from high school to a successful adult life. Transition services can include work-based learning, internships, career exploration, self-assessments, workplace readiness, and counseling.

Arkansas Alliance for Disability Advocacy - Disability Rights Arkansas: The Arkansas Alliance for Disability Advocacy educates and empowers disability advocates, builds awareness about the issues people with disabilities face every day, and fosters collaboration between advocacy programs to give self-advocates, peer advocates, parent advocates, and legislative leaders the tools they need to be active participants in the disability rights movement.

Disability Rights Arkansas: Disability Rights Arkansas (DRA) is the independent, private, nonprofit, nonpartisan Protection and Advocacy organization authorized by Federal and State law to protect and advocate for the civil and legal rights of people with disabilities in Arkansas.

CALIFORNIA RESOURCES:

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AbilityPath: At AbilityPath, we provide a lifetime of support services for children, adults, and seniors with developmental disabilities and their families in the greater Bay Area.

AbilityFirst: AbilityFirst™ stands for, and alongside, people with developmental disabilities and their families. We create a welcoming environment where everyone feels they belong and are valued. Our first consideration is always for the well-being of our participants, and — through the mutual trust that we share — each person is supported to achieve his or her personal best. At AbilityFirst we look beyond disabilities, focus on capabilities and expand possibilities.

RISE Educational Advocacy: Rise Educational Advocacy was founded on the belief that parents and schools can get high quality training to Build a Better IEP™. With online courses and workshops, Rise simplifies the special education journey for everyone.

List of Free or Low-Cost Special Education Advocates: Below are lists showing advocates who self-certify that they offer Special Education services throughout California at reduced-cost or for free. The lists are broken down first by the areas in which services are provided and then by the age groups for which they provide services.

The Rad Lab | High Quality Programs for Neurodiverse Individuals: The Rad Lab aligns with numerous specialists and connects them to our collaborative projects. Our primary focus is to create high quality programs that enhance the lives of neurodiverse individuals and their loved ones.

Ascent Autism | Online Peer Groups | Help Your Child Socialize: Ascent Autism provides social skills group therapy. We help individuals with autism develop their social skills and grow social and emotional bonds with peers. Our expert-designed program from UCSF and Stanford Medical School has fostered lasting social abilities and friendships for over a thousand participants. Ascent Autism's program curates groups of peers on the spectrum and creates a safe and conducive space for them to practice their social skills in order to unlock deeper social and emotional bonds with one-another - and it works. Made with ❤️ in California, Serving families nationally.

The Self-Determination Program Network: An initiative designed to Inspire, Connect & Empower to make Self-Determination accessible and easier for all Californians.

The Village: An inclusive apartment community celebrating and embracing diversity with opportunities for everyone to thrive and grow.

PATH FORWARD FACILITATION: Path Forward Facilitation guides families through the person-centered planning process who are transitioning from traditional services in the Regional Center system to the Self-Determination Program. Families and participants are provided Independent Facilitation and ushered through the entire transition process.

Education Spectrum: We've pioneered a unique blend of community-based programs to foster individuals' social, emotional, behavioral, communicative, and learning potential by implementing research-based intervention techniques. Virtual and live sessions.

Care Parent Network: Care Parent Network is a dedicated group of professionals who are parents of children with special needs. We give you the information and support to help you be the best advocate you can be for your child. Care Parent Network has been serving families of children ages 0-22 (and even beyond) in Contra Costa County for over 20 years. We offer continuous support to you and your family regardless of your child's age.

Wide Smiles: Wide Smiles was founded more than two decades ago with the aim of providing cleft repair surgery coupled with subsequent comprehensive cleft healthcare to thousands of children in California.

ConnectMed International | Camp Cosmos: Camp Cosmos programs provide positive, inclusive and community-building events and activities for children with craniofacial and other visible differences and their families. We are based in San Diego but offer virtual services for families across the USA and Mexico!

In Home Supportive Services (ca.gov): The IHSS Program will help pay for services provided to you so that you can remain safely in your own home. To be eligible, you must be 65 year of age and over, or disabled, or blind. Disabled children are also potentially eligible for IHSS. IHSS is considered an alternative to out-of-home care, such as nursing homes or board and care facilities. The types of services which can be authorized through IHSS are housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming and paramedical services), accompaniment to medical appointments, and protective supervision for the mentally impaired.

Regional Center Services and Descriptions - CA Department of Developmental Services: Regional centers provide a wide array of services for individuals with developmental disabilities. Each center provides diagnosis and assessment of eligibility, and helps plan, access, coordinate and monitor services and supports. Once eligibility is determined, most services and supports are free regardless of age or income; however, there are a few exceptions. For example, the Parental Fee Program requires that the parent(s) of a minor receiving 24-hour out-of-home residential services be assessed a fee for services

Regional Center Listings - CA Department of Developmental Services

The Speech Solution: To minimize planning and set-up time for speech pathologists, teachers and parents while maximizing a child's therapy time.

Achieve Tahoe | Achieve Tahoe: To provide affordable, inclusive physical and recreational activities that build health, confidence, and independence.

UC Davis MIND Institute: The UC Davis MIND Institute is a collaborative international research center, committed to the awareness, understanding, prevention, and treatment of the challenges associated with neurodevelopmental disabilities. Founded in 1998 by families of children with autism, they envisioned experts from disciplines related to brain development to work towards finding and developing treatments to reduce the challenges and improve the quality of life for individuals with neurodevelopmental disabilities and their families.

A Guide for CA Parents: Special Education Due Process and the Resolution Meeting September 2008 edition (dredf.org): Our goal is to help you work with your school to ensure that your child receives the services and supports he or she needs to succeed academically and socially.

Disability Rights Education & Defense Fund: Disability Rights Education and Defense Fund (DREDF), founded in 1979, is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities.

ONEcaregiver Resource Center - Home: A centralized platform to support caregivers and adults with intellectual and developmental disabilities who may be at risk of, or are living with, Alzheimer's disease or related dementia.

California - Best Buddies International: Offering One-to-One Friendship, Integrated Employment, and Leadership Development programs for individuals with and without intellectual and developmental disabilities (IDD) in California.

Childcare & Preschool – ONEgeneration

INRespite.com: INRespite provides quality companion services to developmentally disabled individuals throughout San Diego to provide respite for their families. Services can be regularly or intermittently scheduled to the family's needs. The caregivers can provide relief anywhere from 2 hours to 8 hours a day. Professional caregivers are often explicitly trained and well-versed in providing care to those in need. Whether the patient is medical fragile, elderly, has emotional outbursts or other needs, a professional caregiver can provide the good services they need to remain happy and healthy. While the primary caregiver takes a much-needed hiatus and a well-deserved break, a professional caregiver will step in to provide quality care that will leave the family at ease.

Helen Bernardy Center for Medically Fragile Children | Rady Children's Hospital (rchsd.org): The Helen Bernardy Center for Medically Fragile Children is a skilled nursing and subacute facility for children and adolescents with multiple medical, physical and developmental delays.

Access Santa Cruz County (scaccessguide.com): This guide is an invitation for Santa Cruz County locals and all visitors with disabilities and special needs to explore the sights, sounds and flavors that Santa Cruz County has to offer. It has been written primarily to meet the needs of wheelchair users, people with developmental challenges, and their caregivers. We've included some resources for people with visual and auditory impairments, but our focus for this guide came from the community that Shared Adventures generally serves. Our goal is to be sure that everyone is accommodated.

Adaptive Baby Care: Difficulties participating in child caregiving tasks can have a significant impact on parent stress, well-being, and mental health. Adaptive Baby Care services are available for parents and caregivers who are experiencing barriers in caring for their children in the ways that they wish. Our services are highly individualized to each parent. Our occupational therapists take their time to get to know each family, understand their goals for parenting, and provide specific techniques, strategies, and equipment to help parents care for and enjoy their children.

Autism Family Network Santa Cruz | Autism Awareness, Acceptance & Activities: Dedicated and committed to Bridging the Gaps within our communities for those individuals on the Autism Spectrum and those with Special Abilities, through creating inclusive and proactive events, while providing educational resources, public awareness and a collaborative network of acceptance for all to reach their untapped potential.

The Friendship Factor: The Friendship Factor was founded on the simple premise that we all need friends, whatever labels we have been given, however awkward our needs. Our mission is to develop and expand an immersive approach to

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raising resilient and empathetic children while advancing the neurodiverse community.

Birth to Five Vision Network: Parents and professionals represent the Network with diversified expertise in visual impairment, early intervention, advocacy, deaf-blindness, orientation and mobility, ophthalmologic research, and optometry. Above all we are guided by insight and wisdom from parents of children with visual impairment with whom we work and support through our activities. The Birth to Five Vision Network continues in our dedication to making information, education, services and support readily available to families and professionals working with young children with visual impairments.

CAM_ResourceGuide_Final_EN_Web.pdf (camarin.org)

Care Parent Network: Care Parent Network exists and strives to provide parent-to-parent support and resources for families of children with special needs in Contra Costa County. We provide emotional support, information, training, resources, and help navigating the service systems. We are a one-stop family resource center serving families of children with disabilities and special health care needs. We help families meet the unique challenges of parenting a child with special needs. Staff members are all parents of children with special needs ourselves. We are here to support you as your child grows and transitions from early intervention to preschool to grades K-12 to young adulthood and beyond. There is no charge for our services.

The Painted Turtle - A SeriousFun Camp, Founded by Paul Newman: The mission of The Painted Turtle is to provide a year-round, life-changing environment and authentic camp experience for children with chronic and life-threatening illnesses. The Painted Turtle supports children's medical needs, inspires them to reach beyond their illnesses, and provides care, education, and respite for their families. All campers and families attend completely free of charge.

Project Sebastian: Our Mission statement is straightforward. Project Sebastian is a hub of information, education, and compassion. We will devote the time and energy necessary to educate, advocate, and provide support to fight all rare diseases. We also feel very strongly about connecting those in need that are suffering from all rare diseases. We will provide support groups for those wanting to discuss, share and connect with others going through the rare disease journey.

Children and Adults with Disabilities - Parents Helping Parents San Jose (php.com): Parents Helping Parents supports, educates, and inspires families and the community to build bright futures for youth and adults with special needs.

Comfort for Caregivers: Comfort for Caregivers is a place to find support, encouragement, and hope for those of you who find yourselves in a caregiving role. These resources are provided by Laura Beth DeHority (California LMFT #114979, Virginia LMFT #0717001987).

Common Ground Society™:When your child is born with a disability or unique need, or recently diagnosed, we like to bring you a welcome tote to the hospital or to your home. Each tote is filled with love, support and the thought that You Are NOT Alone.

Common Roots Farm: At Common Roots Farm, people with disabilities join with others to grow healthy food, beautiful flowers and create friendships that sustain everyone. We grow a variety of vegetables, herbs, fruit, and flowers on our urban farm while providing farm skills training, internships, environmental and gardening education, and micro-enterprise opportunities right in the heart of Santa Cruz, CA.

Community Action Marin, Breaking Barriers, Social Services (camarin.org)

Parents for Change Advocacy Group – Parents Helping Parents (php.com): Parents for Change Advocacy Group is FREE online training empowers parents of young and adult children with special needs to create change in their schools and service systems through community leadership and advocacy. Through six monthly meetings, parents gain advocacy skills and strategies, learn about the legislative process, and discover how to work with decision-makers to influence systems and policy. Parents are provided the tools to impact the issues that matter to them and receive the opportunity to collaborate with other parents as part of this dynamic and supportive action community. Join PHP in building a movement of parent change-makers!

Resources Archive – Parents Helping Parents (php.com): Search 2,700 non-profits, individuals, companies, government agencies, etc. that describe themselves as offering services to the Bay Area special needs community. *Please remember that you are the best judge of which to select for your family.

Developmental Disabilities Programs San Jose Bay Area | Hope Services: Hope Services is Silicon Valley's leading provider of services to people with developmental disabilities and mental health needs. "Developmental disability" means a severe and chronic disability attributable to a mental or physical impairment that begins before adulthood, such as intellectual disability, cerebral palsy, epilepsy, autism, and Down syndrome.

Divine Equine Assisted Therapy Center - Horse, Nonprofit (divineequinetherapy.org): Divine Equine Assisted Therapy

Center helps facilitate the connection between horse and human to provide confidence, belonging, and independence beyond the diagnosis.

Family Resource Centers Network of California | FRCNCA: To support families of children with disabilities, special healthcare needs, and those at risk by ensuring the continuance, expansion, promotion and quality of family-centered, parent-directed, Family Resource Centers.

Family Voices of CA – Children and youth with special health care needs in CA: Family Voices of California is a statewide collaborative of parent-run centers working to ensure quality health care for children and youth with special health care needs.

Genetic Disease Screening Program (ca.gov): The Genetic Disease Screening Program works to protect and improve the health of all Californians. We run the largest screening program in the world and set the standard in delivering high-quality, cost-effective genetic services to all Californians.

Kara - Grief Support: Kara’s mission is to provide grief support for children, teens, families and adults. Our guiding values are empathy and compassion. Every day we provide caring support to children and adults affected by loss and grief. Our vision is to see people of all ages compassionately
LEAP for Infants: To the L.E.A.P for Infants homepage. Learning Experiences and Alternative Programs for Infants, also known as L.E.A.P has been dedicated to promoting the development of children within the context of their families and communities.

Local Resources — SPINSC: The following are available resources in Santa Cruz and San Benito Counties. In some cases your child must meet certain eligibility requirements in order to receive services. Please contact individual agencies for more information about their specific requirements or call SPIN.

Love That Surpasses Ministries: A 501(c)3 partnering with the Lord to rebuild, restore hope, and bring healing to the disability community.

Marin Autism Collaborative: We are a partnership of organizations in Marin aiming to identify gaps in services for individuals on the autism spectrum and their families.

Matrix Parents Network: Matrix Parent Network and Resource Center is a parent-founded, parent-operated nonprofit organization founded in 1983. We are parent-operated by intention and design. All of our services are free, supported through grants, contracts, donations, and fundraising activities. Matrix provides both direct services to

Home | Changing Tides Family Services (changingtidesfs.org): Resource and Referral agencies, like Changing Tides Family Services, are located in every county of the state and provide free services to parents, child care providers, and the community related to information and referrals for accessing child care; improving the quality of care through training and professional development for child care providers; providing technical assistance to anyone pursuing licensing to operate a child care center or family child care home; maintaining a comprehensive database of child care providers in the community; providing consumer and community education about child care issues and supply; and operating as part of community services and information during an emergency.

Jacob's Heart: Jacob's Heart Children's Cancer Support Services provides family-centered care that addresses the emotional, practical and financial struggles for families of children and teens during treatment, families experiencing anticipatory grief and those who are bereaved. Our service area includes Santa Cruz, Monterey, San Benito, and South Santa Clara Counties in California.

supported on their journey through grief so they can move toward renewed hope and meaning. We serve individuals who are grieving a death as well as those managing a terminal illness (their own or another's).

families and technical support services to other federally-funded parent centers. Matrix Parent Network and Resource Center serves Marin, Napa, Solano, and Sonoma Counties.

Miracles for Kids: We’re one of the only organizations on the West Coast that provides monthly financial aid, subsidized housing, and counseling to families fighting for their child’s life.

Mitchell Thorp Foundation: Mitchell Thorp Foundation's mission is to support families whose children suffer from life-threatening illnesses, diseases, and disorders by providing financial, emotional, and resource support to their desperate situations.

Monterey Bay Horsemanship and Therapeutic Center: MBHTC is a 501c3 non-profit therapeutic riding center that offers equine-assisted behavioral modification for all levels of physical and emotional needs. We encourage and enable participants of every ability level to reach their full potential in a safe and nurturing environment. We promote and cultivate community participation in all aspects of our working horse ranch, the barn, and its extended life skills programs. We teach skills that transition to work and independence through both mounted and unmounted equine activities. We serve a range of clients of all ages, including those with autism, Down syndrome, cerebral palsy, MS, and para/quadriplegics.

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One Step Closer | Therapeutic Riding (osctr.org): One Step Closer Therapeutic Riding is an award winning, Premier Accredited adaptive horseback riding program to help the participants achieve their full potential – physically, emotionally, and spiritually – to be all that God intends for them to be. One Step Closer offers adaptive horseback riding and equine-assisted-therapy to individuals with disabilities, and to U.S. Military Veterans.

P3EGS | CSER (cser-consortium.org): The UCSF Program in Prenatal and Pediatric Genome Sequencing (P3EGS) will study the utility of whole exome sequencing as a tool for 1) diagnosing infants and children with serious developmental disorders, and, 2) providing genetic information to parents when a prenatal study reveals a fetus with a structural anomaly.

ParentsCAN - Help for parents of children with disabilities in Napa County: We partner with and guide parents when challenges arise in their child's education, health, behavior or development, so children can reach their full potential.

RAINBOW CONNECTION FAMILY RESOURCE CENTER - Rainbow Connection FRC (weebly.com): Rainbow Connection is a Family Resource Center in Ventura County that serves people with developmental disabilities and other special needs and their families. Rainbow is staffed by parents of children and adults with special needs, we draw from our own experiences. We understand the daily joys and challenges of parenting a child or adult with special needs. Whether you are just starting your journey with a baby in the hospital or you are a family member looking at aging issues for someone with special needs, we are here for you to meet and find support, information and training. We are great listeners and can assist families with problem solving.

Resources Archive – Parents Helping Parents (php.com):Search 2,600 non-profits, individuals, companies, government agencies, etc. that describe themselves as offering services to the Bay Area special needs community.

Ride A Wave: To give children with disabilities the chance to feel the thrill of riding a wave and experience a safe, fun-filled day at the beach, whether they are physically, developmentally or economically challenged.

Salt Water | Grief & Loss Community: Salt Water is for those who have lost someone they can't live without – a child, a sibling, a spouse, a parent, a close friend – and the people who love them. We provide a safe harbor where you can find comfort, support and tools to survive your loss and rebuild your life.

Sandy Feet Initiative: A non-profit organization where the siblings of children with special needs, disabilities and chronic illness receive recognition and support through beach-based programs.

Santa Cruz Playground Project | All Kids Need To Play: a group of volunteers who are working in a public-private partnership with Shane's Inspiration, the County of Santa Cruz, and the Chanticleer Park Neighbors Association to design, fundraise, and build LEO's Haven at Chanticleer Park.

Service Center for Independent Life: A Claremont based non profit organization dedicated to increasing the independence of people with disabilities and seniors. 50% of our staff and board are people with disabilities, providing us a unique insight into how to provide the best services.

Shared Adventures: Here at Shared Adventures, we get people outdoors and moving beyond limitation. A non-profit organization dedicated to improving quality of life for those with disabilities, we believe that recreation, fun, challenge, and access to the outdoors are essential to health and fulfillment.

SNAPkids - Together We Swim: Since 1991, SNAP has empowered children with special needs to exercise, swim, connect with others, make friends and enjoy the gifts of childhood through a community based and accessible adapted aquatics program. SNAPkids gives children with special challenges and gifts a place for their lights to shine brightly, to be respected and included, to exercise, play and have fun! Our volunteers work one-on-one, creating unique bonds with our swimmers and developing insights and sensitivities which ultimately make our communities more accepting and inclusive.

Special Kids Connect | Resources & Awareness of All Disabilities: Special Kids Connect develops resources, raises awareness and provides support to children with disabilities and their families in Monterey County.

SPINSC: In 1985 a group of Santa Cruz County parents of children with special needs began meeting together for support. Through the years parents have continued to maintain the organization that, in 1996, became known as SPIN (Special Parents Information Network). In June, 2000, SPIN became incorporated as a 501(c)(3) nonprofit charitable corporation. SPIN continues to support and provide information about resources to strengthen families.

Support for Families: Since 1982, Support for Families of Children with Disabilities has offered information, education, and parent-to-parent support free of charge to families of children with any kind of disability or special healthcare need.

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The Bay School: The Bay School is a nonpublic, nonprofit school in Santa Cruz, Calif., dedicated to serving individuals with autism and developmental disabilities ages 5-22. It is a school where students establish a strong foundation to build a meaningful life.

The Doyle Foundation, Inc. – Helping for a better world for all: The mission of The Doyle Foundation, Inc. is to promote communities of productivity and prosperity with access to education and advancement. To fulfill this mission, the foundation offers scholarships to enable students at qualifying schools to pursue further education and training at universities, career technical education and trade schools, and community colleges. The foundation also provides grants to nonprofit organizations to support resourceful communities. If you need financial assistance as a means of making "your way" in the world, tell us your story…we're here to help you.

The Equine Healing Collaborative: The Equine Healing Collaborative was created to provide a path to recovery, self-discovery, personal growth, a re-connection with the natural world, and/or emotional insight and health. The Equine Healing Collaborative offers more than just traditional talk therapy and utilizes interventions such as equine assisted therapy, mindfulness, and mindful equine massage to promote health and quality of life for individuals seeking change.

The Western States Regional Genetics Network::The Western States Regional Genetics Network, formerly known as the Western States Genetic Services Collaborative, is a federally-funded, multi-state project that seeks to increase access to genetic services and education for medically underserved populations. The participating states and territory are Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. The Western States Regional Genetics Network, formally known as the Western States Genetic Services Collaborative, is a federally-funded project that seeks to improve access to genetic services and education for medically underserved populations. By working together as a region to increase access to and reduce disparities in clinical genetic and newborn screening services, the participating states/territory seek to improve the health of individuals with or at risk for heritable disorders.

Through the Looking Glass: TLG provides direct services to Bay Area families of infants, children, and youth who have a disability, medical issue, mental health challenge, or developmental concern.

Vista Center for the Blind and Visually Impaired: Vista Center empowers individuals who are blind or visually impaired to embrace life to the fullest through evaluation, counseling, education, and training.

Wayfinder Family Services: Wayfinder Family Services is the place to turn for people facing the greatest challenges. We provide expert, individualized support and services to children, youth and adults, from those who have vision loss or profound special needs to foster youth with serious medical conditions or trauma, and their families.

Welcome to Monarch Independent Living - Santa Cruz, CA (monarchils.com): Our person-centered services are designed to support individuals in becoming more independent, empowered, and actively engaged in their community. Programs of instruction and support are highly individualized and developed around the specific needs and goals of each individual. Support may be provided in the home, in the community, at school or work, or within group classes created around shared interests and needs.

https://www.squarepegfoundation.org/we-turn-i-wish-into-i-can/why-square-peg/

Wheel to Walk Foundation: Wheel to Walk Foundation is a non-profit organization that helps children with disabilities, 20 years and younger, obtain medical & adaptive equipment or therapy services not provided by insurance. Our organization strongly believes that no child or young adult with special needs go without items that could improve the quality of their daily life. If you live in Oregon, Washington, Idaho or California and need assistance, please contact us and we will send you an application.

COLORADO RESOURCES:

Ability Connection Colorado: ACCO provides inclusive education, pathways to employment, and statewide family support programs to create opportunities and sustainable change for families across Colorado. We are a Guidestar best practice organization and work hard to ensure .89 cents on every dollar directly supports thousands of individuals and families every year.

AbleLink Technologies: Since 1997, AbleLink has been focused on one overriding goal: To give people with cognitive disabilities access to everyday technology. Our mobile apps for phones and tablets, desktop software, accessible surveys, and cloud services work together to support independent living and community engagement.

Parker Personal Care Homes: Founded in 1995, we are a well-established organization that provides a large variety of services. The supports that we offer include: Foster Care Supports, Children's Extensive Supports, Supported Living Services, Host Homes, Community Participation Services, Supported Community Connections, Specialized Habilitation, Independent Living Services, and Vocational Rehabilitation Services. We believe that we have one of the most important jobs there is: enhancing the quality of peoples' lives. We take the time to gather the right tools and identify the appropriate resources so that we are enabled to provide individuals ample opportunities to make informed and healthy choices about their lives.

Adapted Physical Education | APE: While physical education may have many definitions, the definition, as it applies specifically to students who have disabilities, appears in the Education for All Handicapped Children Act (PL 94-142) and later within the Individuals with Disabilities Act (PL 101-476). Here, physical education is defined as follows: "The term (physical education) means development of: (A) physical and motor fitness; (B) fundamental motor skills and patterns, and (C) skills in aquatics, dance, individual and group games and sports (including intramural and lifetime sports). (Federal Register 1997, 42480)

Adaptive Programs | Colorado Ballet: Colorado Ballet's adaptive dance program takes our existing Education and Community Engagement programs and, with trained staff, adapts them for students with disabilities. We are available to partner with schools, recreation centers, hospitals, day programs and other community venues to create a program specific for people in your community. In addition, we have collaborations listed below that offer weekly dance classes and other services to people with disabilities.

Additional Educator Resources | CDE: Additional Educator Resources include other areas/topics that are covered by The Office of Special Education. You can also access these resources via the navigation menu on the right.

Angels of Colorado: For more than a decade, Angels of Colorado has provided short-term and long-term respite care to families of children and adults with physical and cognitive disabilities. We offer a wide variety of different services and programs to fit your needs.

Assisted Cycling Tours: Assisted Cycling Tours gives people with disabilities the wonderful gift of cycling. We host cycling clinics, day trips, overnight trips and one-of-a-kind adventures. No previous cycling experience is required.

Care and Community: Care and Community was founded in July 2009 and developed by CEO Becky Bowar when the program needed to expand to accommodate the needs of her clients. Becky has worked with Intellectually and Developmentally Disabled children and adults since 1995. Over the past 17+ years, Becky has been a Direct Service Provider working with families in home, school and community settings.

CDE Standards for Placement of Preschoolers: Preschool-aged children with an Individualized Education Program (IEP) may be placed by the Special Education Administrative Unit (AU) in educational programs they determine meet or exceed the CDE standards for educational programs.

Chanda Center For Health: The Chanda Center for Health's mission is to deliver, advocate & educate for integrative therapy and other complementary services to reduce health disparities and costs by improving health equity and outcomes for individuals with physical disabilities through the support of Chanda Plan Foundation donors, grants, and special events.

Chelsea Hutchison Foundation: is a non-profit corporation formed to provide help and support to individuals, particularly children and young adults, who have epilepsy. Chelsea touched many lives during her short 16 years here and we are amazed at how many people she continues to touch through the foundation even after her passing. Her generous heart longed to see love and care come to others.

Chronic Care Collaborative: The Chronic Care Collaborative (CCC) is made up of 50 different voluntary health organizations representing a wide range of chronic diseases. The CCC is dedicated to improving access to quality, affordable, and integrated healthcare.

Chelsea Hutchison Foundation: The Chelsea Hutchison Foundation serves individuals, families and communities affected by epilepsy by raising Awareness of the common yet little-known condition SUDEP (Sudden Unexpected Death in Epilepsy), by providing support and equipment for prevention of this occurrence, and by creating a safe space and raising awareness within the greater community.

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Child Find Directory for Children Ages 3 Through 5 Years Old | CDE: To search on-line for the local Child Find Coordinator in your area, start by clicking a region link below. If you are unsure of which Colorado school district you live in you can search with your address at Great! Schools.org

Child Find for Children Ages 3 Through 5 Years Old | CDE: Child Find for children ages 3 through 5 years old is part of Colorado's system for identifying children suspected of having a delay in development as early as possible. If a young child is not meeting typical developmental milestones, or someone is concerned about the child's growth or learning, a referral can be made to Child Find. Starting at age three, the public school system (school districts and/or Boards of Cooperative Educational Services) has responsibility for the Child Find process and will work with the family about their concerns, with a focus on meeting the child's educational needs.

CO School for the Deaf & Blind: The Colorado School for the Deaf and Blind (CSDB) is a Preschool-12th grade residential school with post high school education, located just east of downtown Colorado Springs, Colorado

Colorado Adaptive Sports Foundation: The Colorado Adaptive Sports Foundation (CASF) aims to bolster independence, improve self-confidence, elevate social interaction and enhance quality of life through organized team sports. CASF is for people of all ages throughout Colorado who have physical disabilities including spinal cord injuries, spina-bifida, amputations and cerebral palsy.

Colorado Classroom: The new season of Colorado Classroom will feature daily literacy, science and math lessons for K-3 children and their families. New episodes begin September 7 on Rocky Mountain PBS and online.

Colorado Cross-Disability Coalition: Colorado Cross-Disability Coalition (CCDC) is the premier organization in Colorado advocating for disability rights. Our mission is to advocate for social justice for people with all types of disabilities (what we call a cross-disability). Members consist of people with disabilities and our non-disabled allies (coworkers, employers, family members, friends, and neighbors), all working together to support disability rights. Cross-disability means that we believe people with different types of disabilities have more in common than not and that we do best when we work together. We have the most power if all disability groups work together for a common good.

Colorado Developmental Disabilities Council: The mission of the Colorado Developmental Disabilities Council is to advocate for systems change by promoting meaningful person-centered participation, self-determination and inclusion for all individuals with developmental disabilities.

Colorado Disability Organizations | PEAK Parent Center: list of state disability resources in Colorado.

Colorado Disability-Specific Organizations | PEAK Parent Center: list of disability specific organizations in Colorado.

Colorado Early Learning & Development Guidelines

Colorado Early Learning & Development Guidelines: The Colorado Early Learning and Development Guidelines provide practical tips and points of reference that anyone can use to help kids grow physically, intellectually and emotionally. The Guidelines support children with different cultures, languages and abilities.

Colorado Fund for People with Disabilities: The Colorado Fund for People with Disabilities (CFPD) seeks to enhance the independence and quality of life for people who are elderly or disabled and their families. CFPD shall actively evaluate, monitor, oversee, coordinate and implement services in partnership with its clients and their families to ensure and maintain their rights, integrity and dignity.

Colorado Genetic Navigator

Colorado Procedures for Securing Adapted-Format Instructional Materials for Students who are Blind/Visually Impaired or Print Disabled per NIMAS Requirements

Colorado Shines

Connections Colorado: Connections is a Center for Independent Living, an inclusive place where people who live with disabling conditions, and those who are Deaf or Hard-of-Hearing, come together to challenge barriers, become empowered, and live with greater independence. It is our mission to enrich the communities we serve with the self-determination, productivity, and leadership of every citizen.

DOVE:Deaf Overcoming Violence through Empowerment (DOVE) is a 501(c)3 nonprofit established in 2000. With the support of DOVE's Board of Directors, our organization is dedicated to providing advocacy services for Deaf, DeafBlind, DeafDisabled, or Hard of Hearing (DDBDDHH) victims and survivors of domestic violence, sexual assault, and other forms of abuse in Colorado.

Developmental Pathways: We are here to provide support, services, coordinate care, and expand our offerings by partnering with community organizations. Serving all ages, from birth to aging, we want to ensure that all individuals with disabilities in our community receive support.

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Disability Resources | Ability Connection Colorado

Disabled Resource Services – A Center Promoting Independent Living: At Disabled Resource Services (DRS) we focus on helping people with all types of disabilities gain, regain or maintain their independence. A Colorado non-profit agency serving Larimer and Jackson counties, we advocate for change through calls to action for more accessible and integrated communities and we develop partnerships to accomplish more for the greater good of people with disabilities.

Domino Service Dogs-Empowering People, 4 Paws at a Time-Home: It is the mission of Domino Service Dogs (DSD) to assist people with disabilities to train their own service dog, using reward-based training techniques.

Early Childhood Care and Education | Colorado Children's Campaign

Early Childhood Leadership Commission: We improve outcomes for young children birth to age eight and their families by advancing the alignment, coordination, and efficiency of programs and services.

Early Childhood Special Education Services | CDE (state.co.us): Early childhood special education is a state and federally mandated program for three and four year old children who are experiencing challenges in their learning and development and meet state eligibility criteria for special education and related services.

Early Intervention Colorado: Colorado's Early Intervention program provides supports and services to children with developmental delays or disabilities and their families from birth until the child's third birthday. Early Intervention Colorado can help families learn ways to support and promote their child's development within their everyday routines and activities.

Early Intervention Colorado: Early Intervention Colorado gives parents the tools and support they need to help their child learn and grow every day. Early Intervention services are offered at no cost to families, and there are no income requirements to participate. Early Intervention Colorado services can be provided in the child's home, child care center, a relative's home, or another community setting.

Easterseals Colorado: Creating a future where people with disabilities, their families, and caregivers all have the opportunity to thrive and fully participate in our communities.

Familt FTW [For The Win] - Reach Out and Read CO: Family FTW (For The Win) is a text message-based service delivering a new activity or resource for families, like story time videos, whole family activities, and self-care resources for caregivers, in English and Spanish. It's easy for families to feel overwhelmed with information right now, so we're offering a single bite-sized, fun activity via text for families to enjoy two times a week.

Family Support Programs Referral List

Family Voices CO: Family Voices is the Family-to-Family Health Information Center for Colorado.

Family Voices Colorado is a grassroots organization run by parents of children with special healthcare needs.

Find My Local Coordinating Organization | Colorado Department of Early Childhood: LCOs support communities as they participate in the Universal Preschool (UPK) Colorado Program. They help to create partnerships in their community and represent the voice and needs of the community. They also support families and providers in navigating resources.

Find Your Special Education Director in Colorado | CDE : To find your school district, click on the first letter of the district name or scroll below. To visit the school district website click on the district name.

Friends of Paha: Friends of Paha is a non-profit organization comprised solely of volunteers with the goal of raising funds to help financially support Camp Paha. Camp Paha and Paha Adults in Transition are the City of Lakewood's summer day programs for youth and young adults with disabilities.

Garden, Inc.: We start from the ground up by cultivating independence & creating interactive yet nurturing experiences for each individual that optimizes their unique strengths while improving areas of challenge. All of our programs are comprehensive, individually tailored & guided by the principals of Applied Behavior Analysis (ABA) by a team of experienced professionals. Beyond our programming, Garden strives to be a foundation of support for our families and community through outreach & advocacy.

Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

IN! Pathways to Inclusive Higher Education: To create inclusive college opportunities in Colorado for students with intellectual disabilities to foster academic growth, social development, and career advancement.

INFINITY FOUNDATION: Infinity Foundation is a 501(c)3 Colorado nonprofit organization. Infinity Foundation was established in 2015 to support individuals and families of our affiliate GoldStar Learning Options Inc. Our role with GoldStar Learning Options (GLO) is to raise the financial resources necessary for families to access specialized programs, equipment, ensure the continuation of services,

Jewish Family Service: JFS is a nonprofit human services organization that serves anyone in need – regardless of their circumstances or religious beliefs. We believe in a shared responsibility to support impactful changes throughout our

JFK Partners: The mission of JFK Partners is to lead the way in evidence-based interdisciplinary clinical care, education, research, and community partnerships to enrich the lives of children, youth, and adults with Intellectual/Developmental Disabilities and special health care needs.

Kids | Denver Public Library (denverlibrary.org)

Legal and Advocacy Information | Ability Connection Colorado

LuBird's Light Foundation: We have a mission to create extraordinary, one of a kind playgrounds for children and families of all needs and enhance existing playgrounds by adding supported swings!

Medicaid & Waiver Information | Ability Connection Colorado

Medical Resources | Ability Connection Colorado

Meeting the Needs of All Families: Each family is unique, leaving its members to be the only ones to define it – in their way, from their culture and through their truth. For children and youth with mental health needs, the definition is often complicated by circumstances that propel their journey among various living arrangements. The following resources are provided to highlight the unique needs of today's diverse families.

Megan's Place: Provide care for children with physical and developmental disabilities ages 3-18. We offer care after school, evenings, and weekends. We provide summer programs with a variety of activities and field trips.

Mountain StatesMountain States Genetics: To ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and information through facilitating a professional network of genetics clinics, key primary care practices, consumer advocates, and state health department resources.

Night Lights: Night Lights provides quality care for children ages 1 month to 13 years old who have special needs and their neuro-typical siblings under the age of 13, helping

obtain emergency funding, apply for campership opportunities for summer camp participation, and receive other essential services which they would otherwise be unable to secure due to the gaps in funding that exist.

community, We currently offer more than 30 programs and services, including food security, housing stability, mental health counseling, aging care, employment support, and disability service.

parents or caregivers have time to take a bath, go out to dinner, go grocery shopping, run errands, or even just read a book. There is an onsite nurse to tend to medical needs and all of the staff and volunteers are background checked and trained.

Office of Special Education | CDE (state.co.us)

Parent to Parent of Colorado: Connecting families of sons and daughters with disabilities or special healthcare needs to emotional and informational supports.

PASCO Resource Center

PASCO Resource Guide 2023

PASCO: PASCO provides home health care services and supports so that every person may live a fulfilled life in their home and community regardless of disability.

PEAK Parent Center: EAK Parent Center is a 501(c)3 nonprofit organization that has been serving families and self-advocates across the State of Colorado, and beyond, since 1986! Since its inception, PEAK has maintained a steadfast commitment to ensuring that people with all types of disabilities can be fully included in their neighborhood schools, their communities, and in all walks of life.

READ Plans and Students with Disabilities: A Guidance Document: The READ Plan is a general education plan that includes tiered instruction/intervention to be provided within a student's general education program. Under the federal Individuals with Disabilities Education Act (IDEA), which is incorporated into Colorado's Exceptional Children's Education Act (ECEA), an Individualized Education Program (IEP) is a statement of the student's special education and related services [34 CFR 300.320; ECEA Rule 4.03]. Importantly, notwithstanding the statement in C.R.S. 22-7-1206(3), quoted below, nothing in the READ Act makes students with disabilities exempt from or otherwise not entitled to the benefits of the READ Act.

Read With Me: legislation was passed in 2019 to strengthen the law, requiring all K-3 teachers to have training on effective reading instruction. The updated law also requires a public awareness campaign that emphasizes the important role parents and caregivers play in helping children learn to read.

RESOURCES – Megan's Place: Below you will find various resources that are available in Denver and Colorado for people with disabilities and their families.

Respite Care, Inc.: Respite Care, Inc. is a nonprofit organization in Larimer County that provides short-term, quality care for children with developmental disabilities and respite to their families, enabling them to enhance their quality of life.

Respite Navigation Guide - Colorado Respite Coalition: The Colorado Respite Coalition has created this guide to help families and professionals navigate the respite system and caregiver supports in Colorado.

Rocky Mountain ADA: The Rocky Mountain ADA Center is proud to serve individuals and organizations throughout Colorado, Utah, Montana, Wyoming, North Dakota, and South Dakota.

Rocky Mountain Human Services: Rocky Mountain Human Services is a nonprofit organization that empowers people with the resources they need to thrive, and to live the lives they envision in their communities of choice. With a staff of nearly 500 talented and dedicated employees, we support more than 15,000 Colorado residents through case management and direct service programs.

Roundup River Ranch: Roundup River Ranch provides free, year-round programs and camp experiences to all children with serious Illnesses and their families from the extended Rocky Mountain region. Our campers experience the true joys of childhood through old-fashioned camp fun as they make friends, try new activities and simply be happy, worry-free kids. Parents have the peace of mind of knowing that our camp is a respectful, safety-conscious, medically-supported place, staffed by incredible employees, volunteers and renowned medical professionals. We also offer a welcoming place for the entire family to join in the fun and live in the happiness of the moment. Roundup River Ranch is a positive, long-lasting, life-enhancing experience for campers, their families, volunteers, staff, and the community. Through camp programs, we help children and families create a world of possibilities.

Secondary Transition Resources | CDE (state.co.us)

Self-Care Education - Care Partners Resource: Offering caregiver self-care education using mindfulness and therapeutic writing to help you practice consistent self-care.

Significant Support Needs (SSN) | CDE (state.co.us): Students with significant support needs are highly diverse learners with extensive needs in the areas of cognition and/or learning, communication, movement and social/emotional abilities. The individual may also have concurrent health, sensory, physical and/or behavioral disabilities.

Social Security Work Incentive Planning and Assistance (WIPA) | Ability Connection Colorado: The WIPA program is a community-based organization that receives funding from Social Security to provide all Social Security Disability Income (SSDI) and Supplemental Security Income (SSI) disability beneficiaries (including transition-to-work age youth) with FREE access to work incentive planning and assistance. Ability Connection Colorado is the only nonprofit approved to provide benefit counseling services through the Social Security Administration program.

Social Skills Groups and Camp• Testing • Counseling | Craig Knippenberg: Specializing in the Testing and Treatment of ADHD, Learning Disabilities, Anxiety Disorders and Autism Spectrum Disorders (ASD) of Childhood and Adolescents.

SPEAKout Blog | PEAK Parent Center

Special Education and UPK (peakparent.org): This document was developed in response to questions related to preschool special education and universal preschool (UPK). The Colorado Department of Education (CDE) is responsible for administering special education, while the Colorado Department of Early Childhood (CDEC) is responsible for administering UPK. These answers were developed by CDE with consultation from CDEC.

Special Needs Child Care and Nanny | Specialized Sitters: Offering in-home care for children with emotional, behavioral, and mental health needs. If you've struggled to find a patient and qualified caregiver for your family, we're here to help.

Stepping Stone Support Center :To meet the needs of individuals with intellectual and developmental disabilities in an authentic and creative way.

The Thrive Center: Colorado's ONLY Community Parent Resource Center (CPRC) &Family-to-Family Health Information Center.

The Traveling Gnomes: The Traveling Gnomes offer inclusive, accessible, and sustainable travel experiences locally and globally for neurodivergent and disabled adventure-seekers.

The West Denver Renaissance Collaborative (mywdrc.org)

Created by: Sierra Phillips @mrs.phillijt
Transportation Services for Preschool Children with Disabilities

Welcome to the Two Angels Foundation!: Having a child with special needs can be challenging and it is the goal of the Two Angels Foundation to help with some of the struggles and make a difference in the lives of these children by helping families purchase adaptive bikes for children living in Colorado.

Where Do I Start? | Ability Connection Colorado: We designed our "Where Do I Start?" Series (also called Quick Resource Guides) to help you in your journey or for you to share with others who may also need support!

Year 6 Genetic Navigator Outreach Presentation (canva.com)

YELD Program | Young Emerging Leaders for Disability Power: The Young Emerging Leaders for Disability Power program brings together a diverse group of young members of the disability community to explore and advance disability rights. If elected for this opportunity, you will develop skills to practice leadership, advocacy, community organizing and civic engagement to make real change in your local communities. Participants will receive a $500 stipend for their participation AND completion of the program.

CONNECTICUT RESOURCES:

Yale Center for Mendelian Genomics: The Centers for Mendelian Genomics will apply next-generation sequencing and computational approaches to discover the genes and variants that underlie Mendelian disorders. The discovery of new genes that cause Mendelian conditions will expand our understanding about their biology to facilitate their diagnosis, and potentially indicate new treatments. The Centers for Mendelian Genomics will provide free exome sequencing and analysis to collaborating investigators for qualified phenotypes.

Rewarding Work: Rewarding Work, an affiliate of TILL, Inc., helps individuals and families hire caregivers and provides a free resource for job seekers. Rewarding Work currently operates in Connecticut, Kansas, and Massachusetts.

Connecticut Leadership Education in Neurodevelopmental and Related Disabilities: The Connecticut Leadership Education in Neurodevelopmental and Related Disabilities (CT LEND) is one of 52 LEND programs across the country that focuses on the training of future leaders from a wide variety of professional disciplines in order to improve the health care delivery system for children with autism and other neurodevelopmental disabilities.

Home | Center for Excellence in Developmental Disabilities Education, Research and Service (uconnucedd.org)

Connecticut | RareAction Network: The mission of the RareAction Network® (RAN) is to connect and empower a unified network of individuals and organizations with tools, training, and resources to become effective advocates for rare diseases through national and state based initiatives across the United States.

Elea: For Parents and Providers of Children with Developmental Disabilities: Elea's mission is to enable parents and providers of children with developmental disabilities to coordinate services and manage their child's care. Elea believes care coordination should be efficient, centralized, and easy to understand. Elea's vision is to modernize families' care coordination across healthcare, educational and community providers. We seek to empower families' with the knowledge and resources necessary to advocate for their children.

The Center for Children with Special Needs: CCSN is an interdisciplinary clinic specializing in the diagnosis, evaluation, and treatment of children, adolescents, and adults with complex developmental and neurological disabilities.

Adaptive Dance Greenwich

Disability Organizations | Center for Excellence in Developmental Disabilities Education, Research and Service (uconnucedd.org): Local & National Disability Organizations.

New England | Autism Speaks: Serving all communities in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism, and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

Adaptive Dance Program - Eastern Connecticut Ballet: Eastern Connecticut Ballet's SHINE (Support and Highlight Inclusion through New Experiences) Program is designed for differently-abled children and adults ages 4 and up. In this program, students will experience a welcoming environment in which people of all abilities can gather to express themselves through dance. We utilize a structured curriculum based on Boston Ballet's Adaptive Dance model, which encourages fine and gross motor development. Students will develop musicality, expression, coordination, and strength. With the help and guidance of volunteer occupational and physical therapists, faculty and volunteers are able to modify the class to accommodate each child's physical and developmental strengths and needs.

Joey's Fund Grant Program | Spectrum for Hope Fund | Flutie Foundation: Today, Joey's Fund serves as a crucial funding bridge for autism families who are advocating, promoting, supporting and seeking out opportunities for their loved ones. Since its inception, 193 families have received over $375,000 in financial support, making their journey just a little bit easier. Must have one family member medically diagnosed with Autism Spectrum Disorder and reside in New England (Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire & Maine). Families are only eligible to apply if they have not received funding in the previous year.

D.C. RESOURCES:

About Us - Children's Charities Foundation (ccfdc.org):

DC Learners and Earners | dds: DC Learners and Earners (DC L&E) initiative was funded from 2016-2022 through the Administration for Community Living's Partnerships in Employment Systems Change (PIE) grants as a new Project of National Significance. DC L&E aimed at improving employment outcomes for youth and young adults with an Intellectual or Developmental disabilities.

Sevita Home and Community Based Health Care: Sevita, formerly The MENTOR Network, is the leading provider of home and community-based specialty health care, with 45,000 employees proudly serving over 55,000 individuals. We believe that people can grow, learn, and be as independent as possible in the homes and communities where they live. We serve adults and children with intellectual and developmental disabilities, individuals with complex care needs, people recovering from brain injury, children in foster care, adults and children with autism, and other individuals who may require care across a lifetime. Our goal is to enable these individuals to be as independent as possible and to live and thrive in their communities. It's what we've done for more than 50 years, and it's what we continue to do today.

University Center for Excellence in Developmental Disabilities (georgetown.edu): Welcome to the University Center for Excellence in Developmental Disabilities (UCEDD) at Georgetown University. The mission of the Georgetown University Center for Excellence in Developmental Disabilities is to advance self-determination among the diversity of people with developmental and other disabilities and their families, throughout the life course, and advocate for their full participation in all aspects of community life.

National Genetics Education and Family Support Center: The National Genetics Education and Family Support Center (Family Center) works to increase access to genetic services by promoting and strengthening family engagement in the genetic healthcare delivery system.

Quality Trust for Individuals with Disabilities: Quality Trust is an independent, non-profit advocacy organization focused on improving the lives of children and adults with disabilities and their families in the District of Columbia and beyond. We work with people and their family members to solve problems, identify opportunities for learning and contribution, Quality Trust looks for creative ways to minimize differences and make the most of each person's abilities.

Family Ties of DC | FTDC: Family Ties of DC (FTDC) is a unique parent-to-parent support program that matches a Support Parent who has child(ren) with disabilities with the Referred Parent, who is seeking emotional support, information and resources from someone who has travelled their path. Parenting is one of the most important full-time positions in the world and includes times of being overwhelmed, lonely, and fearful which is the reason that you need someone who you can share and connect about the similar life experiences from a parent with a listening ear.

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Family Ties of DC | Parent Match Request Form: There is a solution available in DC. The Family Ties of DC (FTDC) is an unique parent-to-parent support program designed to match a parent seeking support (Referred Parent) to an experienced parent (Support Parent) who can provide free and confidential support, information, and connection.

HOPE FOR GRIEVING FAMILIES - Home: Our mission is to support and connect grieving families with children in the Greater DC area. We are different from other grief support organizations as we focus on providing fun, family-oriented events, as well as a network of support for families who have experienced a loss of a close family member. We also help connect families with agencies that provide grief counseling and professional services.

Steel Magnolia Moms - A Special Place For Special Moms: Many support groups within the special needs community are diagnosis centric for the purpose of discussing the children's needs. Steel Magnolia Moms, however, focuses on the Mom. Steel Magnolia Moms reminds these moms to take time out of their hectic schedules to focus on themselves. We share our knowledge and resources, but more importantly, we encourage moms to take a break, have fun, and connect. Local Chapters in D.C., Houston, and Austin.

Capital Counseling | Child Grief Counseling: For nearly two decades, Capital Caring has embraced grieving children and teens by offering grief support through specialized bereavement programs held in individual Capital Caring neighborhoods across the MD, VA and the D.C. metropolitan region. At Capital Caring Kids, we offer grief counseling, support groups and special bereavement programs to not only help our Capital Caring families, but to assist anyone in the community who is struggling with loss in safe and supportive environment.

Easterseals Child Development Center – DC: The Child Development Center in Washington, DC has been serving families in the community since 1959. This inclusive early care and education center is accredited by the National Association for the Education of Young Children (NAEYC) and provides exceptional services for children with and without disabilities and their families in the Columbia Heights community.

Bridging Hands Camps | Where communication differences don't make a difference (bhcamps.org): Bridging Hands Camps, Inc. provides day and overnight camp experiences for deaf/hard of hearing children, and children of deaf adults. Our camps promote communication access and positive interactions between various groups within the diverse, multicultural, and multilingual deaf community.

Jill's House | Respite Care: Jill's House is a Christian non-profit that provides short-term, overnight respite care for families raising kids ages 6-17 with intellectual disabilities in the DC metro area, and around the country. Parents regularly receive 24-48 hours to rest and recharge, while their kids are engaged in fun activities, tailored to their interests and abilities.

thehospicealliance.org: Alliance Kids is the Mid-Atlantic regions collaborative voice and provider of high quality, compassionate pediatric hospice care serving children and young adults in the place they call home. Through our website, we can help anyone with a life-limiting illness to a pediatric palliative and hospice expert. Our vast provider network includes experts across Maryland, Delaware, Washington D.C. and Northern Virginia.

Camp Forget-Me-Not / Camp Erin DC - Wendt Center: program dedicated to providing fun, supportive opportunities to young people to explore feelings, thoughts and life changes since the death of their loved one.

Wendt Center for Loss & Healing | Washington DC: With nationally recognized expertise, the Wendt Center for Loss and Healing is a premier resource for restoring hope and healthy functioning to adults, teens and children who are coping with grief, loss and trauma in the Greater Washington region.

Variety DC – The Children's Charity: Variety of the National Capital Region (Variety DC) serves families in Washington DC, Maryland and Virginia, with a special focus on children with mobility disabilities. By partnering with individual supporters, corporate donors and community foundations, Variety DC provides financial grants and life-changing adaptive equipment to meet the basic needs of these special families.

Let's Move Mountains: I founded Let's Move Mountains in Fall 2021 in an effort to try and bring CME and intensive style therapy to more people in a more convenient manner. At this time it is a in the client's home style of therapy. For 2023 I will no longe be offering my traveling intensives. I will also be switching to a more intensive based schedule versus a mix of weekly and intensives. I am able to offer intensives to local to me DMV families as well as those who have the ability to travel to the greater metro DC area.

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DELAWARE RESOURCES:

Hear Our Voices – Hear Our Voices, Inc. is a Delaware non-profit, member corporation established for the benefit of disabled and special needs children.: Hear Our Voices, Inc. seeks to achieve a better education and life for disabled and special needs children and their families. Join us and make your voice heard today.

thehospicealliance.org: Alliance Kids is the Mid-Atlantic regions collaborative voice and provider of high quality, compassionate pediatric hospice care serving children and young adults in the place they call home. Through our website, we can help anyone with a life-limiting illness to a pediatric palliative and hospice expert. Our vast provider network includes experts across Maryland, Delaware, Washington D.C. and Northern Virginia.

INCLUSIVE PLAYGROUNDS - Inclusive Playgrounds: As exclusive representatives for Landscape Structures, we are able to offer our clients outstanding inclusive playground designs and products. With a wide variety of products, and regular innovation in this product category, Landscape Structures is the leading designer and manufacturer of inclusive playground equipment. Committed to creating play spaces available to all ages and abilities, together we are the go-to local sales agency for inclusive playgrounds in PA, NJ and DE.

fabricATe: Our mission is to address the issue of access to no-tech/low-tech assistive tools for individuals with disabilities and/or developmental delays.

NJDEP| Green Acres | Local and Nonprofit Assistance Program: Green Acres provides grants and low interest (up to 2%) loans to municipal and county governments to acquire open space and develop outdoor recreation facilities. Green Acres works with local governments from the time of application through project completion. Over 80,000 acres have been protected and hundreds of recreation development projects throughout the state have been financed through Green Acres' Local and Nonprofit funding program.

FLORIDA RESOURCES:

FAAST, Inc. - Florida Alliance for Assistive Services & Technology

Becket: Becket's mission is to create opportunities for individuals to live better lives by aligning inspired professionals who are supported and trusted to be a compassionate team with family caregivers and community resources.

LifeConnections Specialized Support Services: LifeConnections Specialized Support Services was created in 2018 as a subsidiary of Becket Family of Services with a goal to create specialized service options for people with complex behavioral health and/or medical needs who were at risk of moving out of state or to higher levels of care due to the lack of service options. Today, we serve youth and adults of all ages in various settings and States, including; Maine, New Hampshire, Massachusetts, Rhode Island, South Carolina and Florida. We are nationally accredited by the Council on Accreditation and are proud members of the National Alliance for Direct Support Professionals.

Camp Boggy Creek: Since 1996, Camp Boggy Creek has made it possible for children with serious illnesses to enjoy a camp experience in a safe, medically- sound environment. Located just a short drive from Orlando, Florida, the 232-acre Camp serves children ages 7-16 who've been diagnosed with a serious illness. As a year-round retreat, Camp Boggy Creek is able to serve thousands of campers and their families through activity-packed weekly and weekend camp programs.

Lighthouse Family Retreat: Lighthouse Family Retreat is a faith-based non-profit that exists to strengthen every family living through childhood cancer. We host restorative retreats and develop helpful resources so that families and their support systems can find hope in God and help in their fight

Deliver the Dream | We help families with serious illness, crisis or disability: Deliver the Dream provides therapeutic programs to special populations including families facing a serious illness, crisis or disability. Most of our participants live in the state of Florida, however, we serve families throughout the United States. Our programs restore hope, strengthen relationships and change perspectives to provide inspiration for the future.

The Family Cafe | Annual Conference: The Annual Family Cafe brings together thousands of people with disabilities and their family members for three days of education, training, and networking each year. The event features a great range of individual breakout sessions, a packed Exhibit Hall with dozens of vendors, and a series of special events including Keynote speakers and The Governors' Summit on Disabilities, The Annual Family Café offers families exposure to a range of public and private resources on a grand scale, opportunities to find support by networking with other families, and unprecedented access to policy-making officials.

Mark's Mission: We provide Financial Assistance, Family Bonding, Sibling Support, Mental Health, and Transportation Services to NICU and PICU families in Northeast Florida.

Myles' Message: Myles' Message is a registered 501(c)3 nonprofit organization that empowers parents by providing accurate resources and a supportive community so that their child with Down syndrome may reach their fullest potential while celebrating each child's worth so they may thrive in a world without limits.

Resources | Myles' Message (mylesmessage.com): Fort Myers Area and State of Florida Resources recommended by Mylee's Message.

The Imprint Project | Myles' Message: The words medical professionals use to deliver a Down syndrome diagnosis are forever imprinted on a parent's heart. The Imprint Project helps professionals deliver this diagnosis in a more accurate and hopeful way.

Family Retreats - Deliver the Dream: Deliver the Dream's Family Retreat program is our most popular and longest-running program. During a Family Retreat, families will participate in therapeutic structured activities, such as indoor and outdoor recreational activities, discussion groups, interactive games, creative workshops, and team building exercises. Ample time is provided for relaxation, connecting with new and supportive friends, and spending time with your loved ones. Each retreat is based on a specific population and is a three-day, two-night weekend experience. The Family Retreat program is intended to be a one-time experience which will allow us to maximize our impact and reach more families

Easterseals Serving Southern Georgia and the Big Bend of Florida: Easterseals provides exceptional services, education, outreach and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities.

Deaf Empowerment Program - CIL Jacksonville: The Deaf Empowerment Program provides services to people who are d/Deaf or hard-of-hearing. The program is designed to assist individuals with hearing disabilities reach their goals for independence.

CIL Jacksonville - Empowering People with Disabilities: CIL Jacksonville empowers independence for people with disabilities through its programs and services. Each person with a disability receives individualized, self-directed services to achieve their unique independent living goals.

Wheelchairs 4 Kids: Wheelchairs 4 Kids is a nonprofit dedicated to improving the lives of children with physical disabilities by providing wheelchairs, home and vehicle modifications as well as other assistive equipment at no charge to the families through our Let's Roll Program. We also have an inclusion program called Wheely Fun Days! We take the kids out for fun adventures such as going to the Bucs Training Camp and WWE events. We even take them indoor skydiving, zip lining and water skiing using adaptive equipment.

Health & Medicine - Schulze Family Foundation: We invest in health & medicine projects that reduce human suffering and advance medical science.

Project 10: Transition Education Network: The mission of Project 10: Transition Education Network, hereinafter referred to as "Project 10," is to assist Florida school districts and relevant stakeholders in building capacity to provide secondary transition services to students with disabilities in order to improve their academic success and post-school outcomes. Project 10 serves as the primary conduit between the Florida Department of Education (FDOE), specifically the Bureau of Exceptional Education and Student Services (BEESS), and relevant school district personnel in addressing law and policy, effective practices, and research-based interventions in the area of transition services for youth with disabilities.

Kesher Academy: Kesher's vision is to be the model and comprehensive resource in the provision of special needs education within Jewish schools. Kesher's mission is to provide, and guide other schools in providing, an education in both Jewish and secular studies to meet the needs of the individual student and empower each student to reach his/her highest level of independent and interdependent functioning.

Children's Ability Center - JAFCO: JAFCO is committed to serving all children, from birth to age 22, who have been diagnosed with a Developmental Disability including Autism

Spectrum Disorder, Intellectual Disability, Cerebral Palsy, Spina Bifida or Prader Willi, developmental delays and those at risk.

Child Enrichment Services - JAFCO: Children with developmental disabilities often don't have the opportunity to engage in social and recreational activities with their peers. We recognize how important these activities are in your child's life to help learn social and life skills, build self esteem, make new friends and just have fun. Your child will be welcome to participate in appropriate enrichment programs.

Respite Services - JAFCO: Many parents and caregivers of children with developmental disabilities report feelings of isolation and are unable to participate in social and recreational activities. We understand that all of your focus is on your child, but parents and caregivers also need time to relax and renew. We provide a few hours, a full day or an extended stay of respite.

Christopher Douglas Hidden Angel Foundation – Multi Sensory Environments, Sensory Stimulation (cdhaf.org): Christopher Douglas Hidden Angel Foundation's primary goal is to promote the use of multi-sensory environments in therapeutic, recreational, and educational settings with the intent of enriching the lives, health, and social well-being of individuals with cognitive, emotional, and physical impairments. We aim to enable productivity, inclusion, independence and self-determination. Our focus is on the design, development, and implementation of Multi Sensory Environments. We support innovative initiatives that demonstrate new approaches to advance education,

https://www.abilitytree.org/

Hidden Angel Companion Pets Program (cdhaf.org): The vision for the 'Hidden Angel Companion Pets' Program, is to develop and place companion dogs to enrich the lives of people with various challenges. Central to the vision is a foundational understanding of sensory stimulation, which is the backbone of the Christopher Douglas Hidden Angel Foundation. Sensory stimulation plays a role in the benefits of the human-animal interaction (to both the humans and the animals) and in how the dogs are developed during the program and beyond.

https://paleyinstitute.org/blog/physicians/matthew-dobbs/?fbclid=PAAaY1UvEd-1GACCCwbBRItvFn2Poh47d_AMRESeCcBwrcei_zNPazyL2t3f0#/

GEORGIA RESOURCES:

A Friend of the Family | Special Needs Childcare: Whether you have an infant, toddler or school-aged child, A Friend of the Family can come to your home and provide expert care. We've been serving families throughout Georgia, North Carolina and South Carolina for over 30 years. They provide special needs care too.

Achievement Center: Our Mission is to provide vocational development services and extended employment programs for individuals with physical, mental and developmental disabilities and for persons without disabilities who are culturally, socially or economically disadvantaged; to assist them in obtaining competitive or extended employment; to help maximize their independent living skills; and to equip them to live at the highest possible level of independence within the community. Serving Opelika, Alabama and Georgia Counties.

Annandale Village: Annandale Village is the only non-profit residential community in the entire southeastern United States that serves adults with developmental disabilities and acquired brain injuries at all levels of care throughout an individual's lifetime.

Walton Foundation: The Mission of the Walton Foundation for Independence is to inspire philanthropy to support programs and services that create an inclusive lifestyle for people with disabilities in our community to live, work and play.

Extra Special People, Inc.: ESP serves participants beginning at birth and with no upper age limit, welcoming participants with diagnoses of Cerebral Palsy, Down syndrome, Autism, Traumatic Brain Injury, Spina Bifida, and many more. Here at

ESP, participants are never turned away because of their ability. Our specialized programs enable our participants to thrive with swimming, dancing, arts and crafts and cooking; family support, retreats, dinners, counseling, and holiday events.

Camp Kudzu | Serving Teens and Children Living with Type I Diabetes: Camp Kudzu is a nonprofit organization serving children, teens, and their families living with type I diabetes(T1D). The life-altering diagnosis of type I diabetes can be isolating and overwhelming- adding new and critical things to a child's daily routine. Day-to-day diabetes management requires the entire family, from checking blood sugar, counting carbohydrates, dosing insulin, and adjusting for physical activity. Camp Kudzu supports over 1,400 children, teens, and their families by providing camping experiences and educational opportunities at various camps in Georgia.

Camp Sunshine: Camp Sunshine enriches the lives of Georgia's children with cancer and their families through year-round recreational, educational and support programs. Camp Sunshine is committed to providing opportunities for normal development for all children with cancer throughout their journey and bringing together those with similar experiences to share and draw strength from one another amid common understanding.

Camps for Kids | Children's Healthcare of Atlanta (choa.org): Our diagnosis specific camps are 6-day, 5-night sleepaway camps. For many kids, summer camp is a rite of passage. At our camps, kids with a chronic illness, disability or other life challenge can connect with other kids who understand the struggles they face, all while participating in fun, traditional camp activities. Camp is a place where kids can get back to just being kids.

ATL Inclusive: A Special Needs Resource Guide - Atlanta Parent

Disabilities Ministry | St. Catherine (stcatherinercc.org): An evening of fun and socialization for individuals with disabilities as well as an opportunity for respite for parents and caregivers. All ages and levels of disability are welcome. Participants must provide their own transportation. Fun Night! meets the second Friday of each month from 6-9p.

Babies Can't Wait | Georgia Department of Public Health: Babies Can't Wait (BCW) is Georgia's early intervention program that offers a variety of coordinated services for infants and toddlers with special needs, from birth to three years of age, and their families. Part C early intervention builds on and provides support and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities.

Bert's Big Adventure: Established in 2002 by Bert Weiss, host of the nationally syndicated morning radio show, "The Bert Show", Bert's Big Adventure is a 501(c)(3) nonprofit organization that provides a magical, all-expenses-paid, five-day journey to Walt Disney World® for children with chronic and terminal illnesses and their families. To qualify for Bert's Big Adventure, children must be between the ages of 5 and 12, live in "The Bert Show" radio listening area (Atlanta), prove financial need and have never been to Walt Disney World®.

Blue Skies Ministries: Our mission is to bring the hope of Christ to families living through the challenges of pediatric cancer so that children who are sick will laugh and play and feel "normal" again; that siblings, who often compete with cancer, will feel cherished and get to have uninterrupted family fun; that moms and dads will grow strong and begin lifelong friendships with others on Kindred Journeys; and, most importantly, that everyone at Blue Skies will experience the love of our Heavenly Father.

Bobby Dodd Institute: By embracing people of differing abilities, we can create a more inclusive community where each person's unique strengths are empowered and employed.

Camp Blue Skies: For over 10 years, Camp Blue Skies has provided camps to adults with developmental disabilities and enhancing their lives through recreation, socialization and life skills education. Our camps are held in the spring and fall in Georgia, North Carolina, and South Carolina. At Camp Blue Skies, people who are 21 and older with developmental disabilities will enjoy recreational activities indoors and outside, along with lots of fun and friendship.

Camp MAGIK: Camp MAGIK provides a safe, nurturing environment where children can express their grief over the death of a loved one and begin the healing process. Campers not only get counseling from professionals but also experience real healing from being around other kids who have faced similar losses. And because it's a camp, kids also get to be kids and participate in typical camp activities like canoeing, ropes courses, hiking, and more! Camp MAGIK is held three times a year and there's no charge for kids to attend.

Camp Trach Me Away: Just because a child is dependent upon a ventilator and or other equipment does not mean he or she can't experience all the fun of summer camp. Camp

Created by: Sierra Phillips @mrs.phillijt

Trach Me Away, offers children with tracheostomies the chance of a lifetime to be a kid at a summer camp with other children who also have tracheostomies. Our summer camp provides a chance to make fond memories and lifelong friendships in a medically safe environment. The weeklong overnight camp is held in Rutledge, Georgia under the attentive supervision of medical professionals. Through generous donations Camp Trach Me Away is free to children ages 7-18.

Disabilities Ministry - Roman Catholic Archdiocese of Atlanta | Atlanta, GA (archatl.com)

Toni's Camp Retreat - Roman Catholic Archdiocese of Atlanta | Atlanta, GA (archatl.com)

Special Needs Ministry (sjnlilburn.com): The Special Needs Ministry is so proud of St. John Neumann Parish for being selected in 2014 to receive the Loyola Press Opening Doors Award for its physical accessibility and inclusion of individuals with disabilities in its parish life. More about this award, and a link to a video about the accessibility of the building can be found by selecting/clicking here. Long before our ministry was even started, much work went into making this parish a welcoming place for people of all abilities

Outreach Commission | Saint Joseph Catholic Church (saintjosephcc.org): FUN NIGHT! is an evening of fun and socialization for children and adults with disabilities. By gathering volunteers with children and adults with disabilities, it builds community by having the opportunity to participate in fellowship. It also provides an opportunity for respite for parents and/or caregivers. FUN NIGHT! is open to any child or adult with a disability, regardless of religious affiliation.

Camp Twin Lakes: For almost 30 years, Camp Twin Lakes has delivered fully adaptive, medically supportive, and deeply impactful camp experiences to more than 10,000 of Georgia's children and young adults each year, helping each camper grow in their confidence and experience the joys of childhood. Through intentional play, we develop mindful and confident children who are prepared to triumph over challenges. By learning perseverance, resilience, and a sense of community, our campers leave transformed and capable of extraordinary things.

Camp Journey: Camp Journey is Spectrum's overnight camp focused on social skills, building friendships, teamwork, manners, and self-esteem. Camp activities include directed social skills instruction in a typical overnight camp setting. Campers enjoy hot meals prepared each day, heated and air-conditioned cabins, and a variety of typical overnight camp activities. Activities may include swimming, hiking, fishing, archery, climbing, canoeing, sports, and more depending on the weather.

Camp Twitch and Shout: Camp Twitch & Shout is a one week overnight camp for children 8 to 17 years of age who have been diagnosed with Tourette syndrome or Tic Disorder. Our Leader In Training program is available to 17 year olds with tics who are interested in eventually becoming a counselor. Camp is organized and managed by Tourette Information Center and Support (TICS), in partnership with Camp Twin Lakes, and is located at Camp Will-A-Way in Winder, Georgia.

Champions for Children: Since the program's inception, Champions for Children has had a clear mission and vision. We help Georgia's medically fragile and special needs children realize their full potential and enjoy a state of well being, including being cared for by their families at home. Additional program goals are to increase awareness throughout Georgia about non-profit services available to medically fragile and special needs children and increase access to healthcare and support services.

Children 1st | Georgia Department of Public Health: Children 1st is the single point of entry for all DPH Child Health programs and services for children, birth - 5 years old, and links eligible children to early intervention services, as well as other public health programs and community-based resources.

Children's Medical Services (CMS) | Georgia Department of Public Health: The Children's Medical Services (CMS) program supports families caring for children with special health care needs. CMS works with healthcare providers and community partners to make sure children and youth with chronic medical conditions have access to timely and quality healthcare services.

Cumberland Academy of Georgia: Autism School Atlanta: Cumberland Academy of Georgia is a fully accredited private school specializing in the needs of children with Asperger's Syndrome, ADD, ADHD, high functioning autism, PDD-NOS, and learning disabilities. Cumberland accepts Georgia Special Needs Scholarship (SB10) and provides need-based GOAL Scholarship funding. We educate students from grades 4th through 12th.

Destiny's Child Inc.: Get quality care for your loved ones today. Destiny's Child Inc. (DCI), located in Atlanta, Georgia, provides in-home community living support for the intellectually disabled.

Developmental Disabilities - DeKalb Community Service Board: DeKalb CSB is dedicated to improving the health and independence of people with disabilities and creating a life with opportunities for everyone. We provide a variety of educational, therapeutic and behavioral support services to individuals, ages 21 and up, and their families. Our programs are designed to provide opportunities for individuals to maximize their independence, increase skills and live meaningful lives.

Developmental Disabilities Ministries | Where Hope Lives (ddmga.org): DDM is a nonprofit, charitable corporation serving adults with developmental disabilities and their families. DDM owns/operates 18 group homes in the State of Georgia, serving approximately 70 residents.

Disabled | Georgia Medicaid

Division of Family & Children Services | Georgia Department of Human Services: The Division of Family & Children Services provides numerous support services and programs to help Georgia families and children in need.

Donate A Car To A Nonprofit (careasy.org)

Early Hearing Detection and Intervention | Georgia Department of Public Health

Easterseals Serving Southern Georgia and the Big Bend of Florida: Easterseals provides exceptional services, education, outreach and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities.

Emmy's Academy: We provide an early learning environment with low student to teacher ratios. We accept all children regardless of diagnosis or special circumstances ages 6 weeks through 6 years old. We offer a tailored experience where all children have access to work on their therapy goals throughout their day.

Equipment Program | FOCUS: FOCUS's Equipment Program offers an opportunity for families to provide their children with equipment to improve their quality of life. The three divisions of the Focus Equipment Program are our Loaned Equipment Library, our Beach Wheelchair Rental Program, and our Equipment Grant Program.

Experience Camps: Experience Camps is an award-winning national nonprofit that transforms the lives of grieving children through summer camp programs and innovative, year-round initiatives. Through compassion, connection, and play, we allow grieving children to embody a life full of hope and possibility. By amplifying their voices, we are creating a more grief-sensitive culture.

Extra Special Saturday Respite | FOCUS: ESS is a wonderful time for the children to enjoy free play, music therapy, and extra attention from FOCUS caregivers and volunteers. Oh, and the parents enjoy the break!!

Fairy Godparent Volunteer Program | Bert's Big Adventure: The Fairy Godparent volunteer program, sponsored by Carter's Charitable Foundation, allows Bert's Big Adventure families to be visited on a daily basis when their child is admitted to a partner hospital. A team has been put into place so that when the organization is notified that a child has been admitted, the Program Manager will schedule volunteer visits throughout the child's stay. Bert's Big Adventure provides each volunteer with financial resources so that gifts, necessities and food may be provided on each visit.

Families and Children | Georgia Medicaid

FOCUS: At FOCUS, our mission is to embrace and equip families of children with disabilities to make everyday life BETTER.

Friends of Disabled Adults and Children: With a strong network of volunteers and partners, FODAC provides refurbished equipment and services for adults and children with disabilities to improve their overall quality of life. Over the years, our model to assist individuals with disabilities has remained the same: to provide free or low-cost wheelchairs and other home medical equipment (HME), vehicle and home adaptations and more. Above all, our staff is like a family that works together to make every day a little easier, and a little more affordable, for people in need.

GA Decal Bright from the Start: Bright from the Start: Georgia Department of Early Care and Learning is responsible for meeting the child care and early education needs of Georgia's children and their families.

Georgia Autism Initiative | Georgia Department of Public Health: The Georgia Department of Public Health (DPH) is committed to helping children and families with autism spectrum disorder (ASD), and related developmental delays, through the DPH Georgia Autism Initiative. Georgia's Medicaid Program began providing coverage for Autism Spectrum Disorder (ASD) services on January 1, 2018.

Georgia Council on Developmental Disabilities: The mission of the Georgia Council on Developmental Disabilities (GCDD) is to bring about social and policy changes that promote opportunities for the wide spectrum of diverse people/persons with developmental disabilities and their families to live, learn, work, play and worship in their communities.

Created by: Sierra Phillips @mrs.phillijt

Georgia Sensory Assistance Project: The Georgia Sensory Assistance Project (GSAP) is a discretionary federal grant-funded through the US Department of Education, Office of Special Education Programs to increase the capacity of education teams and families to educate children who are deaf-blind. GSAP is housed within the UGA Mary Frances Early College of Education, Department of Communication Sciences and Special Education. GSAP provides consultation, training, and resources for educators, service providers, and families of children and youth with combined vision and hearing loss, from birth through 21 years of age, across the state of Georgia.

Hand in Hand Disability Ministry: Hand in Hand exists to come alongside individuals and families touched by disability to facilitate their participation in the ministries of First Presbyterian Church and to minister to them with the love of Christ and the hope of his kingdom. We are committed not to just serving these individuals, but to equipping them to become vital members of the body of Christ. We offer several programs to support individuals with disabilities and to support their families.

Healthy Mothers, Healthy Babies Coalition of Georgia

Help with PAP Applications | NeedyMeds

Hope House: Parents, who often have difficulty locating qualified and willing caregivers, find excellent care for their medically fragile child at Hope House Children's Respite Center. Friendly faces welcome the children as they enter a beautifully decorated, peaceful environment. While at Hope House, the children enjoy our multi-sensory activity room, Hydrotherapy room, wheelchair accessible playground and lots of crafts and fun activities. Parents know that Hope House is a safe place where each child is treasured and receives lots of tender, loving care as they are guided to reaching their fullest potential.

IDD & Physical Disability Resources: We have put together an extensive and invaluable resource guide for families with loved ones with IDD. While we try to vet each source, we recommend that you use this guide only as a starting point and any purchase, medical or legal decisions are made only after you've done thorough independent research.

InCommunity: At InCommunity our experienced staff and direct support professionals are here to ensure that you and your loved one are taken care of, just like family. We strive to be the best provider of support for people with intellectual & developmental disabilities by offering opportunities to join a day program, seek jobs, live with friends, or improve on personal goals. We are dedicated to building awareness and advocating for people with disabilities and the individuals we support.

JF&CS Atlanta | Intellectual & Developmental Disabilities Services: Intellectual & Developmental Disabilities Services (IDDS) is open to people of all faiths and offers programs and services that support individuals with disabilities, their families, and caregivers.

Kate's Club (katesclub.org): Kate's Club empowers children and teens, their families, and young adults facing life after the death of a parent, sibling, caregiver or someone important to them.

The Kyle Pease Foundation: The purpose of the Kyle Pease Foundation (KPF) is to create awareness and raise funds to promote success for persons with disabilities by providing assistance to meet their individual needs through sports. Programs may include scholarship opportunities, purchasing of medical equipment or adaptive sports equipment for others or contributing to other organizations that provide similar assistance to disabled persons as well as participating in educational campaigns to create awareness about Cerebral Palsy and other disabilities.

Kiddos' Clubhouse Foundation: Our mission is to better shape lives for children with special needs. Kiddos' Clubhouse Foundation provides therapy scholarships to help families pay for critical therapies. Through partnerships and generous support from corporate and private donors, grants, and charitable events, we are able to relieve financial burdens and help families regain hope for their children.

Kids In Motion Therapy | Atlanta: We offer customizable therapies and flexible specialized programs so we can benefit each individual child and their unique needs.

Lekotek of Georgia: Using adapted toys, educational materials, computer equipment and iPads, Lekotek provides opportunities for kids to have fun and learn along the way. It is a safe haven from medical appointments and therapies. It is a place where there are no expectations to perform, a place where parents find resources and support.

Love your Story: Love Your Story puts on quarterly meetups for moms and caregivers of kids with disabilities: meetups where caregivers can show up and feel seen. No need to worry about people not getting it. No need to explain things. These meetups are opportunities to connect with other families who get it.

Loving Care Family Services, LLC: Our caregivers are specially trained to care for children, adults with disabilities and to handle emergencies. Our caregivers meet the following qualifications: Specifically trained and CPR/First Aid certified; Pass thorough background screenings; All in-home care staff are either Registered Nurses, Licensed Pratical Nurses, Certified Nursing Assistants or they have Personal and Home Care Aide training and certification.

MJCCA's Inclusion Program: The MJCCA's Inclusion Program strives to provide the necessary accommodations and flexibility for youth who require additional support so they may access the transformative opportunities available at the MJCCA.

MNT4P | Medical Nutrition Therapy for Prevention Program: The Medical Nutrition Therapy for Prevention Program (MNT4P) is a unique initiative in Georgia that provides precise and personalized assistance to patients living with metabolic disorders, as well as their families. MNT4P provides nutrition support that includes bridging the gap for coverage of medical foods, low-protein modified foods, and treatment-related supplies, assisting patients with insurance navigation, and providing comprehensive medical nutrition therapy. MNT4P also serves as a collaborative community for those living with metabolic disorders, providing a space for mutual support, advocacy, and the monitoring and understanding of long-term outcomes.

Marcus Autism Center: We're committed to supporting kids with autism and their families from diagnosis through treatment.

Parent Mentors | Georgia Parent Mentor: The mission of the Georgia Parent Mentor Partnership is to build effective family,

Pass It On Center: The Pass It On Center is actively addressing issues of national significance in AT device reutilization, providing technical assistance to entities engaged in or planning to engage in AT device reutilization, and coordinating and networking entities involved in AT device reutilization.

PeachCare for Kids | Georgia Department of Community Health: a comprehensive health care program for uninsured children living in Georgia.

Playgrounds | Resurgens Charitable Foundation: listing of accessible playgrounds.

Randy & Friends: Randy & Friends, Inc is a 501(c)3 Christian ministry located in Gainesville, GA that equips individuals who have special needs with new skills and friendships. The goal of our organization is to help these youth and adults achieve independence and self worth with life skills and employment to sustain them the rest of their lives.

Resources | FOCUS

Molly's House: We provide free, temporary housing for families traveling to Gainesville, GA to receive care for their child. When families stay at Molly's House, they get a built-in community (if they want one), a fully equipped kitchen, and a place they can temporarily call home.

Ms. Gussies Place: Ms. Gussie's Place offers hope and restoration for your child and family. We believe that every brain is capable of new growth and change. No matter the condition or diagnosis given, the brain can change based upon the input and stimulation it receives.

Next Step Ministries, Inc.: Next Step is a ministry that seeks to enrich the lives of individuals with intellectual and developmental disabilities (IDD) through programs that reinforce their inclusive place in society.

Olmstead Rights: The Disability Integration Project of Atlanta Legal Aid Society has created this website in collaboration with our partners and funders to be a place for everyone to learn about the Olmstead decision. The website also provides resources and information for self-advocates, family and friends of people with disabilities, and legal advocates alike.

Our Neighbor, Inc.: Our Neighbor, Inc. (ONI) is a nonprofit organization that provides housing, job training, and life skills to young adults with disabilities. The primary goal of ONI is to encourage and assist each resident in reaching their maximum level of independence.

school, and community partnerships that lead to greater achievement for students, especially those with disabilities.

Respite | Unique Individual: We provide In-home respite care in and around Metro Atlanta.

Respite Care | InCommunity: Respite care is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. Respite provides planned short-term and time-limited breaks for families and other unpaid care givers of children and adults with developmental disabilities in order to support and maintain the primary care giving relationship. Respite providers are trained, experienced care givers who come to your family's home to provide respite for your loved one. Out-of-home care is also available in providers' homes or group respite homes. Service options include, but are not limited to: a few hours a week, weekend respite, or for up to a week at a time. Emergency Respite is also available for those who qualify.

Restore Place, Inc.: RESTORE PLACE PROVIDES PARENTS OF CHILDREN WITH SPECIAL NEEDS OR LIFE-

THREATENING ILLNESSES A PLACE OF RESPITE WHERE THEY WILL BE REFRESHED, RESTORED AND RENEWED IN THEIR ROLE AS CAREGIVER.

Resurgens Charitable Foundations: the foundation began with the goal to build at least one new specially designed "all abilities" playground for children in the metro Atlanta area each year, but the impact has grown into so much more.

SHINE | Sugar Hill Church: SHINE is a ministry of Sugar Hill Church that allows us to meet the specific needs of families affected by disability. The name SHINE stands for Support, Hope, Include, Nurture, and Embrace, which is what we hope to do for every child and family we are able to serve. Our ministry offers a class each Sunday at 9:15 and 11 in a quiet, sensory environment for friends who may be overwhelmed by the small or large group environments for their age. We also have buddies available to attend small or large group with friends who just need a little extra support.

Sidekicks Respite: Sidekicks is a respite care program designed for children and adults with special needs and their siblings. These fun, inclusive, community-based events are held each month and are FREE to everyone. Guests of all ages and abilities enjoy snacks, activities, and special visitors. Our experienced staff and lead volunteers oversee all events. Sidekicks allows people of all-abilities to enjoy an night of fun and community.

Skye Precious Kids: To provide resources to families in financial crisis who are caring for children facing life threatening illnesses and disabilities to support a healthy and safe home environment, full access to medical care and equipment, as well as educational support.

Snap4kids: Our Mission is to assist families of children with special needs, especially the physically challenged, in helping their child reach his/her fullest potential. We do so through information, workshops, referral, education, support and depending upon availability, modest grants for medical and therapeutic equipment, as well as assistive technology, not covered by health insurance or in the case of no health insurance, throughout the United States, from birth to age 22. By helping children with special needs in reaching their fullest potential, we are giving them the greatest gift that we possibly can.

SPECTRUM Autism Support: Spectrum Autism Support Group was established in 1998 to provide support, education and resources for individuals and families impacted by autism. Spectrum currently serves over 1,500 families in Gwinnett County and the surrounding Metro Atlanta area and has become a well-known resource in the Autism community. Support groups, summer day camps, overnight camps, social skills groups, respite, community training, and family events are offered for all ages and abilities.

Special Touch Ministry: Special Touch Ministry provides lots of opportunities for people with disabilities to experience God, be included in the church, and build meaningful relationships with caring believers.

Special Touch Ministry | Summer Get Away: Special Touch Ministry Summer Get Away is an overnight, residential, camp-style retreat, for people with intellectual or physical disabilities to have fun and find fellowship with others in a Christian atmosphere. Each location is staffed with Medical professionals and volunteer staff.

Southwest Christian Care: Our purpose is to provide compassionate hospice care, refreshing respite care and educational opportunities for medically fragile children and their families, enriching activities for seniors with varying degrees of memory loss or socialization needs, and individualized and group grief recovery care for those who have lost loved ones or whose life circumstances present emotional challenges.

Special Needs Cobb: We provide respite care to relieve some of the stress of caregiving, keeping families strong and together. We connect parents with other families who “get it,” and hold their hands as they navigate the complicated system of resources. Finally, we give people with disabilities a path to greater independence and opportunities to shine and reach their full potential.

SpecialNeedsRespite: Special Needs Respite helps bridge the existing funding gap that many parents have when trying to get childcare for their special needs child. We can provide funds that will pay qualified caregivers to care for these children when no other way to pay is available to the parents.

Stone Soup, Friends of All Abilities Home: To provide a way for families with children or young adults who have special needs to fully participate in and contribute to our community.

Sunshine on a Ranney Day: Sunshine on a Ranney Day is a nonprofit organization that reimagines and builds custom rooms for children with special needs.

TEFRA/Katie Beckett | Georgia Medicaid: he Katie Beckett Medicaid Program (KB), permits the state to ignore family income for certain children who are disabled. It provides benefits to certain children 18 years of age or less who qualify as disabled individuals under §1614 of the Social Security Act and who live at home rather than in an institution. These children must meet specific criteria to be covered.

The Blonder Family Department for Special Needs: The Blonder Family Department for Special Needs creates a place for individuals of all backgrounds and abilities to socialize, learn, grow, and deepen their connections to one another and the community. Led by a team of dedicated, highly trained professionals, our specialized programs and events for children and adults with special needs foster independence, ignite interests, build self-esteem, and allow participants to experience the richness of community.

The Kyle Pease Foundation: The purpose of the Kyle Pease Foundation (KPF) is to create awareness and raise funds to promote success for persons with disabilities by providing assistance to meet their individual needs through sports.

The Next Chapter Bookstore | Our Neighbor, Inc.: The Next Chapter Bookstore offers an interesting and surprising collection of books with a wonderful atmosphere and a great staff. As a non-profit 501(c)(3), the mission of Our Neighbor, Inc./The Next Chapter Bookstore is to assist and inspire those with disabilities to reach their maximum opportunity for independence.

The Rockdale County Autism Support Group: The Rockdale County Autism Support Group is a family-centered organization that aims to enhance and empower the lives of individuals with Autism Spectrum Disorders (ASD) and their families through a variety of community based activities, awareness and education.

Variety: Variety-the Children's Charity of Georgia is an organization committed to providing children with developmental disabilities the adaptive equipment and opportunities needed for activity and inclusion. At the heart of Variety's achievements are the remarkable contributions of people in the community, and it is only through your time and effort that Variety is able to do so much for children and families in Georgia.

Waiver Programs | Georgia Medicaid

Women and Children | Georgia Department of Public Health: Public Health services, comprehensive health exams, testing, and community resources.

The Special Needs Database | Parent to Parent of Georgia: Parent to Parent's comprehensive resource database contains close to 7000 resources in over 200 categories. The Special Needs Database is a user-friendly, online searchable resource available to individuals with disabilities, their families, and professionals throughout Georgia.

Tools for Life: Tools for Life, Georgia's Assistive Technology Act Program, is dedicated to increasing access to and acquisition of assistive technology (AT) devices and services for Georgians of all ages and disabilities so they can live, learn, work and play independently and with greater freedom in communities of their choice.

Unique Individual: Unique Individual programs are designed to meet the needs of children with disabilities, both behavioral and learning. These programs will provide an exciting and engaging environment to enhance the uniqueness of a child with a disability. Our goal is to increase the capacity for learning by offering excellent and caring services.

United Cerebral Palsy of Georgia: United Cerebral Palsy of Georgia (UCPGA) supports adults with intellectual and developmental disabilities by helping them maximize their potential as they continue a lifelong journey of development and growth.

Your Respite | Atlanta: YourRespite provides childcare, in your home, for your special needs children, up to age 19. We understand the needs of parents who care for their children 24/7, and we understand that you love your children too much to trust them to just anyone. You've asked family, friends, church, support groups, and while they often come through, you want to be able to experience rest, respite, and relaxation without transferring your responsibilities on them yet again. Let us step in and help. We will help you by taking care of your child or children for the evening, or even over a weekend, while you enjoy some well-deserved time for yourself. With our experience in Recreation Therapy within the rehab and nursing home community, we can turn the time into a memorable one for both you and your children.

HAWAII RESOURCES:

HUGS

Our Creative Minds: Established in 2006, Our Creative Minds is dedicated to support the special needs of your family. Several of our family members have multiple disabilities, giving us a close, heartfelt connection, helping our clients get the specialty items so desperately needed, processed and shipped to you quickly. Currently Our Creative Minds holds state contracts with the Department of Developmental Disabilities in Washington and Hawaii. As a contracted state vendor, we can help with accessing the funds to purchase items not covered by insurance, including but not limited to assistive technology, adaptive clothing, sensory items, home modification equipment, indoor gyms and adapted bikes.

Signs of Fun Camp: Signs of Fun offers enriching day camps in Virginia and Hawaii. Deaf, hard of hearing children, and their siblings, ages 3 to 18 years old, are welcome to join the fun! Campers will have the opportunity to go swimming, fishing, and many more fun experiences with old and new friends. They will also enjoy hands-on art, games, and sports. Our day camp is rich with experiences that encourage and promote communication.

AccesSurf Hawaii Nonprofit – An Ocean of Possibilities | Access to beach activities for physically and mentally challenged: AccesSurf builds an inclusive community that empowers people with disabilities through accessible beach and water programs.

The Western States Regional Genetics Network: The Western States Regional Genetics Network, formerly known as the Western States Genetic Services Collaborative, is a federally-funded, multi-state project that seeks to increase access to genetic services and education for medically underserved populations. The participating states and territory are Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. The Western States Regional Genetics Network, formally known as the Western States Genetic Services Collaborative, is a federally-funded project that seeks to improve access to genetic services and education for medically underserved populations. By working together as a region to increase access to and reduce disparities in clinical genetic and newborn screening services, the participating states/territory seek to improve the health of individuals with or at risk for heritable disorders.

IDAHO RESOURCES:

Children's Special Health Program: The Children's Special Health Program (CSHP) is a statewide financial assistance program for uninsured children with a qualifying medical condition(s) requiring long-term multi-disciplinary medical treatment and rehabilitative measures to improve ability to function. CSHP works with families, providers, and communities to ensure access to care that is family-centered, community-based, and culturally sensitive.

Northwest ADA Center: he Northwest ADA Center is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and is part of the ADA National Network(link is external). The ADA National Network Centers are a national platform of ten centers comprised of ADA professionals and experts charged with assisting businesses, state and local governments, and people with disabilities as they manage the process of changing our culture to be user friendly to disability and the effect the variety of health conditions can have on society. The regional advisory committee and our state partners are premier leaders in ADA compliance in each of the states served--Alaska, Idaho, Oregon, and Washington.

IPUL: a statewide organization which houses the Idaho Parent Training and Information Center, the Family to Family Health Information Center, Idaho Family Voices and IPUL Arts.

LEAP Adaptive Ballet: LEAP is an adaptive ballet class specifically designed for children with disabilities.

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Wheel to Walk Foundation: Wheel to Walk Foundation is a non-profit organization that helps children with disabilities, 20 years and younger, obtain medical & adaptive equipment or therapy services not provided by insurance. Our organization strongly believes that no child or young adult with special needs go without items that could improve the quality of their daily life. If you live in Oregon, Washington, Idaho or California and need assistance, please contact us and we will send you an application.

ILLINOIS RESOURCES:

Libenu: Libenu is at the forefront of independence and inclusion for people with disabilities and is internationally recognized as one of the most innovative organizations in the United States. Libenu uses person-centered planning to provide a gold standard of care in all of its programs. Libenu's mission is to provide residential, vocational, and respite opportunities for people with disabilities to live with dignity and respect, as fully included members of our Jewish community.

Netivot - Pathways Academy for Special Education (netivotacademy.org): Netivot Academy is an innovative special education school for students with developmental disabilities from across the Chicagoland area. We nurture each child's unique spark within a warm and caring Jewish environment.

S.I.B.S | Supporting Illinois Brothers & Sisters: Here at S.I.B.S., we support you in your role as a brother or sister, but moreover, we support you as an individual. We recognize that siblings have different needs at different times in their lives, and that no two sibling experiences will be the same. In fact, our diverse experiences have helped us learn, grow, and work effectively.

Center for Independence: To help children and adults with physical disabilities maximize their independence. We accomplish our mission by offering affordable Conductive Education programs that develops motor functions in a manner that promotes positive self-determination, self–esteem, and an "I Can!" attitude.

PlayThinks: PlayThinks is a sensory learning center with an innovative educational design that has created an inclusive learning model, enabling people of all ages and abilities to improve their quality of life.

Face the Future Foundation: Face the Future Foundation is dedicated to raising funds and public awareness in support of the multi-disciplinary patient care at the University of Illinois Craniofacial Center, so that every child with craniofacial differences can live a confident, joyful and fulfilling life.

SIT Service Dogs: SIT breeds, trains, and places service dogs for people with disabilities. Often, a service dog can provide that extra little push needed for a person with a disability to become more independent. The daily tasks, such as retrieving important medications or a phone, are an essential to the wellbeing of our clients. Dogs have been linked to positive changes in mood, self esteem, & even blood pressure. Just the touch of a dog can sometimes make us feel a little bit better. The combination of a dog's ability to assist both physically and emotionally is truly life changing.

INDIANA RESOURCES:

Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

Camp Red Cedar: Camp Red Cedar's mission is to encourage children and adults of all abilities to move beyond their boundaries through recreational activities, outdoor education, creative arts and interaction with horses, in an integrated environment, serving people of all abilities. Located in Fort Wayne, Indiana.

HomePointe HealthCare: Our mission and our passion is to help children reach their full potential and maintain optimal health at home by providing skilled, competent, and compassionate care. As a primarily pediatric-based homecare company, we are designed to care for the medically fragile child with acute or chronic illnesses in the comfort of his or her home. From two hours a day to 24-7, you can count on receiving the care you need -- at home.

Benchmark Human Services: At Benchmark Human Services (Benchmark), we help support people throughout life, from infancy to elder years. Our team is 3,400-strong and serves more than 10,000 children and adults throughout the United States. We work with people at home, at work, and in the community, through residential, employment, crisis response, behavioral, recovery, children's services, and day services.

Library | Indiana Institute on Disability and Community: Hoosiers with disabilities, their families, and those who work with and for them need access to disability-related information and resources. The Library at the Indiana Institute on Disability and Community strives to be the primary disability library for residents of the state of Indiana by providing access to appropriate, quality materials and services. We offer more than 6,000 books, kits, and DVDs about disabilities across the lifespan that are available to borrow by anyone in Indiana. Regardless of where you live, we will lend our materials to you through the mail or to help answer your disability-related questions.

Indiana Disability Resource FINDER: Explore our directory of services, programs and helpful articles for the disability community. Follow our step-by-step guide to find the right

Resources | Indiana Institute on Disability and Community: Our centers and library have compiled resources for educators, other professionals, parents, students,

information. You can narrow your search by continuing to choose additional options as they are displayed.

Indiana Institute on Disability and Community: The Indiana Institute is a bridge that connects the university to the broader community through the sharing of ideas and innovations to improve communities and lives. At the Indiana Institute, we work through seven centers to address issues across the lifespan and major life areas.

Finding Your Momma Tribe: Support Groups for Parents: If you're needing some extra love, here is a resourceful list of local, in-person parenting groups worth their supportive salt.

Indiana Resource Center for Autism | Indiana University Bloomington: As Indiana's statewide center on autism spectrum disorders, we are committed to supporting all involved in their efforts on behalf of individuals across the autism spectrum.

Early Childhood Center: Indiana University Bloomington: The Early Childhood Center is dedicated to strengthening universal systems of family support and early education that meet the needs of all young children and their families

Implementation Supports for Inclusion | Indiana University Bloomington: The Early Childhood Center, part of Indiana University's Institute on Disability and Community, has developed this website in partnership with the Indiana Department of Education's Office of Special Education to navigate a pathway to sustainable change in special education services for young children with disabilities.

transitioning individuals with disabilities, and policymakers—and you can browse them all in one place.

IOWA RESOURCES:

ChildServe: Our team of experts helps identify and meet the unique needs of children with developmental delays, disabilities, injuries and other special healthcare needs.

The Heartland Genetics Services Network: The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

Comprehensive Pediatric Home Health Care | Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

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KANSAS RESOURCES:

Home - RareKC: Our mission is to drive innovation in the diagnosis, care and treatment of rare diseases by connecting and inspiring our community.

Rewarding Work: Rewarding Work, an affiliate of TILL, Inc., helps individuals and families hire caregivers and provides a free resource for job seekers. Rewarding Work currently operates in Connecticut, Kansas, and Massachusetts.

STARS for Special Needs Kids & Response System (ssmhealth.com): The Special Needs Tracking and Awareness Response System, or "STARS," is a one-of-a-kind program designed to improve emergency care for children with medical complexities. Through the creation of personalized, emergency care plans that are written specifically for EMS and emergency department staff, intensive training and the development of a centralized web-based system that integrates with 911 dispatching systems, our goal is to make emergency care safer for our most fragile children. STARS is a single program developed and maintained by multiple pediatric hospitals and used by many emergency and EMS agencies throughout Missouri and Illinois. STARS allows medical professionals to access important patient information and care instructions before they even arrive at the patient's side. This way, they can provide faster, more skillful care for better patient outcomes.

The Heartland Genetics Services Network (heartlandcollaborative.org): The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

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KENTUCKY RESOURCES:

Comprehensive Pediatric Home Health Care | Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

Mothers of Special Children of NKy (mscnky.com): We provide emotional support to mothers of special needs children, especially those just learning of their child's disabilities.

The Center for Courageous Kids - A Non-Profit Serving Children: In a world where these children are often told they cannot, at CCK they can. Our campers enjoy every activity and event with no limitations or restrictions because the camping facility is fully accessible. 24-hour supervision by experienced medical specialists so campers can laugh and play safely under the watchful eye of doctors, nurses and therapists who are experienced in their diagnosis. At CCK, children have the opportunity to take a break from their daily medical challenges and focus on enjoying camp!

LOUISIANA RESOURCES:

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Louisiana Resource Directory for Special Needs Programs — Exceptional Lives: We are a non-profit organization providing free tools, information, and resources for families of children with disabilities or special needs.

Southeast Regional Genetics Network (SERN) | Improving health equity and outcomes in individuals with genetic conditions (southeastgenetics.org): The goal of SERN is to improve health equity and health outcomes in individuals with genetic conditions; reduce morbidity and mortality caused by genetic conditions (including congenital and metabolic disorders); and improve the quality of coordinated and comprehensive genetic services to children and their families.

Adaptive Bikes for Children with Special Needs (mclindonfamilyfoundation.org): The mission of the McLindon Family Foundation (MFF) is to provide adaptive bikes to children with special needs so that they can build critical core strength, boost confidence and nurture friendships, all of which help these children maximize their potential and participation in society.

MAINE RESOURCES:

Joey's Fund Grant Program | Spectrum for Hope Fund | Flutie Foundation: Today, Joey's Fund serves as a crucial funding bridge for autism families who are advocating, promoting, supporting and seeking out opportunities for their loved ones. Since its inception, 193 families have received over $375,000 in financial support, making their journey just a little bit easier. Must have one family member medically diagnosed with Autism Spectrum Disorder and reside in New England (Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire & Maine). Families are only eligible to apply if they have not received funding in the previous year.

New England | Autism Speaks: Serving all communities in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism, and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

Becket: Becket's mission is to create opportunities for individuals to live better lives by aligning inspired professionals who are supported and trusted to be a compassionate team with family caregivers and community resources.

LifeConnections Specialized Support Services: LifeConnections Specialized Support Services was created in 2018 as a subsidiary of Becket Family of Services with a goal to create specialized service options for people with complex behavioral health and/or medical needs who were at risk of moving out of state or to higher levels of care due to the lack of service options. Today, we serve youth and adults of all ages in various settings and States, including; Maine, New Hampshire, Massachusetts, Rhode Island, South Carolina and Florida. We are nationally accredited by the Council on Accreditation and are proud members of the National Alliance for Direct Support Professionals.

Maine Adaptive: Founded in 1982, Maine Adaptive is now the largest year-round adaptive recreation program in the state of Maine for adults and children with disabilities. Over 400 volunteers assist our athletes in appreciating the joys and challenges of sports participation.

Adaptive Resources — Maine Adaptive

Androscoggin Learning & Transition Ctr | Becket: ALTC is licensed by the state of Maine Department of Health and Human Services as a day treatment program, which ensures that it is able to provide individualized therapeutic support and wrap-around for our teachers and students. All students have an assigned school social worker and are supported by certified Behavioral Health Professionals. Students receive regular guidance, mentoring, and support, as well as individual, group counseling and assessment, all built on a framework of the latest evidence-based approaches.

Central Maine Learning Center | Becket: Central Maine Learning Center (CMLC) is a state of Maine, Department of Education approved special private purpose school located in the heart of the Belgrade lakes region. All CMLC faculty members are highly trained in accordance with federal and state standards. CMLC is approved to provide educational services to those students identified as special education. Currently, CMLC provides special education services to students in grades K-12.

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MARYLAND RESOURCES:

Believe In Tomorrow Children's Foundation: Believe In Tomorrow Children's Foundation provides exceptional hospital and respite housing services to critically ill children and their families. Our unique programs bring comfort, hope, and joy to children and their families, enabling them to renew their spirits mentally and physically.

HealthWell Foundation: 501(c)(3) independent non-profit organization providing financial assistance to adults and children to cover the cost of prescription drug coinsurance, copayments, deductibles, health insurance premiums and other selected out-of-pocket health care costs.

Resources in Maryland (jhsph.edu)

Easterseals Delaware & Maryland's Eastern Shore | Camping & Recreation: Located outside of beautiful Chestertown, Maryland, Easterseals Camp Fairlee has been providing recreation and respite for individuals age 6 and up since 1954. Camp Fairlee provides a safe and accessible camp experience where campers are challenged to discover their full potential, acquire new skills, and make new and lasting friendships while under the guidance of trained and qualified staff. While campers enjoy their time at Camp Fairlee, their families are able to take a much needed break from caregiving.

Parents' Place of Maryland: Maryland's Special Education and Health Information Center.

Easterseals Child Development Center – NARA: For nearly two decades, the Child Development Center at the National Archives has been serving children and families of employees of the National Archives and Records Administration, other federal employees, and community families. This inclusive early care and education center is accredited by the National Association for the Education of Young Children (NAEYC) and earned a Level 5 rating of the Maryland Excels Program.

Easterseals Child Development Center – Silver Spring: The Child Development Center in Silver Spring has been serving children and their families for over a decade. This inclusive, intergenerational early care and education center is accredited by the National Association for the Education of Young Children (NAEYC) and provides exceptional services for children with and without disabilities and their families.

Resources | Parents' Place of Maryland (ppmd.org): Check out our great resources! To find a resource you need, use the left column to filter by topic and/or language. Still not finding what you need? Use the search bar to search for key words.

Federation for Children with Special Needs | FCSN: The Federation empowers families so that they have the information and resources they need for their children. We work with families with children from birth to adulthood, providing individual assistance, training, and leadership development and support. We focus on education, early intervention, health care, transitions, children in foster care and group homes, and building strong family engagement to support all children, especially those children with disabilities, those at risk, and those with economic, cultural or linguistic barriers.

Capital Caring: For nearly two decades, Capital Caring has embraced grieving children and teens by offering grief support through specialized bereavement programs held in individual Capital Caring neighborhoods across the MD, VA and the D.C. metropolitan region. At Capital Caring Kids, we offer grief counseling, support groups and special bereavement programs to not only help our Capital Caring families, but to assist anyone in the community who is struggling with loss in safe and supportive environment.

About Our Respite Program: | Believe In Tomorrow Children's Foundation

A & C Support Services Inc.: A & C Support Services Inc. program enables persons served and their primary support system with assistance in developing and/or maintaining independence, productivity and progress towards their definition of a fulfilling life. A & C Support Services Inc. is a Maryland DDA Provider for personal supports, respite, support broker and vendor services. We are also a Consortium member for the Arc Montgomery County Respite Coordination Program.

Alliance Kids: Alliance Kids is the Mid-Atlantic regions collaborative voice and provider of high quality, compassionate pediatric hospice care serving children and young adults in the place they call home. Through our website, we can help anyone with a life-limiting illness to a pediatric palliative and hospice expert. Our vast provider network includes experts across Maryland, Delaware, Washington D.C. and Northern Virginia.

Makom: We support and empower people with intellectual and developmental disabilities to achieve the quality of life to which they aspire.

Way to Grow: At Way to Grow we address the whole child from a developmental perspective. We work to understand how your child is functioning in every aspect of their life. All parts of the child’s life are connected.

MOST™ | Makom: At the Sally and Robert Goldberg MOST™ Program, we understand the challenges young adults face when making the transition into adulthood, and we are here to help. Our customized one-year program guides participants through the unfamiliar waters to help them take on the world as their best selves. Currently, we have three MOST™ locations: Montgomery County, MD, Fairfax County, VA, and Loudoun County, VA. We are proud to be a DDA-approved Community Development Services program in MD. In VA we are DBHDS funded, and the services we offer are Community Engagement and Group Day. Our program is primarily comprised of young adults aged 18-24. However, age is just a number, and our focus is on individuals who are transitioning – whatever or whenever this transition may be.

Camp Jamie: Camp Jamie is a special opportunity for grieving children, adolescents and teens to come together to talk about their feelings related to the death of someone special, and learn coping skills for dealing with those feelings. Camp Jamie is held three times per year. Our teen and weekend sleepover camps are held in the spring. Our one day camp is held in the fall. Each camp provides unique opportunities to express and communicate grief in a healthy and safe environment.

Hospice of Frederick | Maryland Health System

MASSACHUSETTS RESOURCES:

Access Sport America – Changing lives through sports and training: The mission of AccesSportAmerica is to inspire higher function and fitness for children and adults of all disabilities through high-challenge sports and training.

Rewarding Work: Rewarding Work, an affiliate of TILL, Inc., helps individuals and families hire caregivers and provides a free resource for job seekers. Rewarding Work currently operates in Connecticut, Kansas, and Massachusetts.

Becket: Becket's mission is to create opportunities for individuals to live better lives by aligning inspired professionals who are supported and trusted to be a compassionate team with family caregivers and community resources.

Berklee Institute for Accessible Arts Education | Berklee College of Music: The Berklee Institute for Accessible Arts Education is a catalyst for the inclusion of individuals with disabilities in all aspects of performing and visual arts education.

Boston Ballet | Adaptive Dance: Boston Ballet believes everyone should have the opportunity to dance and is committed to working with our families to ensure that programming is accessible.

Bridges Associates, Inc.: Since 1989, Bridges Associates, Inc. has helped children and adults affected by disabilities and barriers to school success, take charge of their lives.

Center for Mendelian Genomics | Broad Institute: The Center for Mendelian Genomics is a member of the GREGoR Consortium (Genomics Research to Elucidate the Genetics of Rare Disease) funded by the NHGRI (National Human Genome Research Institute), along with 5 other sites across the country. The central goals of the GREGoR consortium are: to discover variants and genes underlying Mendelian diseases; to collaboratively facilitate gene discovery, validation and follow up; and to generate new methods for improving diagnosis across a wide spectrum of rare disorders.

Eagle Hill School | School for Diverse Learning Profiles: Eagle Hill School is a coeducational college preparatory boarding school that provides an individualized education for students with diverse learning profiles, including those identified as having dyslexia, dysgraphia, dyscalculia, as well as students with ADHD (inattentive type).

Family Ties | Massachusetts: Family TIES of Massachusetts provides information and referral services, emotional support, and training to parents of children and youth with special needs. Driven and staffed by parents of children with special needs, we offer a unique type of emotional and practical support to families with similar life experiences. We are a primary source for information about Early Intervention and maintain a complete listing of Early Intervention Programs in MA.

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Jamal S Helping Hand: Our mission at Jamal's Helping Hands is to provide client-focused support to patients and their families dealing with a chronic illness. We help these patients and families navigate the many and difficult travails of today's healthcare industry. Our services include various resources and educational information to help you better manage your loved-one's healthcare.

Judge Rotenberg Educational Center: The JUDGE ROTENBERG CENTER (JRC) is a day and residential school located in Canton, Massachusetts licensed to serve ages five through adult. Since 1971, JRC has provided very effective education and treatment to both emotionally disturbed students with conduct, behavior, emotional, and/or psychiatric problems, as well as those with intellectual disabilities or on the autism spectrum. Our specific goal is to provide each individual with the least intrusive most effective form of treatment to ensure his/her safety, the safety of others, and promote healthy growth and development. JRC is committed to providing the most effective educational program possible.

Landmark School: Landmark is a coed day and residential school for students in grades 2–12 with dyslexia or other language-based learning disabilities (LBLD). These fall under the broader category of specific learning disabilities (SLD). We celebrate our students' differences by individualizing a program based on their specific needs. The Landmark approach empowers students to reach their academic and social potential. Each faculty member is highly trained and specializes in educating students with dyslexia and other SLDs.

LifeConnections Specialized Support Services: LifeConnections Specialized Support Services was created in 2018 as a subsidiary of Becket Family of Services with a goal to create specialized service options for people with complex behavioral health and/or medical needs who were at risk of moving out of state or to higher levels of care due to the lack of service options. Today, we serve youth and adults of all ages in various settings and States, including; Maine, New Hampshire, Massachusetts, Rhode Island, South Carolina and Florida. We are nationally accredited by the Council on Accreditation and are proud members of the National Alliance for Direct Support Professionals.

Listening, Reflecting, Healing: Supportive Genetic Counseling and Bereavement Services.

Lurie Center for Autism | Autism Patient Resources: At the Lurie Center for Autism, our mission is to treat individuals and support their families across their lifespan. The resources and information provided here aim to address common questions and concerns about ASD with evidence-based answers that have been reviewed by credentialed professionals on our staff. Our goal is to continually update this material as new information is discovered, evidence develops, and new research is published. Click the links below to view and download helpful guides.

Lurie Center for Autism: The Lurie Center for Autism is a multidisciplinary clinical, research, training and advocacy program dedicated to treating individuals with autism spectrum disorder and other developmental disorders across the lifespan.

Massachusetts Resource Directory for Special Needs Programs | Exceptional Lives: We are a non-profit organization providing free tools, information, and resources for families of children with disabilities or special needs.

Massachusetts School Finder: This tool can help you find schools based on where you live and the grade level of your student. You can also search for high schools that offer college and career programs by choosing from the Programs/Pathways drop-down menu.

Massachusetts Sibling Support Network: The Massachusetts Sibling Support Network supports siblings of people with disabilities across the Commonwealth. We strive to create welcoming communities for siblings that are inclusive, empowering, and provide needed answers. We are a leader in promoting the sibling voice at tables across Massachusetts as we provide direct sibling support services, including educational presentations and information and referral support.

Nancy Lurie Marks Family Foundation | Recreational Programs for Adults: The following is a listing of resources relating to recreational and community enrichment programs for adults with autism. Some are specifically for adults on the spectrum and other developmental disabilities. Some are for the general public but by their nature are accessible to autistic adults.

New England | Autism Speaks: Serving all communities in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism, and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

New England Disabled Sports: New England Disabled Sports (NEDS) is a 501 (c) (3) not-for-profit organization, providing adaptive sports instruction to students of varying abilities that meet the General Essential Eligibility Criteria . It is through the generous donations of individuals, corporations, and foundations that close to 600 student-athletes living with disabilities are able to enjoy adaptive sports year-round. Headquartered at Loon Mountain Ski Resort in Lincoln, NH and at the Bretton Woods Ski Resort at Omni Mount Washington Resort NEDS has become a nationally recognized program, providing expert adaptive sport instruction to adults and children living with physical and cognitive disabilities.

Novo Nordisk Foundation Center for Genomic Mechanisms of Disease | Broad Institute: The Novo Nordisk Foundation Center for Genomic Mechanisms of Disease facilitates close collaborations between the Broad Institute and Danish researchers investigating the genetics and gene regulation of common complex disease, including type 2 diabetes and obesity.

Parent Consultant Training Institute: The Parent Consultant Training Institute (PCTI) is an intensive training program designed to provide all families and professionals with a solid foundation in special education laws and procedures. Participants have the opportunity to learn from experts in the field, network with each other, and become part of a community dedicated to supporting children in special education. This course is open to people with all levels of experience and is a great starting place for those interested in bringing their advocacy to a higher level.

Rare disease | Broad Institute: Broad researchers study several rare inherited diseases, including muscle disorders, mitochondrial disorders, and kidney disease. Knowledge about risk factors for rare genetic diseases has the potential to illuminate the biology underlying these diseases, to improve the lives of patients through new diagnostic and therapeutic possibilities, and to shed light on related common diseases.

Room To Dream Foundation: The mission of the Room to Dream Foundation is to create healing environments in bedrooms for children and adolescents who are facing chronic illnesses. As they recuperate and recover, our hope is that their renovated spaces will improve their quality of life, promote strength, imagination, self-worth, and aid in their recovery processes. The Room to Dream Foundation focuses its services on children and families in need. In order to complete each renovation, we purchase all of the furnishings and supplies. Every purchase is tailored to the specific needs of a child or family. Through a caring staff of professional and amateur artists, interior decorators, and volunteers, we design and transform living spaces that give children and adolescents room to dream of a healthier future.

SMILE Mass: Small Miracles in Life Exist (SMILE Mass) is a 501 C3 non-profit organization dedicated to helping families raising children or adults with disabilities enjoy happy, healthy memories through vacation and recreation experiences.

Spectrum For Hope: Spectrum For Hope is committed to supporting families of multiple children with disabilities by providing funding and financial assistance for various therapeutic, educational, medical and recreational opportunities. In addition, Sprectrum For Hope will continue to partner with organizations to fund research for a cure for these disorders. Grant Applications are made available on our website in October and announced in December.

Spring: Vacation Weekend — Grotonwood: Spring Vacation is a weekend retreat designed for adults over 18 years of age with cognitive and developmental disabilities and/or ASD. Hosted at Grotonwood Camp & Conference Center, an award-winning ADA accessible Lake front facility, where children and adults have enjoyed summer camps for over 60 years. Spring Vacation provides a respite from the everyday and inspires campers to participate in things they would not normally get the opportunity to try at home.

Stepping Stones for Stella: Our mission is to help children with disabilities and parents travel on all types of outdoor environments. Whether that be moving across sand, gravel, dirt, grass and even snow our Buggies & Walkers will help you explore in style.

The Genesis Foundation For Children: The Genesis Foundation For Children provides funding for clinical, informational, and therapeutic programs for children born with physical and intellectual challenges and genetic disorders.

Transition Resources | Smile Mass: In a world of raising children and adults with disabilities, the only thing that is guaranteed is constant change. New laws, IEPs, requirements, and lots and lots of paperwork. We have created this resource page with the hope that this can save you some time, and perhaps even give you some of the answers you might be looking for.

VIGOR Study: The VIGOR Study is an NIH-funded endeavor coordinated out of Boston Children's Hospital which collaborates with chosen NICUs that serve underserved populations. VIGOR has created partnership between these leading NICUs to develop and implement a novel virtual model for genomic care with the hopes of proving that a model of tele-genomic care is feasible and reproducible to any NICU.

Yachad - New England: Yachad is dedicated to enriching the lives of Jewish individuals with disabilities and their families, by enhancing their communal participation and their connection to Judaism through social and educational programs and support services.

MICHIGAN RESOURCES:

Detroit JCC - Opening the Doors (jccdet.org): Opening the Doors (OTD), a nationally recognized program, provides inclusive educational services to enable 1,100 children of all abilities and/or mental health concerns to succeed in Jewish early childhood, congregation and day school classrooms. Working in partnership with educational and health organizations, Opening the Doors offers psychoeducation evaluations, a teen leadership program, professional development and community disability and advocacy conferences and events which educate, include and empower.

Beacon Specialized Living - Achieve Your Best Life: Beacon Specialized Living serves individuals with intellectual disabilities and mental health needs. By supporting their self-directed goals with compassion and best practices, Beacon provides the highest level of support — not only meeting their needs, but helping people live their fullest lives.

Family Hope Foundation | Giving the Gift of Ability (thefamilyhopefoundation.org)

Friendship Circle / About: Friendship Circle of Michigan is a non-profit organization affiliated with Lubavitch of Michigan. Our goal is to provide every individual with special needs the support friendship and inclusion that they deserve.

Home - Oxford Kids Foundation: Our goal is to raise and award funds for children to receive beneficial medical therapies not covered by insurance in the state of Michigan.

The Disability Network (disnetwork.org): The mission of TDN is to revolutionize communities to be inclusive and accepting, where all people thrive in the quality of life they create.

Michigan Cleft Network, MiCleft | Facebook: MiCleft is Michigan's ONLY AmeriFace Pathfinder Partner Organization.

Euro-Therapies, Pontiac, MI: Euro-Therapies Family Therapy Center, thrives on our commitment to patient-centered care by providing individualized physical and speech therapy services in a one-on-one environment to help patients of all ages and levels learn new skills to improve mobility, communication, self-esteem, and independence.

JACKS PLACE for Autism Foundation

Judson Center: Judson Center is a non-profit human service agency that provides compassionate, comprehensive services to children and families throughout southeast Michigan.

Kaufman Children's Center Home • Kaufman Children's Center • Pediatric Special Needs Clinic (kidspeech.com): The Kaufman Children's Center is one of the country's premier pediatric special-needs centers, the HQ of apraxia expert Nancy Kaufman, and a really fun place to learn and grow!

Respite Care - Judson Center: provides children's respite care at Lahser Children's Respite Home in Beverly Hills. Our respite home is barrier-free and staffed by well-trained, attentive and compassionate individuals who pay attention to the specific needs of each guest. During their stay, each child is given individualized personal care and supervision based on their specific needs, with a concentration in the areas of homemaking, language development, social skills, orientation to community participation, and applicable behavior plans. Educational and recreational programming is provided in order to ensure continued growth for the children under our care.

Joey's Fund Grant Program | Spectrum for Hope Fund | Flutie Foundation: Today, Joey's Fund serves as a crucial funding bridge for autism families who are advocating, promoting, supporting and seeking out opportunities for their loved ones. Since its inception, 193 families have received over $375,000 in financial support, making their journey just a little bit easier. Must have one family member medically diagnosed with Autism Spectrum Disorder and reside in New England (Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire & Maine). Families are only eligible to apply if they have not received funding in the previous year.

MINNESOTA RESOURCES:

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Ceremony & Ritual (athousandhands.com): I'm here to help you find strength, balance, and beauty through carefully crated ritual, ceremony, and education. Together, we'll discover the best way to bring beauty, meaning and connection for all life's cycles in a genuine way, celebrating moments that matter to you most.

Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

Crescent Cove - First children's Residential Respite and Hospice Home in the Midwest: Crescent Cove Respite & Hospice Home for Kids is Minnesota's first and only home designed just for children and their unique needs, and just the third of its kind in the United States.

Friends of the Angel Christmas Box Angel of Hope Statue | Maple Grove Arboretum: To help others honor, remember and keep the memory of their loved ones alive. To offer hope, encouragement, and fellowship through our common connection of loss by hosting events at the Angel of Hope statue.

Brighter Days Family Grief Center: Brighter Days Family Grief Center is an unparalleled "family-focused" grief center dedicated to grieving Minnesota families since 2017. We are the only nonprofit Family Grief Center in Minnesota providing free resources and services to children, young adults, and adults who are grieving the terminal diagnosis or death of a beloved family member.

Schulze Family Foundation: We invest in health & medicine projects that reduce human suffering and advance medical science.

Fraser: To make a meaningful and lasting difference for individuals and families living with diverse intellectual, emotional, or physical needs, by providing a lifetime of quality healthcare, housing, education, employment, and support services.

Home - Open Arms of Minnesota (openarmsmn.org): We create an inclusive and joyful community to provide high-quality medically tailored meals, nutrition education, and hope to our clients.

Halos of the St. Croix Valley: Halos of the St. Croix Valley is a recognized 501(c)(3)non-profit foundation in the State of Wisconsin that provides emotional and financial support to bereaved parents who have lost a child from miscarriage through age 20 and reside in Minnesota or Wisconsin.

FamilyMeans: FamilyMeans is a multi-service, nonprofit organization that was founded in 1963. We are funded by grants, donations, and client fees. FamilyMeans is headquartered in Stillwater, Minnesota, with branch offices located throughout the Twin Cities metro area, southeastern Minnesota and western Wisconsin.

HopeKidsMinnesota Chapter - HopeKids

Jack's Caregiver Coalition - Home (jackscaregiverco.org): Welcome to the not so secret club for caregivers. We're a non-profit on a mission to improve the way guys think, feel, and act through every phase of their caregiving journey.

PACER Center - Champions for Children with Disabilities: PACER Center enhances the quality of life and expands opportunities for children, youth, and young adults with all disabilities and their families so each person can reach his or her highest potential. PACER operates on the principles of parents helping parents, supporting families, promoting a safe environment for all children, and working in collaboration with others. With assistance to individual families, workshops, materials for parents and professionals, and leadership in securing a free and appropriate public education for all children, PACER's work affects and encourages families in Minnesota and across the nation.

Pathways Minneapolis: The mission of Minneapolis Pathways is to provide resources and services for people with life threatening or chronic physical illness—as well as caregivers—to explore and experience complementary healing approaches.

Help Me Grow MN

Smile Again Ministries: It's never easy to experience the death of a child. At Whitetail Lodge, located near Crosslake, Minnesota, Smile Again Ministries offers the opportunity to heal in a warm, friendly environment. Together, we will help you and your family navigate the uncharted territories that often accompany grief.

The Garden of the Sleeping Angels: The Garden of the Sleeping Angels is created specifically for those who have experienced the loss of an infant or child—in utero, stillborn, or after birth. It serves as a living reminder that although we can no longer hold or touch our loved ones, we can remember them always. It is not a cemetery; it is a series of gardens with memorials representing our missing children.

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Our hope is that visits to this peaceful setting will enable you to remember, reflect, grieve, and begin healing as you celebrate your sweet one's all too short time on this earth. We also welcome visits from caregivers—those who have been blessed to be part of the angels' lives. We welcome all families and angels regardless of religious (or non-religious) beliefs.

MISSISSIPPI RESOURCES:

SouthSeq – HudsonAlpha Institute for Biotechnology: SouthSeq is a NIH-funded research study looking at how a new kind of genetic test, called whole genome sequencing, can be used to try to find the reason for medical problems among newborns in a neonatal intensive care unit (NICU).

MISSOURI RESOURCES:

June Jessee Memorial Foundation The June Jessee Memorial Foundation (JJMF) is a nonprofit organization that provides relief to help support and care for children with devastating medically complex, neurological conditions and their families, providing needed resources, services and connections to help make their lives easier.

STARS Program – Osage Ambulance District: Osage Ambulance District STARS (Special Needs Tracking & Awareness Response System) is a program designed for children with moderate to severe medical conditions who utilize special medical equipment and/or present with uncommon symptoms.

STARS PROGRAM | Eureka MO Fire Dist. (efpd.org): Eureka Fire Protection District is a proud participant of Cardinal Glennon's STARS program to the areas it serves and protects. The Special needs Tracking & Awareness Response System has been specifically developed for special needs patients through the age of 21, their families, and your Eureka first responders. Through the STARS program, our youngest and most vulnerable residents will be receiving the greatest care possible.

STARS | SCCAD: St. Charles County STARS [Special Needs Tracking & Awareness Response System] is a program designed for children with moderate to severe medical conditions who utilize special medical equipment and/or present with uncommon symptoms. Utilized by both St. Charles County Ambulance District and City of St. Charles Fire Department, STARS provides Paramedics with important information about the patient prior to their arrival on the scene of an emergency call. When a family opts to participate, our STARS Coordinator will work with them to obtain important medical information about the child. Data is uploaded into a secure, electronic record available on all ambulances in the county.

Home - RareKC: Our mission is to drive innovation in the diagnosis, care and treatment of rare diseases by connecting and inspiring our community.

RideKC_Freedom_Eligibility.pdf: RideKC Freedom is the transportation service to persons with disabilities, older adults and/or low-income persons traveling in Johnson and Wyandotte Counties, Kansas City, Mo., Independence, Mo., – and some of the surrounding metropolitan area. Customers have access to door-to-door or curb-to-curb service depending on the geographic area RideKC Freedom serves.

The Arya Foundation: The Arya Foundation is a 501(c)(3) tax-exempt non-profit that provides need-based adaptive equipment to children with special needs in the Greater St. Louis Region.

Special Health Care Needs Family Partnership Initiative – umkc.ihd: The overall goal of this project is to build a network of support for family members of CYSHCN and provide the Department of Health and Senior Services-Special Health Care Needs with input regarding specific needs as requested. This project addresses issues related to HRSA's core system outcomes and work to improve family/professional partnerships, access to medical home, system navigation, health insurance, and financing, and early and continuous screening.

Mid-America Transplant Family House: The Mid-America Transplant Family House offers comfortable mid- to long-term transplant housing for families who must relocate to St. Louis for lifesaving transplant care.

HavenHouse St. Louis: HavenHouse St. Louis is a hospital guest house with the mission to provide the comfort of home and community of support to patients and their families traveling more than 25 miles to receive care. HavenHouse provides lodging, two meals a day, transportation to 19 St. Louis regional medical facilities, and around-the-clock support services to patients of all ages with any medical condition.

Kyleigh's Gift: Kyleigh's Gift provides infant wellness education and parental support to families at Liberty Hospital.

Liberty Hospital Foundation: Our team is dedicated to the Mission, Vision, and Pillars of Charity to improve the Health, Education, Wellness, and Care of Liberty Hospital patients, individuals, families, and staff.

Treehouse – Liberty Hospital Foundation: The TreeHouse is open to guests from the Liberty area as well as from cities and towns further away. Guests often travel an hour or more to receive medical care, as Saint Luke's Health System and the University of Missouri Medical Center frequently refer their patients to Liberty Hospital to receive such specialized care that is unavailable in their hometown.

Patient Assistance Program – Liberty Hospital Foundation: The Patient Assistance Fund's mission is to enhance the overall health of Liberty Hospital patients and reduce unnecessary, expensive hospital re-admissions.

Barnes Lodge - Lodging - Patients & Visitors - Barnes-Jewish Hospital (barnesjewish.org): Conveniently located at Barnes-Jewish Hospital and Washington University Medical Center, Barnes Lodge provides a home away from home for families and patients who travel to St. Louis for medical treatment. Barnes Lodge provides a safe, comfortable and affordable atmosphere with staff on duty 24 hours daily to provide support and assistance.

Community Resources – umkc.ihd: This page has community resources that can be helpful to anyone with a disability and people getting older. The list shows services that you can only get if your income is low, have a disability, or are a certain age. The list also shows resources that are free or are available to the public.

Missouri Family to Family Statewide Resource Center: Missouri Family to Family is a family driven organization that can support you, as we do other families, by listening, training, and connecting you with quality resources specific to your situation. Think of us as your resource center.

Missouri Family to Family Health Information Center – umkc.ihd: The Family to Family Health information Center, housed within the Missouri Family-to-Family Resource Center, focuses on creating collaborative and respectful partnerships between families of children and youth with special health care needs (CYSHCN), health care providers, policymakers, programs and agencies at local, state, and national levels. Through peer support, leadership and advocacy education, and informational resources, this project seeks to increase opportunities for families of CYSHCN to be empowered and access services that are most beneficial to them.

Rare And Black: Our mission is to empower and amplify voices of Black people living with rare diseases.

STARS Program - West County EMS & Fire Protection District (westcounty-fire.org): The goal is to have pertinent patient information in the hands of the medical professionals before they even arrive at the patient's side. This way they can provide the care needed immediately and skillfully. This ultimately helps decrease anxiety and painful, unnecessary measures and in achieving better outcomes, faster.

The Heartland Genetics Services Network (heartlandcollaborative.org): The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

Comprehensive Pediatric Home Health Care | Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

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umkc.ihd – Partnerships for Effective Social Change: UMKC IHD is the federally designated University Center for Excellence in Developmental Disabilities (UCEDD) for the state of Missouri. We are a member of the Association of University Centers on Disabilities (AUCD) and one of 67 UCEDDs located in every state and United States territory. We build partnerships that lead to effective social change through research, training, community development, and information sharing.

MONTANA RESOURCES:

Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

Year 6 Genetic Navigator Outreach Presentation (canva.com)

Genetic Ambassador Program - Mountain States GeneticsMountain States Genetics

Rocky Mountain ADA: The Rocky Mountain ADA Center is proud to serve individuals and organizations throughout Colorado, Utah, Montana, Wyoming, North Dakota, and South Dakota.

NEBRASKA RESOURCES:

Domesti-PUPS Home: Domesti-PUPS is a community organization based in Lincoln, Nebraska. We provide therapy dogs, service dogs for persons with disabilities, and obedience trained rescue dogs. Our mission is to improve the quality of life for persons with special needs through the assistance of animals, and to promote awareness through education.

Enable Savings Plans - Enable Savings: The Enable Savings Plan (the "Plan") is sponsored by the State of Nebraska and administered by the Nebraska State Treasurer. The Plan offers a series of investment portfolios within The Nebraska Achieving a Better Life Experience Program Trust. The Plan is intended to operate as a qualified ABLE program to be used only to save for Qualified Disability Expenses, pursuant to the Achieving a Better Life Experience Act of 2014 and Section 529A of the U.S. Internal Revenue Code.

Answers4Families: Answers4Families connects Nebraskans with special needs to resources and support. We empower, educate, and strengthen relationships between human service agencies by developing online solutions.

Home | Nebraska Early Development Network: provides early intervention services for families with children birth to age three with developmental delays and/or health care needs and connects families to needed services.

Lifespan Respite Brochure (ne.gov)

Home | Nebraska Lifespan Respite Network:

Contact a Respite Coordinator | Nebraska Lifespan Respite Network: Call the Nebraska Lifespan Respite Network to speak with a Respite Coordinator: 1- 866-RESPITE (1 - 866-737-7483). Are you interested in learning more about programs and services in Nebraska that may be of assistance to you or your loved one? Or do you have additional questions?

form-RespiteSubsidyProgram.pdf (unmc.edu): The Lifespan Respite Subsidy Program application may be filled out by caregivers who reside in their own home and care for an individual with a disability of any age. This program provides up to $125/month that may be directed toward the cost of respite. There is additional funding available to families that are applying for or are already approved for the Lifespan Respite Subsidy funds. Please complete the Exceptional Circumstances/Needs application and if approved it can be worth up to $1,000 a contract year to help pay for outings, camps or additional Respite each month.

Sherlock Service Dog Trainin (sherlockdogtrainingllc.com): Our unique program tailors your training time aournd your schedule. The in-home approach allows handler and service dog to train in the environment they will live and work in.

Family Care Enhancement Project | Munroe-Meyer Institute | University of Nebraska Medical Center (unmc.edu): The FCEP places parent resource coordinators (PRCs) in medical clinics to provide information and support to families who have children with disabilities and special health care needs.

Health and Housing Coalition Launches First-Ever Medical Respite Program in Nebraska | Business Wire

Nebraska Caregiver Coalition | Lincoln NE | Facebook

Down Syndrome Alliance of the Midlands | Omaha (dsamidlands.org): DSA is a non-profit agency founded in 1999 and based in Omaha, Nebraska. We are parents, advocates, educators and medical professionals. DSA is affiliated with the National Down Syndrome Society, the National Down Syndrome Congress, the Global Down Syndrome Foundation and Down Syndrome Affiliates in Action.

Behaven Kids | Children Mental Health Services in Omaha, NE: Behaven Kids provides services that are centered on building hope through the mental wellness of children. We offer specialized programming options for young children and adolescents who are in need of all-encompassing care that is tailored to address the hurdles that a child may face. From outpatient therapy services to specialized day programs to medication management, Behaven Kids strives to provide the services a family needs to maximize each child and adolescent's potential for individual success.

MMI Caregivers Corner | Facebook: An MMI parent resource coordinator (PRC) is the administrator/moderator for this group and provides content but the inclusion of events and links do not imply MMI or UNMC endorsement. The Munroe-Meyer Institute may not be directly involved with all activities but we share them as a courtesy to our MMI family. MMI's community engagement department staff provide oversight for this page.

maggiewelby.org

Home | Warren G. Sanger Human Genetics Laboratory | University of Nebraska Medical Center (unmc.edu)

Lifespan-AlongtheWayGuide.pdf (unmc.edu): Directory of Resources for Individuals with Intellectual and Developmental Disabilities.

Care Coordination | Munroe-Meyer Institute | University of Nebraska Medical Center (unmc.edu): A life changing diagnosis or event may leave you feeling out of control, alone and fearful. If you are seeking answers, a clinical diagnosis, services, resources, or you are looking to determine a plan of care – care coordination is available to assist you navigate the health care system.

Home | Munroe-Meyer Institute | University of Nebraska Medical Center (unmc.edu): We transform the lives of all individuals with disabilities and special health care needs, their families and communities through outreach, engagement, premier educational programs, innovative research and extraordinary patient care. With approximately 230,000 people with disabilities in the state of Nebraska, our specialized programs and support services are vital resources.

The Heartland Genetics Services Network (heartlandcollaborative.org): The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

Angels Among Us : We provide support, comfort and hope to families battling pediatric cancer… it's our mission. Our programs are designed to further this mission and provide much needed services and support for the pediatric cancer families we serve.

Home - The Collective for Hope: The Collective for Hope combines the strength of its program brands and co-located services to lead response to loss, elevate the value of grief companionship, and promote healthy survivorship.

Comprehensive Pediatric Home Health Care | Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

NEVADA RESOURCES:

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Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

Year 6 Genetic Navigator Outreach Presentation (canva.com)

Genetic Ambassador Program - Mountain States GeneticsMountain States Genetics

Ariana Rye Foundation: The Ariana Rye Foundation was developed to help families in need of medical equipment for their children with disabilities. We help dozens of families each year get equipment that insurance companies deem unnecessary or non-essential for these children. Not only is this equipment necessary for proper development, it helps build confidence in the children and eases the burden on the families caring for them.

NEW HAMPSHIRE RESOURCES:

An-Overview-of-the-Early-Childhood-Transition-Process.pdf

Becket: Becket's mission is to create opportunities for individuals to live better lives by aligning inspired professionals who are supported and trusted to be a compassionate team with family caregivers and community resources.

Camp Allen: Camp Allen's mission is to provide opportunities for growth, friendship and fun to children and adults with developmental and/or physical challenges in an outdoor environment. Located in Bedford, New Hampshire, Camp Allen provides both day and residential camp.

New England Disabled Sports (nedisabledsports.org): New England Disabled Sports (NEDS) is a 501 (c) (3) not-for-profit organization, providing adaptive sports instruction to students of varying abilities that meet the General Essential Eligibility Criteria . It is through the generous donations of individuals, corporations, and foundations that close to 600 student-athletes living with disabilities are able to enjoy adaptive sports year-round. Headquartered at Loon Mountain Ski Resort in Lincoln, NH and at the Bretton Woods Ski Resort at Omni Mount Washington Resort NEDS has become a nationally recognized program, providing expert adaptive sport instruction to adults and children living with physical and cognitive disabilities.

Camp Bernadette & Fatima: Camp Fatima reserves a few weeks each summer to provide a fabulous camp experience to campers with special needs. Our founder was committed to providing children and adults with disabilities with a classic camp experience, and we have remained steadfast in this commitment.

CMF Kids | Crotched Mountain Foundation: CMF Kids is committed to improving educational outcomes for the hardest to reach children with disabilities. We believe every student deserves the opportunity to succeed in school and in their own communities.

Community Bridges NH - Resources - Provider List: Community Bridges coordinates direct services for individuals and families with the following vendors.

Family Connections Program: Family Connections partners families 1:1 with an altruistic approach for cross-disabilities from birth thru life span. Matches are made for a parent seeking information and/or emotional support with a parent who has experienced the same or similar situation. These connections encourage families to make better informed choices and fosters family strengthening. The success of the Family Connections program is built upon altruism, compassion and a collaborative community commitment to ensure no family is left behind.

NH Family Ties: NH Family Ties was established in 2012 when Community Bridges adopted the existing Parent to Parent USA Alliance Membership for the state of New Hampshire. In an effort to express our overall mission to Connect, Inform and Strengthen Individuals and Families, we have changed the name of the Parent to Parent program to the "Family Connections Program."

Community Bridges NH - Services - START Services (statewide): At Community Bridges, we're proud to provide the START service model across the Granite State. START stands for Systemic, Therapeutic, Assessment, Resource, and Treatment. First developed in 1988 by Dr. Joan B. Beasley and colleagues in Massachusetts, START provides services for

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individuals ages 6 throughout their lifespan who have developmental disability and co-occurring mental or behavioral health concerns. Only seventeen states in the U.S. provide START services, and New Hampshire is one of the first to offer these services statewide.

Community Bridges: Individuals with disabilities and their families work with Community Bridges to manage their unique challenges, maneuver the obstacles, and thrive in their communities. For over 35 years, Community Bridges has provided the tools and support to individuals with disabilities, so they become welcomed and active contributors to our community, and that makes it a better place for everyone!

Community Partners: We are the designated Community Mental Health Center, Developmental Services Provider and Family Support Center for NH region 9. We offer a wide variety of behavioral health and developmental services across the lifespan to individuals and families living in Strafford County.

Community Support Network, Inc.: Supporting agencies that serve individuals with developmental disabilities and acquired brain disorders.

Crotched Mountain Foundation: Since its inception Crotched Mountain Foundation, one of New England's most iconic non-profit organizations, has worked towards one goal: helping children, students, and adults with disabilities achieve maximum independence to live a great life in the community.

Easterseals New Hampshire | Home: Easterseals NH, VT & Farnum is a community of care for all ages, for all abilities, for life. We welcome your support and participation in making our programs the best they can be for those who depend on them to live life to the fullest.

Family Resource Center - Lakes Region Community Services (lrcs.org): Strong families lead to strong communities. This core belief drives the Family Resource Center of Central New Hampshire. For hundreds of families living in the Lakes Region, the Family Resource Center provides respectful, non-judgmental services to help families build resiliency, make positive connections and prepare their children for ongoing success. The Family Resource Center offers programs and services in both Laconia and Plymouth, serving families in Belknap & Southern Grafton counties.

Family-Guide-to-FCESS.pdf (picnh.org): This booklet provides a brief overview of NH's Family Centered Early Supports and Services (ESS) system. By gaining knowledge and skills you will be able to better support your child's learning and development. This guide also includes questions you can ask your ESS providers as they assist you in helping your child. We have also included resources where you can get more information and support.

FRC-June-2015-Guide.pdf (lrcs.org)

Granite State Independent Living: Today, as a statewide non-profit and New Hampshire's only Center for Independent Living, we stay close to our roots with a focus on our 5 core services of education, information, advocacy, support and transition services for people with disabilities and underserved youth. We are able to speak and think with authority on behalf of the people we serve and support because we are led by a board of directors and staff of which over 51% are people with disabilities.

HOME - ABLE NH: Advocates Building Lasting Equality in NH advocates for the civil and human rights of children and adults with disabilities; and promotes full participation by: improving systems of supports, connecting families, inspiring communities, and influencing public policy.

Home - Parent Information Center of NH (picnh.org): PIC is a statewide family organization that provides families and youth, with a focus on children/youth with disabilities/special health care needs, and the providers who serve them, with the knowledge and support they need to make informed decisions that enhance each child's development and well-being. We achieve positive outcomes through our partnerships with families, youth, educators, organizations, and others.

Institute on Disability | University of New Hampshire (unh.edu): Through innovative and interdisciplinary research, academic, service, and dissemination initiatives, the IOD builds local, state, and national capacities to respond to the needs of individuals with disabilities and their families.

Lakes Region Community Services (lrcs.org): LRCS is one of 10 designated Area Agencies in New Hampshire that provides community-based services to individuals with developmental disabilities or acquired brain disorders, and their families. NH's Area Agency system serves in excess of 10,000 individuals and families.

LifeConnections Specialized Support Services: LifeConnections Specialized Support Services was created in 2018 as a subsidiary of Becket Family of Services with a goal to create specialized service options for people with complex behavioral health and/or medical needs who were at risk of moving out of state or to higher levels of care due to the lack of service options. Today, we serve youth and adults of all ages in various settings and States, including; Maine, New Hampshire, Massachusetts, Rhode Island, South Carolina and Florida. We are nationally accredited by the Council on

Accreditation and are proud members of the National Alliance for Direct Support Professionals.

Manchester Community Music School | The Miracle Project® | Private Music Lessons| Music Lessons | Suzuki Method | Music Therapy | Music Classes| Manchester, NH (mcmusicschool.org): Miracle Project® is an all-inclusive theater and expressive arts program geared specifically towards children and young adults with autism and other special needs, as well as their typically developing siblings and peers.

MDS - HOME (mds-nh.org): For 40 years, Monadnock Developmental Services has specialized in providing individuals with developmental and related disabilities the means to live as independently as possible in their own community.

MDS - NEW HAMPSHIRE (mds-nh.org)

Medical Genetics | Dartmouth Health Children's: The Medical Genetics Department provides comprehensive diagnostic evaluations, clinical management and genetic counseling for children and adults who have a genetic condition, or are suspected to have a genetic condition. All genetic counseling and testing services are provided in a confidential setting.

New England | Autism Speaks: Serving all communities in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism, and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

New England ADA Center

New Hampshire Family Voices: New Hampshire Family Voices is part of a network of families and friends of children and youth with special health care needs/disabilities around the nation.

New Hampshire Speech-Language-Hearing Association: We are dedicated to providing students, professionals and consumers with accurate information regarding the speech, language and hearing sciences.

NH CarePath: In New Hampshire, there are many paths available to help people of all ages live better in their communities. NHCarePath connects you to a range of information, assistance, and care throughout New Hampshire, from caregiver resources and services for aging, disability and independent living to counseling and financial planning tools. NHCarePath also connects you to statewide partners that provide services and supports.

NH Developmental Services Area Map: The NH developmental services system offers adult individuals with developmental disabilities a wide range of supports and services within their own communities. All direct services and supports to individuals and families are provided through ten (10) designated non-profit area agencies .pdf Icon that represent specific geographic regions of NH.

NH EASY - Gateway to Services

Northeast Passage: Empowering individuals with disabilities to define, pursue, and achieve their Therapeutic Recreation and Adaptive Sports goals.

Northern Human Services – Support for Mental Health and Developmental Disabilities (northernhs.org): Designated as Region I by the New Hampshire Bureau of Behavioral Health and Bureau of Developmental Services, Northern Human Services, a private non-profit organization, is one of two agencies in the state designated as a service provider for both developmental services and mental health services.

One Sky Community Services - Area Agency (oneskyservices.org): Our mission is to assist people with Developmental Disabilities and Acquired Brain Disorders to live as valued and participating members in their communities.

Parker Academy: Parker Academy is a private day school located in Concord, New Hampshire designed for families seeking a small individualized program for their son or daughter. We are approved by the State of New Hampshire for grades six through twelve (ages 11-21) including special education placements by school districts.

PathWays of the River Valley: PathWays is a non-profit agency that serves people with disabilities in their home communities in Sullivan and Lower Grafton counties. PathWays works with children, adults, and their families to provide ongoing, individualized support. PathWays works with local agencies, programs and businesses to provide individuals with meaningful work, recreation and community life.

Reaching Higher NH: All children deserve an honest, high-quality, and student-centered education that prepares them for college, careers, and life. Reaching Higher NH provides decision makers, educators, and communities with the tools they need to deliver on that promise.

REM – Lovingly Restored Medical Equipment: We're here to make your life easier with affordable, safe, pre-owned equipment that you can access when you need it.

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Resources | Institute on Disability (unh.edu)

Resources | The Moore Center

Serving Families and Individuals with Disabilities or Chronic Health Conditions (communitycrossroadsnh.org): Community Crossroads' mission is to provide people in need of long term supports, either through age or disability, with the information, guidance, support and advocacy they need to remain in their chosen homes and live full, independent lives.

Sled Hockey | Northeast Passage (nepassage.org): Sled hockey is an ice sport that allows individuals with disabilities the opportunity to enjoy and participate in the popular winter sport. Sled hockey is played as a team sport and the concepts and rules are the same as "stand-up" hockey. Instead of standing up to skate, participants sit on an adaptive device known as a sled. To propel themselves, players use two shortened hockey sticks with a blade on one end and metal picks for propulsion on the other end.

Special Education Resources | Crotched Mountain Foundation (cmf.org)

STABLE NH: STABLE NH is helping Granite Staters to achieve greater independence and financial security through the power of STABLE accounts.

The Moore Center: The Moore Center serves people with intellectual, developmental and personal challenges by creating opportunities for a good life.

Therapeutic Services | Speech Therapy | NC Speak Easy (nhhorsetalk.com)

Transition from Family-Centered Early Support Services Guide: The purpose of this guide is to help families and professionals understand their roles and responsibilities in the transition process. It also includes a Transition Dictionary to clarify the language used during the transition process and to encourage clear communication among all team members.

UpReach Therapeutic Riding Center: UpReach is a 501 (c) 3 organization dedicated to inspiring hope, fostering independence and improving the physical, emotional, and psychological well-being of individuals with and without disabilities by partnering with the power of the horse.

Volunteer Advocate Training Program - Parent Information Center of NH (picnh.org): The VA program enhances PIC's capacity to reach and serve families statewide. We therefore strive to ensure that the VA network encompasses every region of the state, including rural areas and inner-city neighborhoods, and that it is representative of the families PIC serves (the full-range of disabilities, children from birth to age 26, including underserved families). To support the needs of underserved families, PIC encourages applications from parents from traditionally underserved groups (minority families, including refugee families; families in which the parents and/or children have limited English proficiency; low-income families; and parents with disabilities).

NEW JERSEY RESOURCES:

Best Accredited Jewish Special Education School | SINAI Schools: Operating inclusive special education schools for children through age 21 as well as programs for adults, SINAI is widely regarded as one of the country's leading Jewish schools for children with learning or developmental disabilities whose needs cannot be met in a regular education setting.

Family Guide to Transition Services: SPAN is pleased to provide you with this Family Guide to Transition Services in New Jersey. By providing one cohesive document on the transition process, services, and supports, we hope to make the journey easier for everyone. Transition can be a complicated time—this guide can answer your questions and can make transition a successful period for families and youth/young adults with disabilities.

FamilyMatters: FamilyMatters offers specialized case management and support services to assist families in times of crisis in Greater Philadelphia and Southern New Jersey. We serve families who are facing the impact of trauma and challenges such as mental health and substance abuse issues, divorce and custody issues, single parenthood, grandparent or other relative caregivers, and raising children with special needs.

Inclusive Playgrounds: As exclusive representatives for Landscape Structures, we are able to offer our clients outstanding inclusive playground designs and products. With a wide variety of products, and regular innovation in this product category, Landscape Structures is the leading designer and manufacturer of inclusive playground equipment. Committed to creating play spaces available to all ages and abilities, together we are the go-to local sales agency for inclusive playgrounds in PA, NJ and DE.

Joshua Harr Shane Foundation: Joshua Harr Shane Foundation helps those in need of care, support, assistance and love. JHSF is different from most non-profits because we go directly to the people who need help. Cash is never given. All bills are paid directly to their sources. The Joshua Harr Shane Foundation supports special needs programs such as horseback riding at Blue Riders Stables and Special Stride, the theatrical at the Columbia Theatre for the Arts and ski lessons through Stride, necessary special needs equipment, special needs schooling, special needs sports, and activities both in and out of school.

New Jersey Self-Advocacy Project (arcnj.org)

SCHI School - Welcome: SCHI has grown into a world-renowned, cutting-edge therapeutic and educational center dedicated to fulfilling that mission. Dedicated to helping students reach their goals, SCHIhas helped over 700 severely-developmentally delayed, medically fragile, and socially-emotionally challenged children & young adults with what they need to let their talents flourish.

Special Needs – The Chapel: We believe every person is uniquely designed by God with great purpose. It is our goal to meaningfully include those with special needs of any age in the life of The Chapel as well as to support their families, so that all may flourish.

The Arc of New Jersey | Developmental Disabilities Services & Support (arcnj.org): The Arc of New Jersey is the state's largest organization advocating for and serving children and adults with intellectual and developmental disabilities and their families.

https://www.frainc.org/

The Special Children's Center: The Special Children's Center (The Center), a 501(c)(3) non-profit, is located in Lakewood, New Jersey and Brooklyn, New York. The Center is focused on a multi-faceted service program for children and adults with complex developmental disabilities. Begun in 1996 by two compassionate teens volunteering their time to provide respite care for families with children with developmental disabilities,

NEW MEXICO RESOURCES:

Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

Genetic Ambassador Program - Mountain States GeneticsMountain States Genetics

Year 6 Genetic Navigator Outreach Presentation (canva.com)

NEW YORK RESOURCES:

Adaptive Design Association Inc.: Adaptive Design Association advances healthcare, education, and social well-being by engaging everyone—novice to expert—in building custom adaptations, discovering untapped potential, and nurturing communities that thrive with diversity.

Support for Blind and Visually Impaired Kids and Teens | Lighthouse Guild: Our Youth and Teen Programs for New York students ages 6-21 feature social and recreational activities to build self-confidence, as well as guidance, rehabilitation, and career services to prepare for life after high school. Students ages 14-20 must be legally blind to enroll.

Angela's House: Coordination of complex home care services and Residential services for medically fragile children.

Able Athletics - Inclusive Sports for individuals with special needs.: guided by our consulting partners who consist of physical, occupational & speech therapists, professional coaches, and general and special education instructors, we provide opportunities for individuals with and without learning differences, disabilities, and the need for accommodations to play sports in an inclusive and judgment free environment.

Braverhood: Formely Hand in Hand Family Services. For those struggling with developmental disabilities, medical challenges and emotional needs. Offering respite ComHab, day hab, after-school, eligibility navigation, children's waiver program, care management, self direction, HCBS and no-cost services.

Endeavor Therapeutic Horsemanship: Endeavor Therapeutic Horsemanship Inc.'s mission is to empower individuals with a broad range of needs by providing the highest quality equine-assisted services in an inclusive and welcoming environment.

Camp Kaylie: At Camp Kaylie we do not differentiate between campers with or without developmental disabilities. All campers eat together, sleep in the same bunks and enjoy a majority of activities together.

Chesed 24/7: Chesed 24/7 provides extensive and innovative services to the sick, the elderly, the developmentally disabled, and any individual or family facing a life challenge. Chesed 24/7's philosophy is that no one should ever be without food, shelter, and emotional support – no one should ever feel alone. We remain firmly committed to providing assistance whenever and wherever we can – 24 hours a day, 7 days a week.

CSB CARE – Independence Through Technology: CSB CARE's mission is to give clients independence through assistive technology. CSB CARE specializes in electronic braille for the blind and eye tracking communication and computer access for ALS and other neurodegenerative disorders.

Unique Life Inc.: Unique Life Inc. is built on the concept of person-centered planning, setting goals, and improving the quality of life for our individuals. Through enrichment programs, structured activities, volunteer work and more. We provide our individuals with a variety of resources that will allow them to live a meaningful and integrated life within their community.

David's Refuge | Caring for the Caregiver: David's Refuge partners with 22 locations throughout Central New York, the Southern Tier and Western New York. David's Refuge is for parents or guardians who care full-time at home for children with special needs or life-threatening medical conditions.

Everyday Wishes Program - Angela's House: This program utilizes donations and grants to assist families by paying for medical supplies, equipment, and other support services that cannot be funded through other means.

FACES | Finding a Cure for Epilepsy and Seizures: FACES (Finding a Cure for Epilepsy and Seizures) enables faculty and staff at NYU Langone's Comprehensive Epilepsy Center to advance exceptional clinical care, cutting-edge research, ongoing patient education, and community support programs for children, adults, families, and caregivers who live with epilepsy and seizures.

FreedomCare: FreedomCare is your leading in-home provider for patients and their caregivers. We provide you the power to select your caregiver and get them paid by your Medicaid program. Whether you're hiring your daughter, son, nephew, friend, or previously hired aide, you'll be sure you have a caregiver you can trust to help you each day, in the comfort of your own home.

Friendship Walk NYC: At Friendship Circle Upper East Side we are dedicated to bringing happiness and companionship to Jewish children, teens and young adults with special needs, as well as bringing energy, support and peace of mind to their families.

www.audreymccarton.com: This blog is about my daughter, Audrey McCarton. Audrey was born with microcephaly and is missing part of her cerebellum (MICPCH). This is due to a CASK Gene mutation. Audrey is one of 54 documented cases with a CASK Gene mutation (Now about 170!). This site started with my first blog when she was diagnosed with microcephaly and it is one of hope that I would like to share with you. The doctors told me she would never "walk, talk or be a ballerina" So she became a surfer instead! Thank you all for being a part of her amazing story #audreystory

INCLUDEnyc: Equity and access for young people with disabilities. INCLUDEnyc connects young people to resources and helps them thrive in school, at work, and in the community.

Jake's Help From Heaven: Jake's Help From Heaven, founded in 2011, is a non-profit foundation dedicated to supporting individuals with multiple medical challenges and disabilities. Countless challenges occur in caring for medically fragile, special needs individuals. Our goal is to assist individuals affected by debilitating illnesses. Jake's Help From Heaven welcomes applicants of all ages living within 100 miles of Saratoga Springs, NY.

JTCF: Provide hospitals and child-care facilities with therapeutic and recreational equipment. Support families with financial assistance to defray medical expenses. Offer sick and needy children toys throughout the holiday season. Fulfill patient's (ages birth to 18 years old) wish lists throughout the year. Assist sick and underprivileged children.

Keep Moving Forward: Founded in 2009, Keep Moving Forward Inc, became the first Intensive Physical Therapy clinic on Long Island. With its state-of-the-art gym, Keep Moving Forward Inc offers a unique and effective Physical Therapy programs for children and adults in which individuals are trained to reach their maximum potential of strength, endurance, and function. Our gym is fully equipped with the most up-to date tools and continues to evolve to provide our patients with the best interventions possible. Our staff continues grow through education courses based on the latest evidence-based practices available in Physical Therapy. With a combination of unique interventions, and up-to date continuing education, intensive programs are customized to individuals in order to overcome obstacles and smile at the victories.

New York Genome Center - A Nonprofit Academic Research Institution: The New York Genome Center (NYGC) is an independent, nonprofit academic research institution that serves as a multi-institutional hub for collaborative genomic research.

NYCKidSeq: "Bringing cutting-edge genetic testing to help diagnose health problems in children from diverse NYC families".

Ohel Children's Home and Family Services: Ohel helps adults and children with developmental disabilities find deep friendships, build strong families, foster meaningful relationships, and maintain dignified employment. We provide a full range of outpatient and residential services to individuals with developmental disabilities — while providing caring support to their families.

Pay it Forward Program - Angela's House: Angela's House Home Store accepts donations of medical equipment and supplies. When available we give it out FREE to our Angela's House families and to the public as a service to the community. We have also been able to send truckloads of equipment overseas to assist countries in need of them. We have helped THOUSANDS of families with this program. This equates to over $500,000 of equipment and supplies being donated.

Rayim: Rayim is an organization that helps people with developmental disabilities enjoy more meaningful lives by delivering high-quality supports and services to them and their families. Our goal is to enable those we serve to acquire the skills they need to live more happily and independently in the settings and communities of their choice. Our services range from Medicaid service coordination to home-based care and respite to providing financial assistance to alleviate the tremendous costs that can be incurred with an exceptional child.

Special Needs Resources on Long Island : Get your child with special needs the proper services they need in Nassau and Suffolk county.

Steffi Nossen School of Dance | Adaptive Dance: Steffi Nossen adaptive dance classes give children and adults with special needs a dance class of their own; movement is adapted so that everyone can participate and be successful. Classes encourage physical movement which promotes kinesthetic intelligence and builds gross and fine motor skills, promotes positive social interactions, self-confidence, and focus. Our dance classes also provide an opportunity for creative expression, of particular importance for children who have difficulty expressing themselves verbally or understanding emotions. Please note that this is not dance therapy.

https://guardian-study.org/

The Special Children's Center: The Special Children's Center (The Center), a 501(c)(3) non-profit, is located in Lakewood, New Jersey and Brooklyn, New York. The Center is focused on a multi-faceted service program for children and adults with complex developmental disabilities. Begun in 1996 by two compassionate teens volunteering their time to provide respite care for families with children with developmental disabilities,

Yad HaChazakah: Welcome. Yad HaChazakah-The Jewish Disability Empowerment Center works with people of all ages with obvious or hidden disabilities or ongoing health conditions to become empowered.

Yedei Chesed: Yedei Chesed was founded in 1992 with the mission of providing individualized services and supports to people with developmental disabilities and their families. Our array of programs spans from birth through the life cycle. Through the provision of personalized service, Yedei Chesed has earned a reputation as an organization that sees each of its people as individuals with their own unique needs and interests.

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NORTH CAROLINA RESOURCES:

ACCESS of Wilmington (accessilm.org): Accessible Coastal Carolina Events, Sports, and Services, Inc. - ACCESS of Wilmington - is a nonprofit organization that operates six different programs eliminating barriers to health and wellness through sports, recreation and fitness for those in our community with disabilities. ACCESS of Wilmington started in 2008 to raise funds to build The Miracle Field and Kiwanis Miracle Playground in Wilmington, North Carolina.

Age-Based Genomic Screening | Program for Precision Medicine in Health Care: ABGS is a new approach to introducing genomic screening into routine healthcare for young healthy children.

Camp Rainbow : A week-long Camp Rainbow is held each summer to help children and youth deal with the grief issues they may be facing. Trained hospice staff and volunteers lead grief-related activities -- some serious and others fun. Camp Rainbow offers a mix of recreational activities and structured creative opportunities to foster sharing and healing. The camp is designed for children and youth who have recently experienced a loss and can use tools to help them cope. Camp Rainbow is provided free of charge to children grades K-12, and space is limited.

Child Developmental Behavioral Support | Kind Connections:Family support, Provider mentorship,Consultations.

Childcare - A Friend of the Family: Whether you have an infant, toddler or school-aged child, A Friend of the Family can come to your home and provide expert care. We've been serving families throughout Georgia, North Carolina and South Carolina for over 30 years. They provide special needs care too.

CooperRiis - Residential Mental Health, Asheville, NC Anxiety, Bipolar, Depression, Personality Disorders, PTSD & Schizophrenia

Frank Porter Graham Child Development Institute | (unc.edu): The UNC Frank Porter Graham Child Development Institute transforms the lives of children and families through interdisciplinary research, evaluation, implementation, technical assistance, and outreach.

Families & Communities Rising | FCR: Families & Communities Rising, formerly Chapel Hill Training Outreach Project, is a Durham, NC based nonprofit organization with locations in Durham, Orange and Chatham Counties of NC and programs that reach nationwide. FCR was established in 1969 and is a national provider of training and technical assistance services, audiovisual and print materials, and offers direct services to children, families and communities. We are proud that our local and national programs have a longstanding success rate of enhancing the lives of children, their families and the communities they live in. Our services concentrate on families from low-income households, families caring for the elderly, children with disabilities or chronic illness, and children at risk of abuse and neglect.

Camp Blue Skies: For over 10 years, Camp Blue Skies has provided camps to adults with developmental disabilities and enhancing their lives through recreation, socialization and life skills education. Our camps are held in the spring and fall in Georgia, North Carolina, and South Carolina. At Camp Blue Skies, people who are 21 and older with developmental disabilities will enjoy recreational activities indoors and outside, along with lots of fun and friendship.

Grief Support Services | Duke Health

Hospice & Palliative Care of Iredell County : Hospice & Palliative Care of Iredell County is a community-based nonprofit organization that provides physical, social, emotional and spiritual support for those with life-limiting illnesses, as well as assistance with pain and symptom management for those with chronic conditions.

IGNITE | Program for Precision Medicine in Health Care (unc.edu): The IGNITE demonstration projects, funded through the National Human Genome Research Institute (NHGRI), incorporate genomic information into the electronic medical record (EMR) and provides clinical decision support (CDS) for implementation of appropriate interventions or clinical advice.

Me Fine: To provide hope through emotional support and financial assistance to families whose children are receiving care at North Carolina partner hospitals.

NCGENES 2 | CSER (cser-consortium.org): The North Carolina Clinical Genomic Evaluation by Next-generation Exome Sequencing 2 (NCGENES 2) study will generate evidence regarding the clinical utility of genomic sequencing as a first-line diagnostic test using a prospective randomized controlled trial that compares usual care plus exome sequencing to usual care. Patient-reported data, electronic health records data, and administrative claims data will be used to evaluate defined health outcomes, to address pressing questions about the utility of exome sequencing.

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PARADIGM Initiative: The PARADIGM initiative has a three-part mission: 1) to carry out advocacy efforts among members of underrepresented communities to increase understanding about and uptake of genomic sequencing in health care; 2) to raise awareness about careers in genomic medicine and foster diverse trainees entering genomics-related training paths, and 3) to conduct research that identifies and addresses disparities in genomic medicine.

Precision Health Genetic Screen | Program for Precision Medicine in Health Care (unc.edu): The Precision Health Genetic Screen is a blood test that screens for well-known genetic conditions. People with one of these conditions should follow special medical guidelines. The Precision Health Genetic Screening test only screens for DNA changes known to cause these genetic conditions: Inherited Breast & Ovarian Cancer Syndrome | 2 GENES, Lynch Syndrome Hereditary Colon & Uterine Cancers | 5 GENES, Familial Hypercholesterolemia Inherited High Cholesterol | 4 GENES.

Rainbow Kidz Grief Counseling: Whether you or a child you know has experienced the loss of a loved one, Rainbow Kidz is here to help you find healing and support during this difficult time. Rainbow Kidz is a unique community resource dedicated to meeting the special needs of children and their families.

Rainbow Kidz Parent Guide

Special Needs Resources: The following web sites provide information about resources for children with Special Needs.

STEMIE: The STEM Innovation for Inclusion in Early Education (STEMI2E2) Center aims to: Develop and enhance the knowledge base on engagement in STEM (science, technology, engineering, and mathematics) learning opportunities for young children with disabilities (O-5) Implement high-quality technical assistance and professional development to increase engagement for young children with disabilities in STEM opportunities; and Engage partners and stakeholders from diverse disciplines and industry in work to increase the inclusion of young children with disabilities in early high-quality STEM learning experiences.

Tar Heel Reader | Books for beginning readers of all ages: Welcome to the Tar Heel Reader, a collection of free, easy-to-read, and accessible books on a wide range of topics. Each book can be speech enabled and accessed using multiple interfaces, including touch screens, the IntelliKeys with custom overlays, and 1 to 3 switches.

The Children's Cochlear Implant Center at UNC: To preserve and/or restore the hearing of all individuals through high-quality patient care, research, teaching, and service.

Victory Junction: Free from the confines of disease, illness or disability, children discover that they can just be kids! How does this happen? Victory Junction is a medically safe, yet exhilarating camp, that challenges children who have a serious medical condition to try things they never imagined possible. As they conquer activities like zip lining and archery or experience bowling, fishing or swimming, children build confidence that will shape how they view the rest of their lives.

NORTH DAKOTA RESOURCES:

The Heartland Genetics Services Network (heartlandcollaborative.org): The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

Rocky Mountain ADA: The Rocky Mountain ADA Center is proud to serve individuals and organizations throughout Colorado, Utah, Montana, Wyoming, North Dakota, and South Dakota.

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OHIO RESOURCES:

Home - Zane's Inc (zanesinc.org): Providing Services for Children and Adults with Special Needs in Northeast Ohio

All Kinds of Voices: SPEECH-LANGUAGE THERAPY FOR KIDS WITH COMPLEX COMMUNICATION NEEDS.

Aaron W. Perlman Center | Cincinnati Children's (cincinnatichildrens.org): If your child has cerebral palsy or another chronic physical condition, we can help. The experts of the Aaron W. Perlman Center are renowned for providing children who have physical disabilities with the therapy and support they need to thrive. We are a specialty center designed to address the complex therapy, developmental, assistive technology and care coordination needs of children, youth and adults with cerebral palsy and other physically limiting conditions.

Flying Horse Farms: Flying Horse Farms makes it possible for children with serious illnesses to heal, grow, and thrive.

Assistive Technology | Aaron W Perlman Center (cincinnatichildrens.org): The Perlman Center is a one-of-a-kind regional resource for helping children, youth and adults with cerebral palsy and other disabilities use assistive technology to actively participate in their environment. Through assistive technology, we are able to break through barriers of disability and chronic illness.

Home - Solon Community Living: To provide a quality, community-accessible, sustainable housing option for individuals with disabilities so they can safely live, work, socialize and thrive with the support they need.

Maryssa's Mission Foundation: The Maryssa's Mission Foundation aspires to change and positively impact the lives of families facing the challenges of caring for a medically fragile child.

Abilities First – Potential Made Possible: Abilities First empowers children and families living with differing abilities to discover and to fulfill their unique potential within their communities.

The Red Oak Family Foundation: The Red Oak Family Foundation is a registered 501(c)(3) charitable organization that supports families with family members on the autism spectrum by providing networking opportunities, social and educational events, and connections to resources.

Home - OPMP (osu.edu): Ohio Parent Mentors has helped families navigate local and state special education processes and services so that children with disabilities can get the most out of their educational experience. Using our lived experience and an evidence-based approach, we work in collaboration with families, schools, and agencies to create the conditions for success for your child.

Ohio Grandparent/Kinship Coalition – Organization consisting of kinship caregivers, kinship caregiver advocates, and agencies throughout Ohio (ohiograndparentkinship.org)

Building Blocks for Kids - Home (bb4k.org)

The Cooper Foundation Cleveland (thecoopfoundation.com)

Compassion and Kindness | Aubrey Rose Foundation

FINANCIAL ASSISTANCE FOR FAMILIES - Aubrey Rose Foundation

Early Learning and Development | Ohio Department of Job and Family Services

The Different Needz Foundation

Welcome to Kya's Krusade: Your informational resource dedicated to Arthrogryposis (kyaskrusade.org)

Kinship Caregivers Connect - Kinship Caregiver Support Group: We are an online, statewide, support groups for kinship caregivers in Ohio. We meet weekly on Zoom. This page provides more information on the group and has a resource hub for caregivers.

Ohio P2P – OhioF2F: Ohio P2P is part of the statewide Ohio Family to Family Health Information Center (Ohio F2F), based within the University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD). The UCCEDD believes that people with disabilities should and can be active, included and fully participating members of their communities. The UCCEDD's vision is that all people, including children and adults who have a disability or special healthcare need, and their family members, fully participate in society and live healthy, safe, self-determined and productive lives.

Recreation Unlimited: Recreation Unlimited typically serves approximately 2,800 individuals with disabilities and health concerns representing up to 14 physical and developmental disability groups from approximately 57 counties in Ohio and five surrounding states. Recreation Unlimited is the largest provider in the state of Ohio serving individuals with disabilities in the area of sports, recreation and education with the most comprehensive and quality program offerings.

Caregiver Assistance Network - Catholic Charities Southwestern Ohio (ccswoh.org): Through the services we provide, caregivers can learn how to take care of themselves while caring for a family member, and gain the valuable resource information they need to care for their loved ones. Importantly, caregivers can learn how to maintain a loving relationship with their family member. If you have a question about care giving, please contact us.

RePlay for Kids: non-profit organization of volunteers who repair and adapt toys and assistive devices for children with disabilities in Northeast Ohio. RePlay for Kids provides these services at no cost for non-profit organizations that provide medical, educational, or recreational resources for children with disabilities in the Northeast Ohio area.

A Kid Again - Serving Children with a Life-Threatening Condition: Year-round fun-filled adventures that allow children with life-threatening conditions to feel like A Kid Again. A Kid Again works to create a communal and interactive environment. Our program establishes ongoing, nurturing experiences that complement but do not overtake their day-to-day living.

United Way of Greater Cincinnati | www.uwgc.org

Ohio Parent Advocacy & Consulting, LLC. | Special Education Advocate: I help families of children with disabilities wade through the process of ensuring public schools provide a Free and Appropriate Education and to ensure your child's educational rights are being met.

Building Blocks for Kids - Home (bb4k.org):for Kids envisions a community where the needs of all children, regardless of their challenges, are being met. Our mission is to provide support, resources, scholarships, and hope to families who have children with physical, emotional, and/or developmental challenges.

Respite Center – St Joseph Home: The Harold C. Schott Respite Center provides a much-needed break for families caring for someone with a disability at home. Think of us as a highly-equipped hotel. Our short-term-stay model allows families to travel for work or vacation, run typical errands, reconnect and rest while we take care of supporting their loved one. Nurses and DSPs staff the designated Respite Center 24/7.

4C for Children: 4C for Children is a Child Care Resource & Referral Agency that supports everyone who cares for young children, from parents to child care providers, to ensure high-quality early education and care for all children.

Positive Leaps - Specialized Day Program: Positive Leaps Day Treatment Center mimics the look and feel of a Early Childhood Learning Center or preschool. Children (18 months to 8 years old) accepted for treatment in the Day Treatment Center have experienced significant behavioral difficulty and therefore are generally struggling to succeed at home, preschool, early grade school or when out in the community. Our trained, professional staff understands your frustration and works with your child to develop more effective behavior patterns

Ongoing Support Resources (cincinnatichildrens.org): Formerly known as the Special Needs Resource Directory, these Ongoing Support Resources connect you to local, state, national and international websites - no matter where you or your child are in your care journey.

Department of Developmental Disabilities | Ohio.gov

Comprehensive Pediatric Home Health Care | Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

Parker's Purpose | Helping Others in Need (parkerspurpose.net): The mission of Parker's Purpose is as follows: As individuals of Parker's Purpose we commit as part of our team to provide the highest level of service to individuals or groups in need. We will perform our service with integrity and respect to all individuals or groups and also hope to foster a positive self worth and self esteem to the individual giving. We will strive to provide funds and professional services, regardless of race, color and/or religion, as representatives of Parker's Purpose.

Home - Ohio SIBS: Ohio SIBS is a grassroots organization of siblings of people with disabilities that came together in 2000 to acknowledge the sibling role in the life of a person with a disability. We support siblings throughout the lifespan by connecting them with resources and creating a community of siblings that support the disability community.

Stepping Stones (Ohio) (steppingstonesohio.org): We offer a variety of educational and recreation programs for individuals with disabilities at four locations, including sites in Batavia, Indian Hill, Norwood and Western Hills. Our programs support children, teens and adults on the pathway to independence and empower them to more fully participate in their community.

[St Joseph Home | Cincinnati's Trusted Complex Disability Care Provider](): St. Joseph Home is a Cincinnati based nonprofit that provides much needed support systems for people with complex disabilities and their families. Through our residential, respite and day programs, we fill a variety of unmet needs.

[Weekend Respite Program I Stepping Stones Ohio](): In Stepping Stones' Weekend Respite program, teens and adults with disabilities find adventure on two-night retreats at our location in Batavia, Ohio. The overnight program traditionally runs September through April and offers weekend respite care in an encouraging and highly inclusive environment. Participants age 16 through 64 are invited to enjoy a two-night stay at Stepping Stones' Allyn Campus. With 47 acres, this scenic property is the perfect setting for an adventurous weekend respite and includes accessible trails, lakes for boating and fishing, in and outdoor program spaces, a commercial kitchen and more.

[TelAbility / Home](): TelAbility is an innovative, community oriented, interdisciplinary program from the UNC Department of Physical Medicine and Rehabilitation that uses telecommunications to improve the lives of children with disabilities. Using real time video-conferencing and internet technologies, TelAbility provides comprehensive, coordinated, family centered care to children with disabilities across North Carolina and offers education, training, and peer support for people who care for them.

OKLAHOMA RESOURCES:

[Red Rock Behavioral Health Services](): Oklahoma Mental Health d/b/a Red Rock Behavioral Health Services started from a small grassroots group of individuals and a budget of $50,000. Today, Red Rock BHS has become one of the largest Community Mental Health Centers (CMHC) in Oklahoma and one of the first Certified Community Behavioral Health Clinics (CCBHC), and we operate with a budget of over $50 million.

[Kids Gym Indoor Playground | We Rock The Spectrum Oklahoma City, OK](): provides children with a fun and motivational environment to help them in the areas of strength, movement, sensory processing, communication, positive behavior modification, social interactions, and self-care skills. Our unique equipment assists all children in their neurological growth and development.

[A New Leaf](): Empowering people with developmental disabilities and autism for a brighter future.

[Wings (wingsok.org)](): Wings exists to enhance the lives of adults with developmental disabilities through social, vocational and residential programs guided by principles of the Bible. Every day is approached by channeling intentionality and joy into our members' lives, which has a ripple effect on their families, our communities and those of us who are blessed to interface with them.

[Special Olympics Oklahoma](): The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.

[DOSA (dosausa.org)](): To serve dads of children with special needs by providing tools and resources that equip them to become healthier mentally, physically, and spiritually in order to lead their families well and embrace their role as a dad on special assignment.

[Home « Autism Oklahoma](): AutismOklahoma was founded by parents in Oklahoma to improve quality of life and create opportunities for our loved ones with autism. We provide a platform for parents, providers, professionals and community partners who have a heart to serve families affected by autism. Creating unique opportunities is our secret for Quality of life, for life!

[Evolution Foundation](): The Evolution Foundation provides resources , support, and technical assistance to families, community coalitions, and children behavioral health service providers in the state of Oklahoma.

[Ability Connection Oklahoma (acok.org)](): Ability Connection Oklahoma is a non-profit organization serving children and adults with disabilities, statewide. Our mission is to...Advance the independence, productivity and full citizenship of people with cerebral palsy and other physical disabilities.

ABLE (okable.org): ABLE provides a vocational and residential program for special needs adults in the Norman, Oklahoma area.

Ally's House | Camp Live-A-Dream: Camp Live-A-Dream is a camp sponsored by Ally's House that allows young people who have ever been diagnosed with cancer to enjoy everything that makes summer and summer camp special. At Camp Live-A-Dream, we provide a normal, active, and safe camp experience where children can celebrate life through their cancer journey.

Ally's House | Supporting Oklahoma kids with cancer: Ally's House was established in 2004 as a 501(c)3 non-profit organization to provide support to pediatric cancer families of Oklahoma. This support is primarily in the area of financial assistance. To date, Ally's House processed more than 1,200 financial assistance applications for our families.

KJE - Kids Joining Eternity: Kids Joining Eternity was formed in Central Oklahoma with the intent to help parents, siblings, family members, friends and caregivers come to terms with the loss of a child whether it be through miscarriage, stillborn loss, sudden infant death, and/or chronic childhood illness.

Hearing Aids Oklahoma City, OK - Hearts for Hearing | Audiologist (heartsforhearingaids.org): Hearts for Hearing was established in 2003 to provide funding for the initial set of hearing aids for children with hearing loss in Oklahoma. In 2007, the mission was expanded to become a comprehensive hearing health program for both children and adults, offering auditory-verbal therapy. In 2013, to meet the growing demand for adult hearing healthcare, the mission expanded again to open a clinic specifically designed for adults.

Camp Claphans: Camp Claphans is a residential summer camp for kids with disabilities ages 8 to 20 and is an outreach program of the McCarty Center. Six camp sessions are offered each summer. The camp is located on the center's campus and features two cabins and an activities building that are located next to an 11-acre lake. Activities for campers include archery, arts and crafts, canoeing, fishing, horseback riding, talent shows and swimming. Each camper is assigned to a counselor with the camper/counselor ratio of 1:1. Our staff members are typically university students working toward a degree in allied health-care fields (physical therapy, occupational therapy, speech-language pathology); special and general education; outdoor recreation; nutrition; and other related fields. Prior to camp, staff members attend training.

Camp Courage - Calm Waters: Camp Courage is a half-day art camp over three days at Calm Waters. Camp Courage is for children who have experienced a recent loss through death, divorce, incarceration, deportation, deployment, and/or foster/adoptive care issues.

Camp Erin | Tristesse Grief Center (thegriefcenter.org): Camp Erin Tulsa is a free, overnight bereavement camp for youth who are grieving the death of a significant person in their lives. Children and teens ages 6 to 17 attend a weekend camp experience that combines grief education and emotional support with fun, traditional camp activities. Led by bereavement professionals and caring volunteers, campers are provided a safe environment to explore their grief, learn essential coping skills, and make friends with peers who are also grieving.

Catholic Charities of Eastern Oklahoma (cceok.org)

Cavett Kids: We offer camps and year-round programs completely FREE of charge, for kids with chronic and life-threatening illnesses. Our programs allow them to have fun while also connecting to others with similar medical conditions.

Cleaning for a Reason – Free house cleaning for cancer patients: Cleaning for a Reason provides free home cleaning to patients battling cancer. When cancer makes life at home difficult, our trusted network of residential cleaners, cleaning industry volunteers, and community volunteers come together to support cancer patients and their families.

CSC Tulsa 211 Oklahoma Statewide - CSC Tulsa: 211 is a 24/7 free service available to all Oklahomans across 77 counties operated by two nonprofit organizations: Heartline, Inc. for the western half of our state, and the Community Service Council for the eastern half. Through a direct phone call, live chat, text message or online search, certified resource specialists in Oklahoma City and Tulsa connect people across the state who need help to the social services in their area that can help. We monitor our database continuously for accuracy, and also serve as a clearinghouse for disaster resources during community emergencies.

DDS Provider List (oklahoma.gov): Provider Agencies contracting for Community Services through Developmental Disabilities Services Division (DDSD). The following is a list of current contracted providers.

Deaf Blind Project (ou.edu): The Oklahoma Deaf-Blind Technical Assistance Project (OKDBTAP) provides technical assistance and training to children (birth to 21) who have both a hearing and vision impairment. Services are offered at no cost to families, educators, administrators, related service providers, and early intervention providers. This project is supported by the U.S. Department of Education, Office of Special Education Programs (OSEP)

Developmental & Behavioral Pediatrics for Children in Oklahoma | Okahoma Children's Hospital OU Health: At OU Health Physicians in Oklahoma City, you'll find expert developmental and behavioral pediatric specialists as well as child and adolescent and psychologists, who work with you and your child to develop an accurate diagnosis and an individualized treatment plan to address the specific issues.

Home - Disability Advocate of Oklahoma (disabilityadvocateok.com): We at Disability Advocates of Oklahoma (DOA) assist Parents in developing Individualized Education Plans (IEPs) for their children with special needs. We also assist families in obtaining all benefits and services available to children with special needs as guaranteed by Federal and State law.

Down Syndrome Association of Central Oklahoma: The Down Syndrome Association of Central Oklahoma, Inc. is a 501(c)3 non-profit founded in January 2000, by parents of children with Down syndrome. The purpose of the organization is aligned with its mission which is "raise awareness and provide resources, as well as promote acceptance and inclusion for people with Down syndrome."

Down Syndrome Association of Tulsa: The Down Syndrome Association of Tulsa (DSAT) is a non-profit organization that exists to enhance the lives of individuals with Down syndrome, their families and communities. This is accomplished by fostering positive attitudes & opportunities for people with Down syndrome via empowerment, inclusion, educational events & purposeful connections while celebrating their extraordinary lives.

Down Syndrome Association of Tulsa - State and Federal Resources (dsat.org)

F.A.I.T.H.KIDS: We are a non-profit 501(c)3 organization that helps local community outreach programs, local charities and local kids fighting life threatening illnesses. We provide financial assistance to families with children battling life threatening illnesses. Many families need help with the most basic needs for their families during this fight for their child's life. Some must leave work for months and even years to care for their sick child and the financial loss can be devastating. Our goal is to help as many families being treated locally as possible.

Families Fighting Childhood Cancer – Oklahoma Family Network: Families Fighting Childhood Cancer (FFCC) is a support network through Oklahoma Family Network that provides resources and emotional support for families who have a child with cancer or a blood disorder. Our staff and family support parents have walked the challenging path of having a child diagnosed with cancer or a blood disorder. They can provide a listening ear, share their experiences, ease your fears and give you hope.

Go Mitch Go: Go Mitch Go is a group of athletes that combine our passion for athletic challenges with our desire to give back—fighting the big cancer fight. GMG helps all levels of athletes train and compete in endurance events all around the world while raising money specifically for cancer research and patient services

Calm Waters: We help children and families in their grief journey caused by death, divorce, or other significant loss.

Rainbow Fleet Child Care Resource and Referral: We provide innovative child development programs and services that enhance the quality of life in Oklahoma.

United Way Payne County: Improve lives of individuals in Payne County by uniting resources. Many think of United Way as simply an organization that provides funds to other nonprofits, but we have evolved beyond that to a very different organization. United Way of Payne County is a "Collective Impact" organization. Our real power comes from bringing together local nonprofits, businesses, elected officials and community leaders to collaborate and implement solutions to some of our community's most pervasive challenges.

The Brain Injury Alliance of Oklahoma: The Brain Injury Alliance of Oklahoma (BIA-OK) is Oklahoma's foremost advocacy organization serving persons with traumatic/acquired brain injuries (TBI/ABI), their families, professionals and the community. As a 501(c)(3) non-profit organization, we strive to educate lawmakers and the public about all matters related to brain injury and connect those affected by brain injury to community resources.

MPower (mpowerok.org): MPower, formerly known as the Sheltered Workshop for Payne County (SWPC), was established in 1969 to provide services to individuals in Payne County with developmental disabilities.

NewView Oklahoma (nvoklahoma.org): Since 1949, NewView Oklahoma has served as a life-changing source of hope and empowerment for those in Oklahoma living with blindness and low vision. We strive to restore the independence that so many fear they may have lost.

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parentPRO: parentPRO promotes Oklahoma families with young children by linking you with programs that best fit your family. Many of Oklahoma's parenting programs can be provided in the convenience of your home. No need to find childcare or transport the family to the clinic. Professionals help reduce the stress that comes with being a parent by modeling skills, providing information, and connecting to resources.

Tristesse Grief Center: The Grief Center offers an innovative approach to address Oklahomans' need for grief counseling to assist the bereaved as they journey towards improved health and renewed sense of worth in the wake of loss.

Home Page (oklahoma.gov): Our mission is to help individuals with developmental disabilities and their families help themselves to lead safer, healthier, more independent and productive lives. Developmental Disabilities Services (DDS) serves persons ages 3 and up who have a primary diagnosis of intellectual disabilities. Persons served may also have other developmental disabilities in addition to intellectual disabilities such as autism, cerebral palsy, Down syndrome, etc.

smilesforsophieforever: Our Foundation is dedicated to honoring Sophie's memory by providing financial support to those families burdened by pediatric brain tumors through the "Smiles For Sophie Forever Endowment Fund" at University Hospitals Rainbow Babies & Children's Hospital of Cleveland, by increasing global awareness of pediatric brain tumors and by providing financial support to St. Jude Children's Research Hospital where Sophie was treated, and other viable organizations committed to the treatment of pediatric brain cancer.

https://earcinc.org: Our mission is to provide a better quality of life and encourage greater independence to individuals with developmental disabilities. What started out as a way to increase public awareness and education about developmental disabilities, has become an organization that provides employment and residential services to adults living with developmental disabilities.

Kaleidoscope Grief Support | Norman, OK: The mission of Kaleidoscope is to provide peer support in a safe and understanding environment for children and their families who are grieving the death of a loved one.

Larry W. Brummett Foundation: The foundation's primary focus is to provide financial or negotiated in-kind support to cancer patients for essential needs that assist in daily living and/or help in normalizing life in a way that is otherwise unmet by other charitable organizations.

LeadLearnLive: To establish, raise awareness and support degree and/or certificate inclusive post-secondary education programs for students with Intellectual/Developmental Disabilities in Oklahoma that increase independence, social skills, academic abilities and career development..

Making Life Work Is Our Life's Work - Bios (bioscorp.com): BiosHome provides support at home and in the community. We are dedicated to improving the lives of people with intellectual and developmental disabilities in Oklahoma and Tennessee.

OKDHSLive!: The OKDHSLive! web site is an easy way to see if you might be eligible for Food Benefits or SoonerCare Medicaid. You may also use this web site to renew your eligibility for SNAP, SoonerCare or Child Care: or to request (apply for) these benefits. Key information about those benefits is also available below.

Oklahoma ABLE Tech: ABLE Tech is funded through the Administration for Community Living of the U.S. Department of Health and Human Services, made possible through the Assistive Technology (AT) Act of 1998, as reauthorized in 2022. Our mission is to improve the lives of all Oklahomans by providing assistive technology (AT) devices and services, financing opportunities, digital accessibility services, advocacy, and education.

Oklahoma Family Network: The Oklahoma Family Network (OFN) informs and connects individuals with special health care needs and disabilities, their families, and professionals to services and support in their communities.

Home - Oklahoma STABLE (okstable.org): Oklahoma STABLE is helping Oklahomans to achieve greater independence and financial security through the power of STABLE accounts.

Oklahoma | RareAction Network

(1) Oklahoma Rare Action Network | Facebook

Oklahoma Parents Center: The OPC specializes in special education support for people with disabilities from birth to age 26 and their families. We have been providing services to Oklahoma parents and family members of children with disabilities, young adults with disabilities, and the professionals who serve them since 2000!

Oklahoma Sibling Leadership Network (ouhsc.edu): Sooner SUCCESS launched OKSIBS in 2017 and is now an official recognized chapter of (SLN) - www.siblingleadership.org. SLN is a national nonprofit based out of Chicago, IL and is dedicated to providing support and information to siblings of people with disabilities across the lifespan. This program is for

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adult siblings that have grown up with a brother or sister with special needs. We are currently looking for adult siblings to get together with other adult siblings in a relaxed social environment. If you are interested to learn more, please contact sooner-success@ouhsc.edu.

Oklahomans for Independent Living (oilok.org): Oklahomans for Independent Living (OIL) is a nonprofit, consumer controlled, free standing organization that was formed in the spring of 1985 as the direct result of a public forum on disabilities sponsored by the City of mcAlester's Mayor's Committee on Disability Concerns and the Oklahoma Department of Human Services Rehabilitation Division. Since then, OIL has connected numerous individuals with resources they need to live freely and happily.

On the Road Conference (ouhsc.edu): A one day conference that assists families and caregivers, who live with an individual with a disability, navigate a complex system.

Online Resources (ouhsc.edu)

Pervasive Parenting Center: Pervasive Parenting Center is a not-for-profit organization made up of families, local educators, community leaders, and health-care professionals. We strive to provide a better life for the families in eastern Oklahoma who are coping with disabilities because we work and live with those same issues every day. Our passion is to provide assistance to families in eastern Oklahoma affected by autism and other developmental disabilities.

Oklahoma Autism Center

SFFLC | Sports & Fitness Complex: THE MISSION OF THE SANTA FE FAMILY LIFE CENTER IS TO IMPROVE THE HEALTH OF OKLAHOMANS BY PROVIDING SPORTS AND FITNESS PROGRAMS FOR ALL ABILITIES.

Hoofbeats For Hope: Equine Assisted Activities for Kids and Adults with Special Needs.

Coffee Creek Riding Center: The mission of Coffee Creek is to help children with disabilities gain strength, coordination, balance, and self-image – utilizing the horse as a motivator in therapeutic riding classes.

OKFD.org – Caring for Adults with special needs since 1960: Our mission is to improve the quality of life for adults in central Oklahoma with specialized developmental needs by providing them with high-quality and transformative learning programs and services that include life skills training, recreational activities, and socialization inclusion opportunities in a safe, caring, and compassion-focused environment.

Podcast Topics and Categories – Oklahoma Family Network

Programs for Adults with Intellectual Disabilities (pathwaysok.org): HELPING ADULTS WITH INTELLECTUAL DISABILITIES LIVE HAPPIER, HEALTHIER, AND MORE ENRICHING LIVES.

Residential Service | Measurable Training | Fretzpark Homes: Fretzpark Homes is dedicated to providing superior, quality, residential service to people with developmental disabilities and their families.

RESOURCE CENTER | Rainbow Fleet: Our Resource Center is stocked with developmentally appropriate toys, books and games. It is available for anyone to utilize with an annual membership fee of $40. Membership at Rainbow Fleet means cost savings for you.

Resource Directory – Oklahoma Family Network

Resources – Oklahoma Parents Center

Resources | INTEGRIS Health (integrisok.com): It is the hope that this page will serve as a resource for you and your family.

Resources | parentPRO

resources_and_facilities_with_disability_services.pdf (dsaco.org)

Respite Locator - OK Cares: Respite is planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver. Please click on the respite programs below to determine which best fits your caregiving situation.

Respite Voucher Program (ouhsc.edu): Respite vouchers let caregivers hire another person to temporarily care for their loved ones. The Lifespan Respite Grant Voucher program provides respite services for caregivers who do not qualify for other respite programs.

Respite Voucher Programs (ouhsc.edu)

Savannah Station TRP - Home: At Savannah Station Therapeutic Riding Program our mission is to offer Hope and Healing to people with special needs through the amazing power of the Horse.

Sibshops (ouhsc.edu): Sibshops are opportunities for brothers and sisters of children with physical, developmental or intellectual disabilities or mental health concerns, to obtain peer support and education within a recreational context. The workshops are lively, pedal-to-the-metal celebrations of the many contributions made by brothers and sisters. Sibshops acknowledge that being the brother or sister of a person with special needs is for some, a good thing, for others a not-so-good thing, and for many, somewhere in between. Sibshops are 3 hour events open to school-aged children 5-15, generally held monthly during the school year, offering lively, recreational activities facilitated by trained volunteers. Information and discussion activities are interspersed with fun games and age-appropriate programming.

Sooner Success (ouhsc.edu)

Sooner Works (ou.edu): The University of Oklahoma's Sooner Works is a comprehensive integrated program for students with an intellectual or developmental disability who desire a postsecondary experience on a college campus. Sooner Works started the fall of 2019. The program is a four-year certificate program offering a college experience to prepare participants for competitive employment and independent living through a combination of coursework and career exploration. Students in Sooner Works live on campus and take traditional university courses in conjunction with courses specific to Sooner Works. In addition, students participate in internships and social organizations on the beautiful University of Oklahoma campus.

SoonerStart Families | Oklahoma State Department of Education

Special Education | Oklahoma State Department of Education: OSDE Special Education Services is committed to providing guidance and support to promote excellence in education from infancy to adulthood for children with disabilities as outlined in the Individuals with Disabilities Education Improvement Act (IDEA).

Special Care, Inc. - Oklahoma City, OK (specialcareinc.org): To nurture all children with and without special needs in safe, inclusive and supportive environments through education, therapeutic intervention and community acceptance.

Oklahoma Adaptive Sports Association (okasa.org): Our mission is to develop, sponsor, and promote recreational and competitive athletic opportunities for individuals with physical challenges.

Stillwater CARES: Stillwater CARES is a nonprofit community benefit organization that is dedicated to helping people who help people. Stillwater CARES exists to assist other organizations to collectively address the prevention and alleviation of poverty in relational and responsible ways. We specialize in coordinating strategic community alliances and synchronizing best practices so that the maximum number of people can be served with the available community resources.

Supporting Parents with Disabilities (ouhsc.edu): Resources and Information on Supporting Parents with Disabilities.

The Arc of Oklahoma: The Arc of Oklahoma's mission is to promote and protect the human rights of people with intellectual and developmental disabilities (IDD) and actively support their full inclusion and participation in the community throughout their lifetimes.

The Heartland Genetics Services Network: The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

The Isaiah Alonso Foundation: We are a registered 501(c)(3) public charity founded in September of 2010 in memory of 6 year old Isaiah Alonso. Heading the foundation are Isaiah's parents Cheryl and Vinnie Alonso. Together they share a passion to keep the light of Isaiah forever flickering. One way this is accomplished is by helping other families and raising awareness for Childhood Cancer.

The Kids' Place: The Kids' Place is a faith-based support group for children and teens that are experiencing mourning after the death of a loved one or friend. We offer a safe and supportive environment where the children can recognize and learn to share their feelings. Children experiencing the death of a loved one or friend very often feel alone and isolated. Children may feel sad, scared, confused, angry and even guilt over the death. They may hide their feelings because they do not want to burden you or they do not know how to express what they are feeling.

Tulsa Community Foundation (tulsacf.org): In 1998, TCF was established to assist nonprofit agencies, corporations, individuals and families with flexible charitable giving solutions.

Tulsa, OK Sibshops | Facebook

United Way of Central Oklahoma: United Way of Central Oklahoma is committed to improving the health, safety, education and economic well-being of individuals and families in need in central Oklahoma by connecting community resources with responsive and accountable health and human services agencies.

United Ways in Oklahoma | United Way Worldwide

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J. D. McCarty Center: We work to enrich the lives of children with developmental disabilities and equip them with resources and support to enhance their skills. We provide medical care and physical, occupational, ABA and speech and language therapy for children on an inpatient and outpatient basis. We also offer specialized clinics for children and resources for families.

WovenLife, Inc.: WovenLife offers a Child Development Program for children ages birth through five-years-old, an Adult Day Health Center for adults and seniors, and onsite Speech, Physical, and Occupational Therapy. All programs are inclusive to people living with or without a disability.

OREGON RESOURCES:

The Dougy Center for Grieving Children & Families | Portland, OR: Dougy Center provides support in a safe place where children, teens, young adults, and families who are grieving can share their experiences before and after a death. We provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children in grief.

My Little Waiting Room | Providence: My Little Waiting Room™ offers a fun, safe, drop-in child care environment for children whose families are tending to medical appointments or visiting patients at Providence St. Vincent Medical Center or Providence Portland Medical Center. The program is designed specifically for children aged 6 weeks to 10 years old.

Direction Service :In 1976, Direction Service began a heartfelt ambition to provide a space where people with disabilities and special needs would be treated with respect, dignity, and compassionate care, regardless of their situation. Today, Direction Service continues that legacy of service as a multi-program family support nonprofit serving all of Lane County. Guided by our five core values, we operate as an independent and private agency with offices in Springfield and Eugene. With funding from local and federal partners, our services are accessible throughout Lane County.

Special Education: A Guide for Parents and Advocates (squarespace.com): This Guide was written to provide parents and advocates with accurate information and answers to questions about special education for children enrolled in Oregon's public schools from Kindergarten to 21 years of age. The information in the Guide reflects recent changes to the major federal and state laws and regulations that affect special education.

FACT Oregon: FACT Oregon empowers families and transforms how communities perceive disability. Our peer support, trainings, and resources equip and empower families, transform how they see disability, and help them have high expectations and dream big dreams for their children. We support families to navigate disability and special education, drawing on the lived experience of our team, many themselves parents of youth experiencing disability, and we call out the critically important role of parent/caregiver as a child's number one fan and advocate.

Northwest ADA Center | ADANW (nwadacenter.org): he Northwest ADA Center is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and is part of the ADA National Network(link is external). The ADA National Network Centers are a national platform of ten centers comprised of ADA professionals and experts charged with assisting businesses, state and local governments, and people with disabilities as they manage the process of changing our culture to be user friendly to disability and the effect the variety of health conditions can have on society. The regional advisory committee and our state partners are premier leaders in ADA compliance in each of the states served--Alaska, Idaho, Oregon, and Washington.

The Western States Regional Genetics Network: The Western States Regional Genetics Network, formerly known as the Western States Genetic Services Collaborative, is a federally-funded, multi-state project that seeks to increase access to genetic services and education for medically underserved populations. The participating states and territory are Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. The Western States Regional Genetics Network, formally known as the Western States Genetic Services Collaborative, is a federally-funded project that seeks to improve access to genetic services and education for medically underserved populations. By working together as a region to increase access to and reduce disparities in clinical genetic and newborn screening services, the participating states/territory seek to improve the health of individuals with or at risk for heritable disorders.

Wheel to Walk Foundation: Wheel to Walk Foundation is a non-profit organization that helps children with disabilities, 20 years and younger, obtain medical & adaptive equipment or therapy services not provided by insurance. Our organization strongly believes that no child or young adult with special needs go without items that could improve the quality of their daily life. If you live in Oregon, Washington, Idaho or California and need assistance, please contact us and we will send you an application.

Disability Rights Oregon (droregon.org)

Children's Intensive Therapy NW: At Children's Intensive Therapy NW we provide advanced individualize treatment and a lifetime of follow-up care to newborns, infants, children, adolescents, and into young adult hood with disabilities and/or complex medical needs.

PENNSYLVANIA RESOURCES:

Reagan's Journey: Often times, insurance will only cover one piece of equipment every five years. That is a hardship to families when children experience growth spurts and developmental changes. We've been able to partner with many local agencies, therapists, and hospital social workers to keep our closet full of equipment and supplies.

Pediatric Palliative Care Coalition: Pediatric Palliative Care Coalition (PPCC) is a Pennsylvania-based statewide coalition providing information and resources for families of children with life-limiting conditions, and for the medical providers who support them.

TeamPHCA: TeamPHCA is a social services agency, founded to support adults with special needs, ID, down syndrome and autism. TeamPHCA utilizes community resources to support individuals with housing, job/volunteering opportunities and meaningful lives. Between our staff, partnerships, community, families and individuals - over 100s of people trust us to secure the most valuable resources to provide individuals with the highest quality of care, whilst ensuring the highest level of compliance. Our highly trained staff are certified and our person-centered approaches allow us to develop a life-course framework designed to support everyday lives in everyday ways!

Judith Creed Horizons for Achieving Independence: Judith Creed Horizons for Achieving Independence (JCHAI) is a multi-faceted organization with cutting-edge inclusive, supportive vocational programs and living options that serves nearly 200 adults with intellectual disabilities and autism throughout the community.

Respite Care Program Brochure: For an eligible child or adult, a family will receive a predetermined budget for Respite Care services, and additional funds available for each additional eligible family member, per year (June 1–May 31). The family selects a provider and the provider receives reimbursement by submitting the Request For Payment form to the Department of Human Services Respite Care Program Specialist.

SD Department of Human Services | Respite Care Program: For an eligible child or adult, a family may receive authorization to receive up to $600.00 of Respite Care services; with $200.00 for each additional eligible child or adult, up to a maximum of $1000.00 per family, per year (June 1-May 31). The family selects a provider and uses the Request For Payment form to purchase Respite Care Services. The provider receives reimbursement by submitting the Request For Payment form to the Department of Human Services Respite Care Program

Center for Creative Works - a progressive art studio in Philadelphia: The Center for Creative Works is a unique art studio focusing on developing creative workplace potential and cultural identity for people with intellectual disabilities. With locations on the Main Line and Kensington, we work with artists in the Philadelphia area and beyond.

Clover Genetics: Clover Genetics focuses on the utilization of our national telehealth services to increase accessibility to genetic healthcare. We partner directly with patients, providers, and the community at large to provide genetic counseling, facilitate genetic testing, or offer other personalized solutions.

Adaptive Dance - Pittsburgh Ballet Theatre (pbt.org): Designed for students with autism spectrum disorders or other sensory sensitivities. We emphasize creative movement principles and modified ballet technique in a welcoming and structured studio environment. Classes are taught by PBT School instructors experienced in adaptive dance with limited space available. Live music/percussion accompanies each class.

Caregivers may observe and/or participate in classes if they wish.

Gwendolyn's Gifts – Make a Difference Today for Someone Who's Fighting for their Tomorrow (gwendolynsgifts.org): Our Mission is to provide emotional support and financial support to families of children on palliative and/or hospice care. We strive to spread joy by delivering Smile Bags, celebrating holidays, and/or fulfilling a special request for a child on hospice care. Additionally, we strive to provide financial assistance to relieve the heavy financial burden associated with caring for a child with a terminal diagnosis. Overall, we strive to make a difference today for any child fighting for their tomorrow!

Now I Can Foundation: Now I Can stands apart from other physical therapy centers in many ways, including the use of the Intensive Model of Therapy (IMOT). Our therapists treat patients 4 hours a day, five days a week for intensive sessions, Now I Can physical therapists design a tailored program for each patient to help them reach their greatest level of independence. Over the course of a three-week intensive session, children reach their goals and gain developmental skills as therapists have the needed time to use repetition and all the tools at their disposal to help kids meet their potential. It's very common for patients to make more progress in three weeks of intensive therapy than they do in 12 months of traditional therapy!

Fred's Footsteps: Fred's Footsteps provides financial relief to working families in the Philadelphia region who find themselves in a crisis due to the costs associated with caring for a seriously ill, injured, or disabled child.

FamilyMatters: FamilyMatters offers specialized case management and support services to assist families in times of crisis in Greater Philadelphia and Southern New Jersey. We serve families who are facing the impact of trauma and challenges such as mental health and substance abuse issues, divorce and custody issues, single parenthood, grandparent or other relative caregivers, and raising children with special needs.

Canine Partners for Life: The mission of Canine Partners for Life is to increase the independence and quality of life of individuals with physical, developmental, and cognitive disabilities or who are in other situations of need. We achieve our mission by providing and sustaining professionally trained service and companion dogs. CPL's primary efforts will be focused on an area within a 250-mile radius of Cochranville, Pennsylvania, but we look forward to continuing to place dogs with recipients from across the nation who come to us because our dogs and services are held in such high regard.

INCLUSIVE PLAYGROUNDS - Inclusive Playgrounds: As exclusive representatives for Landscape Structures, we are able to offer our clients outstanding inclusive playground designs and products. With a wide variety of products, and regular innovation in this product category, Landscape Structures is the leading designer and manufacturer of inclusive playground equipment. Committed to creating play spaces available to all ages and abilities, together we are the go-to local sales agency for inclusive playgrounds in PA, NJ and DE.

New Hope Assistance Dogs Inc.: New Hope Assistance Dogs Inc., is a non-profit 501(c)(3) organization located in Warren, Pennsylvania. We provide custom trained Assistance Dogs for seizure, mobility, hearing, PTSD related issues and a multitude of other disabilities for both children and adults.

Service Dogs for People With Disabilities | UDS Foundation (udservices.org): UDS service dogs are trained from pups for over two years by a team of dedicated volunteers and professionals. Then, they're partnered with people who have a mobility disability, autism or PTSD to help them live fuller lives. We're here to provide help with get a service dog in PA.

RESOURCES | Wersnc (specialneedsconsortium.org): Working together to increase the awareness of resources available to the special needs community through networking, promotion, and advocacy. We exist to provide a place where all services and opportunities can be shared to support families and individuals.

Selah's Rest | Free Rentals for Moms — Selah's Heart (selahsheart.org): Selah's Rest provides mom's a peaceful place to get away and rest. We currently have 2 Air BnB locations in Lancaster, Pennsylvania where moms are able to take some time for themselves, free of charge. If you're interested in staying at one of these locations for a few days, let us know.

RHODE ISLAND RESOURCES:

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Joey's Fund Grant Program | Spectrum for Hope Fund | Flutie Foundation: Today, Joey's Fund serves as a crucial funding bridge for autism families who are advocating, promoting, supporting and seeking out opportunities for their loved ones. Since its inception, 193 families have received over $375,000 in financial support, making their journey just a little bit easier. Must have one family member medically diagnosed with Autism Spectrum Disorder and reside in New England (Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire & Maine). Families are only eligible to apply if they have not received funding in the previous year.

New England | Autism Speaks: Serving all communities in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism, and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

Becket: Becket's mission is to create opportunities for individuals to live better lives by aligning inspired professionals who are supported and trusted to be a compassionate team with family caregivers and community resources.

Paul V. Sherlock Center on Disabilities (ric.edu): The Sherlock Center, founded at Rhode Island College in 1993, is a University Center for Excellence in Developmental Disabilities (UCEDD). UCEDDs are evidence driven and designed to advance policies, practices and research that improve the health, education, social and economic well-being of people with disabilities, their families, and their communities. The Sherlock Center is also a LEND (Leadership Education in Neurodevelopmental and Related Disabilities) Program.

Rhode Island Developmental Disabilities Council | RIDDC: The Rhode Island Developmental Disabilities Council believes that people with developmental disabilities should fully participate in community life. Men, women, and children should be able to enjoy family life. Children and adolescents should go to school. Adults should work. All should have decent homes, have friends, and live as independently as possible.

Rhode Island Resources | RIDDC

Disability Rights Rhode Island (drri.org): Our mission is to assist Rhode Islanders with disabilities in their efforts to achieve full inclusion in society and to exercise their civil and human rights through the provision of legal advocacy.

LifeConnections Specialized Support Services: LifeConnections Specialized Support Services was created in 2018 as a subsidiary of Becket Family of Services with a goal to create specialized service options for people with complex behavioral health and/or medical needs who were at risk of moving out of state or to higher levels of care due to the lack of service options. Today, we serve youth and adults of all ages in various settings and States, including; Maine, New Hampshire, Massachusetts, Rhode Island, South Carolina and Florida. We are nationally accredited by the Council on Accreditation and are proud members of the National Alliance for Direct Support Professionals.

SOUTH CAROLINA RESOURCES:

Box of Hope (childandfamilyresourcefoundation.com): send a Box of Hope to a grieving child. Each box is filled with therapeutic items and activities to help heal their heart through the journey of grief.

Camp Blue Skies: For over 10 years, Camp Blue Skies has provided camps to adults with developmental disabilities and enhancing their lives through recreation, socialization and life skills education. Our camps are held in the spring and fall in Georgia, North Carolina, and South Carolina. At Camp Blue Skies, people who are 21 and older with developmental disabilities will enjoy recreational activities indoors and outside, along with lots of fun and friendship.

Childcare - A Friend of the Family: Whether you have an infant, toddler or school-aged child, A Friend of the Family can come to your home and provide expert care. We've been serving families throughout Georgia, North Carolina and South Carolina for over 30 years. They provide special needs care too.

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Children and Family Services | DDSN (sc.gov): The South Carolina Department of Disabilities and Special Needs (DDSN) is the state agency that plans, develops, coordinates and funds services for South Carolinians with the severe, lifelong disabilities.

Medicaid Home and Community-Based Waiver Services | DDSN (sc.gov)

Darlington County First Steps: Darlington County First Steps is a county partnership of South Carolina First Steps, serving Darlington, Hartsville, Lamar, and Society Hill communities. We offer several programs that focus on parenting, school transitioning, and health.

Upstate Family Center (upstatefrc.org): We are a non-profit organization located at 1850 Old Furnace Road in Boiling Springs, South Carolina. We provide families tools, guidance, and encouragement to become self-sufficient and strong. Our focus is to support and strengthen families in the Boiling Springs and Chesnee communities through assistance and educational programs.

The Parenting Place (tppupstate.org): To build relationships and provide services, resources and support to prevent all forms of child abuse and neglect across Upstate SC.

Family Connection of South Carolina - Family Connection of South Carolina (familyconnectionsc.org)

Statewide Resource Network – Children's Trust of South Carolina (scchildren.org): Children's Trust supports a resource network database powered by findhelp. It provides parents and families with information to find assistance in their communities, and it helps organizations coordinate care for their clients and constituents.

Genetic Services for Families Brochure: he Department of Disabilities and Special Needs (DDSN) and the Greenwood Genetic Center work together to provide genetic services for individuals and families who are dealing with issues such as developmental delay, intellectual disability, autism, or birth defects. The purpose of this evaluation is to find the cause of an individual's disability in order to provide appropriate guidance to all who participate in their care.

Greenwood Genetic Center Foundation (ggc.org): The GGC Foundation is a nonprofit 501c3 established to serve as the philanthropic arm supporting the Greenwood Genetic Center (GGC) in their work of serving families in the fight against genetic diseases, birth defects and autism. GGC has provided over 40 years of compassionate clinical care, unparalleled diagnostic lab services, globally-renowned research discoveries and innovative educational programs.

Greenwood Genetic Center (ggc.org): The Greenwood Genetic Center is a nonprofit institute organized to provide clinical genetic services, diagnostic laboratory testing, educational programs and resources, and research in the field of medical genetics.

Bridges of Hope | A community for children, teens & their families grieving a death (bridgessc.org): We provide a safe group environment to support & empower children, teens & their families grieving a death.

CareFIRST Carolina Foundation | CareSouth Carolina (caresouth-carolina.com)

Camp Hands of Hope - Camp Hands of Hope: Camp Hands of Hope, a program under the Hospice & Palliative Care Foundation is a weekend-long bereavement camp for children ages 5 to 18 and their parent(s) or guardians who live in South Carolina and have experienced the loss of a loved one.

Child & Family Resource Foundation (childandfamilyresourcefoundation.com): The Child and Family Resource Foundation gathers in one place a wide range of necessary fundamental services that address the mental health, education, and overall wellness of children and families. Our services help develop positive outcomes in children and their families using awareness of social-emotional skill development, parent education, and school preventive measures, in addition to addressing social-emotional problems that currently exist within families.

Hospice | Hospice and Palliative Care Foundation | SC, United States (hpcfoundation.org): The mission of the Hospice and Palliative Care Foundation (HPCF) is to discover and address the unmet needs of individuals and families facing end-of-life issues through innovative and collaborative programs and services, and includes financial, educational, technological, and grief support.

Created by: Sierra Phillips @mrs.phillijt

The Therapy Place, Inc. – Innovative Therapies for Kids | Resources for Families: At The Therapy Place, we are dedicated to providing exceptional Occupational Therapy, Physical Therapy, and Speech and Language Therapy services as well as offering therapeutic preschool services for children with special needs in an environment that is family-friendly. The Therapy Place is the only nonprofit pediatric therapy center in the midlands that offers a therapeutic preschool. We serve more than 150 children with doctor-prescribed physical, occupational, and speech therapies. We strive to help each child reach their full potential!

SOUTH DAKOTA RESOURCES:

2023 DDD Stakeholders Schedule: Interactive sessions which create opportunities for attendees to ask questions and provide feedback from DDD regarding specific topics and initiatives.

Early Childhood Enrichment Sites (sd.gov): Below you will find the five different ECE sites located throughout the state. View the map in order to find your region.

Birth to Three, SD Department of Education: SD Birth to Three contributes to the success of children with developmental delays and their families by providing dynamic, individualized early intervention services and supports by building on family strengths through every day routines and learning experiences. The South Dakota Birth to Three Early Intervention Program serves children from birth to 36 months with developmental delays or disabilities and their families.

Home | Early Childhood Connections: Early Childhood Connections is a not-for-profit 501(c)(3) corporation established in the summer of 1995 to offer various services that provide support and education to childcare providers, teachers, and parents involved in the care of children.

A Guide to Natural Supports (usd.edu): This guide was created by self-advocates for self-advocates. It will introduce the concept of natural supports and provide examples of how to find, develop and use natural supports. This guide is meant to be a resource to assist self-advocates in thinking about how to start conversations about natural supports with important people in their lives. When reviewing this guide for the first time, some self-advocates may find it helpful to do so with the support of a family member or friend; this provides practice in using a natural support.

One Foundation, One Mission - Avera Foundation

Ability Building Services: Ability Building Services is a private not-for-profit community support provider. Our services include pre-vocational activities, vocational training, residential services and other supports and services as needed by people with developmental disabilities.

Resources | Sanford Health

The Right Turn: PROVIDING LIFELONG LEARNING OPPORTUNITIES, INSPIRING SELF-SUFFICIENCY AND PERSONAL GROWTH FOR INDIVIDUALS IN CENTRAL SOUTH DAKOTA.

AdaptiveAquaticsBroch.pdf (sd.gov): The program is directed and taught by the pioneer of Adaptive Aquatics in Sioux Falls, SD, Carole Wolf. Carole has been working with special needs students for over 25 years.

ADVANCE: ADVANCE is a private non-profit organization that supports more than 115 people with intellectual and developmental disabilities. We also provide services to people who have conditions caused by accident, traumatic brain injury, spinal cord injury, or diseases such as muscular dystrophy.

Child and Family Resource Network | South Dakota State University (sdstate.edu): The Child and Family Resource Network was established in 1990 as an outreach office at South Dakota State University to provide information and resources for users and providers of child care and their families. Currently, the Child and Family Resource Network is a state and locally supported Early Childhood Enrichment (ECE) program which provides training, education and resources to adults who are involved in the day-to-day care of children and youth.

Aspire SD: Aspire supports people who work at local businesses. We provide training opportunities for people to obtain work experience. For people who do not have employment goals, Aspire provides opportunities for people to be involved in the community in whatever way is meaningful to them.

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Golden Halo Foundation | Helping Children With Medical Conditions: The Golden Halo Foundation provides financial assistance, in the way of grants, to help those children with medical conditions that require specialized care. The financial assistance is to help seek medical treatment, diagnostic evaluations, durable medical equipment and expenses related to securing medical care. The Foundation currently serves families in the Midwest region.

Benchmark Human Services: At Benchmark Human Services (Benchmark), we help support people throughout life, from infancy to elder years. Our team is 3,400-strong and serves more than 10,000 children and adults throughout the United States. We work with people at home, at work, and in the community, through residential, employment, crisis response, behavioral, recovery, children's services, and day services.

South Dakota Rx Card - Free Statewide Prescription Assistance Program: All residents are eligible to get pharmacy discounts through this program. The program may be used to provide savings on prescriptions not covered by your health insurance or Medicare Part D. The program may also be used instead of your insurance coverage when it offers greater savings than your copay.

BHSSC Developmental Disabilities Division: BHSSC's Developmental Disabilities (DD) Division is one of 20 Community Support Providers in South Dakota who support people with intellectual and developmental disabilities (I/DD).

Catch the Wave | A Guide to Post-Secondary Education for Students with Disabilities: This document is designed to help students, families and IEP team members to improve their knowledge of postsecondary disability issues, and ultimately, to improve the success rate of students with disabilities in those settings.

SD Department of Human Services | Cochlear Implant Program: This program is designed to provide financial assistance to an eligible individual who is uninsured or to help offset the deductible or coinsurance for an individual with an insurance plan that covers cochlear implants. The program provides funding for the cost of the implant surgery for one ear or both ears, one or two implant devices, surgeon fee, hospital fee, the initial mapping and up to a maximum of 12 follow up mappings within one year post surgery.

Center for Disabilities | University of South Dakota (usd.edu): Our mission is to improve the lives of individuals with disabilities and their families across the state of South Dakota, the region and nationally. The Center for Disabilities carries out its diverse capacity-building efforts through community education, clinical services, interdisciplinary training, technical assistance, research, information dissemination and policy/advocacy work.

Center For Independence: The Center For Independence is a community support provider in east-central South Dakota. We're all about meeting the needs of individuals with disabilities in a way that promotes choice and encourages independence.

Children's Health Insurance Program | CHIP: The South Dakota Children's Health Insurance Program, more commonly referred to as CHIP, provides quality health care (including regular check-ups, Well-Child Care exams, dental and vision care) for children and youth.

CHOICES Program Brochure: Community, Hope, Opportunity, Independence, Careers, Empowerment, Success (CHOICES) is a program that provides services to children and adults with intellectual and developmental disabilities.

CHOICES Providers: Case Managers & Community Support Providers Roles & Responsibilities (sd.gov)

Community Support Providers of South Dakota (cspofsd.com): Our role as Community Support Providers is to support individuals as they find their unique purpose. With clear purpose, individuals find their natural passion unleashed and multiplied.

CommunityConnections: CCI strives to provide the highest quality services to meet the changing needs of people with disabilities to assure that every person, regardless of ability, reaches their fullest potential.

Dakota at Home | South Dakota's Aging and Disability Resource Center: Dakota at Home is a free information and referral service. We provide objective information and options planning to help individuals, regardless of age, disability, or income, identify and access public and private services and supports in their local communities.

Dakota Milestones: Dakota Milestones is a private, non-profit corporation that provides needed services to persons with developmental disabilities in a community setting. Our primary goal is to provide services to foster work and living skills. Ultimately, services provided will further develop peoples skill to their fullest potential, to allow each person to become as independent and as productive members of the community as possible.

DakotAbilities: DakotAbilities is a nonprofit organization based in Sioux Falls. We support South Dakotans from across the state with services including housing, employment, day services, nursing, and more. These supports create a more inclusive and connected world for everyone.

Dakotalink: DakotaLink began providing direct services to individuals with disabilities and the elderly. These services include individual assessments, equipment sales, installation and training of assistive technology. This one stop concept has helped DakotaLink evolve in to a statewide organization that has 6 certified rehabilitation technicians located in 4 regional offices. Our offices are located in Rapid City, Aberdeen, Sioux Falls and Brookings. The office in Rapid City is a storefront environment where people can drop in at any time. Appointments do need to be made at the other facilities.

Deaf-Blind Program | University of South Dakota (usd.edu): This program provides technical assistance, training and resources to families and service providers of children (birth to 21) with varying levels of both hearing and vision loss.

Disability Rights South Dakota: We are a federally funded, independent non-profit protection and advocacy agency dedicated to preventing, investigating and pursuing cases of abuse, neglect and exploitation of South Dakotan's with disabilities. DRSD's legal team works to protect the rights of the disability community.

DME Providers Enrolled with South Dakota Medicaid

DSU STRONG - Dakota State University: The Dakota State University STRONG Services are geared towards supporting students on the Autism Spectrum. These free services promote independence, confidence, and self-advocacy, along with helping to create a positive social support network. Services are committed to helping students build campus connections that will assist in achieving academic, social, and professional developmental success.

Economic Assistance | Medical Expansion (sd.gov): Below are some key resources related to Medicaid Expansion which takes effect July 1, 2023.

Front Door to supports Workgroup.pdf (sd.gov): Improve the experience of people with disabilities and their families as they navigate complex service delivery systems by creating a single "front door" to DDD services.

Guidance for Children Transitioning from Part C to Part B (sd.gov): The purpose of this guidance document is to provide clarifying information regarding the transition process from IDEA Part C (Birth to Three) early intervention into IDEA Part B special education preschool services.

Home - Resources for Human Development (rhd.org): WE SUPPORT TENS OF THOUSANDS OF PEOPLE OF ALL ABILITIES EVERY YEAR WITH EFFECTIVE, INNOVATIVE, AND PERSON-CENTERED PROGRAMS.

Home and Community Based Services: Home and Community Based Services provides South Dakota Medicaid for individuals with developmental disabilities who would otherwise be institutionalized in a Medicaid-funded hospital, nursing facility or an intermediate care facility.

Homepage - NAMI South Dakota: NAMI of South Dakota is an organization of families, friends and individuals whose lives have been affected by mental illness. Together, we advocate for better lives for those individuals who have a mental illness.

Human Service Agency: We are a Community Support Provider and Community Behavioral Health Center with a mission to provide high quality human services that enable people to develop their fullest potential while maintaining the highest standard of ethical and fiscal responsibility. The Human Service Agency offers services to over 2700 individuals a year in Watertown, Sisseton, and Milbank.

Inter-Lakes Community Action Partnership (interlakescap.com): Inter-Lakes Community Action Partnership is a community based non-profit organization which serves primarily low-income families and senior citizens in a 14-county area of East Central South Dakota. We administer a variety of programs supported through grants, donations, and other community resources to assist participants and their communities. Our vision is to have sustainable communities where children, families, and individuals reach their full potential.

iTransition South Dakota Application: This app is for students with disabilities with an Individualized Education Program (IEP), ages 14 and older.

Learning Library - SD Department of Human Services (assistguide.net): Find useful websites, read about important topics, and make informed choices.

LifeQuest | Mitchell SD (lifequestsd.com)

LifeScape: providing exceptional services and creative solutions for people with varied needs and complex care across their life span. Through collaborative partnerships, LifeScape will become a destination for research, and the development, implementation, and training of technology-based solutions to improve the lives of people we support.

Microsoft Word - Expansion Brief_Eligibility.docx (sd.gov): Starting July 1, 2023, South Dakota's Medicaid expansion will allow an estimated 52,000 new individuals to qualify for Medicaid by raising the income requirement to 138% of the

Federal Poverty Level (FPL), up to $41,400 for a family of 4, and adding childless adults.

Northern Hills Training Center: Northern Hills Training Center currently provides supports to approximately 135 individuals across the Spearfish and Belle Fourche areas, so that these individuals can become active members of their community. In order to provide a variety of choices for people, these supports are offered in a variety of residentials settings, such as group homes, supervised apartments, traditional community housing, and family homes.

Oyàte Circle | University of South Dakota (usd.edu): The Oyàte Circle is a resource, education, outreach and training effort that serves Native Americans with disabilities in South Dakota.

PLANSSpeakingOutAboutServices.pdf (sd.gov)

Possibilities 2022 (usd.edu): This publication was created as a way to share the successes of individuals with disabilities and their families. It is our goal to continue to raise awareness and highlight the skills and unique talents of people with disabilities.

Pre-School Section 619, SD Department of Education: The Preschool Grants Program, authorized under Section 619 of Part B of IDEA, was established in 1981 to provide grants to states to serve young children with disabilities, ages 3 through 5 years. All states and eligible jurisdictions and outlying areas have participated in the program since fiscal year 1992. As of December 1, 2000, slightly less than 600,000 children were receiving special education and related services nationwide

PROTECTION & ADVOCACY DEVELOPMENTAL DISABILITIES | PADD: Any person in South Dakota may contact the PADD Program regarding issues that relate to or arise because of a developmental disability. Services provided by the PADD Program are typically free. Any fees for services are discussed during the course of representation.

PROTECTION & ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS | PAMI: The PAIMI Program pursues a variety of rights protection and advocacy strategies to assist individuals with mental illness. Learn more about our services below or by downloading our brochure.

PROTECTION & ADVOCACY VOTING ACCESS | PAVA: The PAVA Program is designed to provide services to assist in the effort to ensure full participation by South Dakotans with disabilities in the electoral process, including providing information on voting eligibility, registering to vote, and accessing polling places.

Protection and Advocacy Assistive Technology Program | PAAT: The Protection and Advocacy Assistive Technology Program provides services to individuals who have assistive technology needs. This is done through a variety of strategies focusing on the individual and delivery systems. Activities are coordinated with the DakotaLink Project and the state Division of Rehabilitation Services. PAAT provides information, including referral, research, and analysis to overcome legal, administrative and other barriers to obtaining assistive technology. PAAT also provides legal representation to pursue issues that are unique to assistive technology as well as education and training to empower individuals with the skills to address and overcome barriers in obtaining assistive technology.

Resource Guide for People with Disabilities (usd.edu): The Resource Guide for People with Disabilities is a product of the Center for Disabilities, Department of Pediatrics, Sanford School of Medicine of The University of South Dakota. It is produced with federal funds as part of a grant from the South Dakota Council on Developmental Disabilities. It is our hope that this Resource Guide for People with Disabilities will assist individuals with disabilities, their families, professionals, educators, and the public in their quest for information and resources. The purpose of this Resource Guide for People with Disabilities is to provide you with enough information to identify the agencies and organizations to contact for more detailed information and assistance.

Respite Care – PLAN for it

RISE Custom Solutions | LifeScape (lifescapesd.org): RISE Custom Solutions has been providing orthotics, prosthetics, and wheelchair and other mobility solutions for children and adults in the upper Midwest since 1999. Formerly called Rehabilitation Medical Supply, the name RISE Custom Solutions better reflects what we do – we are focused on solutions for our patients, to help them be as independent and comfortable as possible--customizing wherever needed. We strive to rise above and beyond to provide innovative solutions for each person's needs.

Rocky Mountain ADA: The Rocky Mountain ADA Center is proud to serve individuals and organizations throughout Colorado, Utah, Montana, Wyoming, North Dakota, and South Dakota.

SD Department of Human Services | developmental disabilities providers

SD Department of Human Services | Division of Developmental Disabilities : The mission of the Division of Developmental Disabilities is to ensure that people with developmental disabilities have equal opportunities and receive the services and supports they need to live and work in South Dakota communities.

SD Department of Human Services | FAMILY & SELF-ADVOCATE RESOURCES

SD Department of Human Services | Family Support 360 Brochure

SD Department of Human Services | Family Support 360 Provider List

SD Department of Human Services | Family Support 360: Family Support 360 serves people with intellectual and developmental disabilities. This program assists participants and their families in self-directing the services they need to live as independently as possible in the community.

SD Department of Human Services | service to the blind and visually impaired: The mission of the Division of Service to the Blind and Visually Impaired (SBVI) is to provide individualized rehabilitation services that result in optimal employment and independent living outcomes for citizens who are blind or visually impaired.

SD Department of Human Services | south dakota developmental center: The mission of the South Dakota Developmental Center (SDDC) is to provide comprehensive specialized services designed to enhance quality of life and community inclusion for people with Intellectual Disabilities and/or Developmental Disabilities

SD Department of Human Services | The Division of Rehabilitation Services: The Division of Rehabilitation Services (DRS) can help individuals with disabilities to obtain or maintain employment, economic self-sufficiency, personal independence and full inclusion into society. We are a part of the Department of Human Services, and as such, are committed to enhancing the quality of life of people with disabilities.

SD Lifespan Respite Brochure

SD Lifespan Respite: Lifespan Respite is taking a break from the daily responsibility of providing care to a family member or another loved one regardless of age who due to aging, Alzheimer's/dementia, brain injury, chronic illness, disability, or mental health needs ongoing assistance and support. Respite allows caregivers to take time for themselves, and when used effectively, reduces caregiver fatigue and care recipient stress. Respite also creates opportunities for family members and other primary caregivers to keep or make new social connections and attend community activities.

SD Parent Connection | Resources for Families with Disabilities: Connecting families who care for individuals birth to age 26 with disabilities or special health care needs to information, training, and resources in an environment of support, hope and respect.

SD Parent Resource Information: The following resources are available through various South Dakota agencies. For additional information, please contact Child Care Services at 1(800)227-3020.

SD TBI Resources

Search Child Care Providers (sd.gov)

Sesdac | Services & Support for People with Disabilities | Vermillion, SD: By developing both social skills and job skills, we have helped hundreds of people move on to paid employment, independent living, and rich, well-rounded lives. Although everyone receiving our services is unique, the goal is always the same. Our support leads to a seamless transition to the adult service system and helps navigate the years between school and age 21 by fostering development and offering guidance.

South Dakota Agencies for People with Disabilities

South Dakota Early Childhood Transition from Part C to Part B Timeline Requirements

South Dakota's Aging and Disability Resource Center: Dakota at Home's on-line Resource Directory provides you with the information and knowledge you need to make informed choices and decisions on aging and disability long-term services and supports. Searching for agencies, organizations, providers, and resources can be confusing and overwhelming. Dakota at Home can help answer your questions and identify the services and supports that are available in South Dakota. Use the map below to search for organizations and providers by county. Click on the name of the county you wish to search or Click Here to search by service or key words.

Special Education, SD Department of Education: Special Education Programs provides leadership and support for educators, parents, and students with disabilities receiving special education and related services throughout South Dakota's public schools and communities. We strive to support districts and families to improve outcomes and ensure a free appropriate public education for students with disabilities.

SPED 2023 – Time for S'more Learning (wordpress.com): The annual Special Education Conference provides a unique experience to gather with South Dakota educators, related service providers, and parents. This in person event allows participants to learn about evidence-based innovations, educational trends leading towards best practices, and provide practical solutions for special education classrooms.

Standardized ISP-Therap User Guide: The Standardized ISP and guide materials have been developed by the Division of Developmental Disabilities in partnership with the Conflict Free Case Management subcommittee of the Financial Workgroup and Therap Services. The guide is intended to provide information for completion of the Personal Focus Worksheet, the ISP Agenda, and the Individual Support Plan within Therap.

The Brain Injury Alliance of South Dakota (braininjurysd.org): The Brain Injury Alliance of South Dakota is a 501(c)(3) nonprofit group, working to assist brain injury survivors and their families. We attempt to connect people with services and supports throughout South Dakota, as well as advocate for improving and expanding brain injury services in South Dakota.

The Disabled Children's Program: The Disabled Children's Program provides South Dakota Medicaid for certain disabled children in South Dakota. The program is intended for children with disabilities who have medically fragile conditions requiring skilled nursing care in a medical facility if they were not being cared for at home.

The Heartland Genetics Services Network: The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. This website provides information and resources to professionals, families, and collaborators to facilitate communication and work within the Network. Heartland welcomes you to use the resources contained in this site and invites your participation.

Tools and Resources Related to Special Education Eligibility

Transition-In-Action | University of South Dakota (usd.edu): The Transition-In-Action Clinic generates recommended "next steps" to successful transitions for young adults with a disability and/or significant chronic health care needs.

TSLP | Apps to Support Transition

TSLP | Tips for Parents: The intent of this brochure is to assist you and your child in preparing for the future. More knowledge of the transition process typically means feeling more confident and comfortable in advocating for services and programs that will lead to a better quality of life for your child.

TSLP | Transition Resource Booklet: This resource guide was put together to provide a variety of resources that would be helpful in providing pre-employment transition services to South Dakota's students with disabilities. The following icons have been added to give you a better idea of what each link entails.

TSLP | Transition Services Liaison Project: The mission of Transition Services Liaison Project (TSLP) is to enable students with disabilities to reach their maximum potential in their transition from high school to the adult world.

Valiant Living: Valiant Living is all about helping people get the most out of life. We are a non-profit organization committed to assisting people with developmental disabilities to share their talents, skills and dreams with our entire community.

Watertown Social Services Resource Directory

Weatherization Assistance (sd.gov): The Weatherization Assistance Program is designed to help low income South Dakota households overcome the high cost of energy by making their homes more energy efficient. Weatherization work is completed by four different community action programs serving specific counties throughout the state. See the list of community action programs below to contact the program serving your county.

Welcome to SD My Life: SDMyLife is an online career exploration and academic program for South Dakota students and educators. We are here to help students become prepared for life after high school. SDMyLife's goal is to help students understand how their interests, skills, and knowledge relate to real-world academic and career opportunities. SDMyLife is packed with activities, resources and information to help students in each step along the way.

Western SD Community Action (wsdca.org): Western South Dakota Community Action, Inc. is a private, nonprofit anti-poverty corporation. The agency was incorporated in 1965. The activities are administered by a volunteer Board of Directors. The agency's purpose is to make a positive impact on the causes and effects of poverty. It accomplishes this by supplying those living in poverty with the tools and assistance necessary to help themselves overcome these conditions. This partnership allows individuals to influence their own future well-being.

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TENNESSEE RESOURCES:

Patient and Family Resources | Pediatric Rare Disease Center (vumc.org): Following is a list of rare diseases we focus on at the Pediatric Rare Disease Center, along with corresponding resources specific to each rare disease. We are currently offering quarterly clinics for patients with Fabry and adrenoleukodystrophy (ALD). To learn more about our Fabry and ALD-specific clinics, navigate to the clinic link under the Fabry and ALD tabs.

CLIMB Intensive Pediatric Therapy: Welcome to Climb Intensive Pediatric Therapy! We are excited to be the first and only pediatric therapy clinic in Tennessee to offer Intensive DMI Therapy services. We recognize that your child is one of a kind and deserves a specialized experience. For this reason, we will build an intensive program that is customized to their specific needs. We are passionate about helping your child achieve new heights.

Adaptive Dance: New Perspectives (Ages 4+) — Nashville Ballet: Adaptive Dance: New Perspectives is a universally-accessible dance program created by Occupational Therapist Hannah Mathews, OTD, OTR/L, and Linnea Swarting, former Nashville Ballet company member with adaptive dance education training. This tuition-free program provides an opportunity for children of all abilities to experience the joy of dance while developing body awareness, coordination, and balance in a traditional studio environment.

Healing Hope Ministries | Loss of a Child Retreat Center (healinghopes.com): Healing Hope Ministries helps families and their support systems find hope and healing after the loss of a child. We provide encouragement, compassion and support through retreats, small groups and events. Through love, we meet people where they are and hold a safe space to process grief. It is our desire to light a path for hope and healing.

Making Life Work Is Our Life's Work - Bios (bioscorp.com): BiosHome provides support at home and in the community. We are dedicated to improving the lives of people with intellectual and developmental disabilities in Oklahoma and Tennessee.

TEXAS RESOURCES:

BCM-HGSC | Baylor College of Medicine Human Genome Sequencing Center: The fundamental interests of the BCM-HGSC are in advancing biology and genetics by improved genome technologies. One of three large-scale sequencing centers funded by the National Institutes of Health, the BCM-HGSC's location at the heart of the Texas Medical Center provides a unique opportunity to apply the cutting edge of genome technologies in science and medicine.

Project Angel Fares: Project Angel Fares is a 501c3 nonprofit created in 2012 with the goal of “Providing Special Friends with Special Dreams”. Project Angel Fares serves families who have a child with a disability or special needs and otherwise would not be able to afford the opportunity to visit San Antonio, Morgan’s Wonderland & Inspiration Island with a 4 day, 3 night trip of a lifetime, with paid travel expenses.

Adaptive Dance - Ballet Lubbock Dance Abilities: SPECIFICALLY DESIGNED FOR THOSE ON THE AUTISM SPECTRUM OR WITH DOWN SYNDROME, AND OTHER SPECIALIZED NEEDS, DANCE ABILITIES BLENDS CLASSICAL BALLET TECHNIQUE AND MUSIC ACTIVITIES WITHIN A FUN, POSITIVE, AND EMPOWERING ATMOSPHERE! LEARN MORE ABOUT ADAPTIVE DANCE AT BALLET LUBBOCK.

Project MEND - Homepage - Medical Equipment Reuse: Project MEND is committed to improving the quality of life for individuals living with disabilities and illness through the refurbishment, reuse and distribution of medical equipment and other assistive technology.

Home (sunshinecottage.org): Sunshine Cottage School for Deaf Children promotes early identification and intervention for children who are deaf or hard of hearing and helps them develop their maximum potential through listening, spoken language and literacy.

Community-Resource-Directory-March-2022.pdf (arcofsa.wpenginepowered.com): Organizations included in this directory are not directly or indirectly endorsed by The Arc of San Antonio.

Home - The Arc of San Antonio (arc-sa.org): Serving children and adults with intellectual and developmental disabilities and the families who care for them.

Created by: Sierra Phillips @mrs.phillijt
CHCS Home Page | The Center for Health Care Services (chcsbc.org): Every day, we work with children and adults across Bexar County to provide counseling, resources, and the support they need to make life better. Whether it's people struggling with addiction, or providing support and therapy to people with mental health conditions and/or other intellectual and developmental disabilities, The Center is committed to changing lives, restoring families and producing healthier communities one person at a time.

Easterseals North Texas | Home: Easterseals North Texas helps more than 4,500 individuals every year become more independent. Our therapists, job coaches, and other professionals make profound differences every day in the way people live, learn, work, and play. As a part of the community since 1939, we deliver high-quality, customized care to our neighbors.

Microsoft Word - AIM flyer-Feb 2019.docx (txp2p.org): AIM is a growing community of active adults with IDD who live independently, with appropriate supports, in a walkable, vibrant area of Central Texas.

Special Education in Texas A-Z Index | Texas Education Agency

Labeled & Loved : North Houston | Labeled and Loved: Affiliated with the national organization Labeled & Loved, this local chapter's mission is to embrace and strengthen families with disabilities by providing connective experiences and educational resources igniting personal growth and systemic change within the community.

Labeled & Loved RGV | Labeled and Loved: Introducing, Labeled & Loved : Rio Grande Valley, a chapter of the national Labeled & Loved with a mission to embrace and strengthen families with disabilities by providing connective experiences and educational resources for the primary caretaker igniting personal growth and systemic change within the community.

Annie's Place — Mommies in Need: Annie's Place is a childcare center at Parkland Hospital meant primarily for children of patients. This program opened in the Fall of 2020 and has already helped hundreds of families! We believe that families should never have to choose between taking care of their own health and having safe, loving, expert care for their children. Annie's Place is a first-of-its-kind facility with specially trained teachers who care for children while their parents or family members are attending medical appointments.

School, Family, and Community Engagement Network – Partners Resource Network (prntexas.org): Partners Resource Network and Region 10 Education Service Center are working with the Texas Education Agency (TEA) on the School, Family, and Community Engagement (SFCE) Initiative. The goal of the SFCE is to help school staff and parents build collaborative relationships and increase positive outcomes for students with disabilities.

Partners Resource Network – Empowerment Through Education (prntexas.org): Partners Resource Network (PRN) has been empowering families of children and youth with disabilities since 1986. We can help you understand your child's disability, understand your rights and responsibilities under IDEA, obtain and evaluate resources and services, and effectively participate as an equal team member with professionals in planning services for your child.

RespiteCareSA – Caring for Children with Special Needs: Respite Care of San Antonio's (RCSA) mission is to protect, love, build trust and nurture growth of children with special needs and complex medical conditions while strengthening the families caring for them.

Brighton Center - Here there are only abilities | San Antonio TX (brightonsa.org): We exist to provide the right help at the right time to children of all abilities, empowering them to discover new possibilities. Theory of Impact: (We achieve our Mission by) Providing a holistic and integrated set of developmental and educational services individualized for each client, ensuring the child and the family are equipped with the resources and tools they need to succeed now and into the future.

Find Your PTI – Partners Resource Network (prntexas.org): Every state has at least one Parent Training and Information Center (PTI) funded by the Office of Special Education Programs (OSEP) at the U.S. Department of Education, under the Individuals with Disabilities Education Act (IDEA). In Texas, there are four PTI projects: PACT, PATH, PEN, and TEAM. Partners Resource Network (PRN) is a non - profit agency that operates the Texas PTI projects as a statewide network that serves parents of children and youth with disabilities ages of 0 - 26 as well as youth self - advocates ages 14 - 26.

TEAM Project – Partners Resource Network (prntexas.org): The TEAM Project is one of four federally funded Parent Training and Information Centers (PTI) serving Texas parents of children and youth with disabilities ages 0-26. We serve families living in ESC regions 1, 13, and 20. TEAM Regional Coordinators are here for you! We can help you understand your child's disability, understand your rights and responsibilities under IDEA, obtain and evaluate resources and services for your child, and fully participate as a team member with professionals in planning services for your child.

PEN Project – Partners Resource Network (prntexas.org): The PEN Project is one of four federally funded Parent Training and Information Centers (PTI) serving Texas parents of children and youth with disabilities ages 0-26. We serve families living in ESC regions 9, 12, 14-19. PEN Regional Coordinators are here for you! We can help you understand your child's disability, understand your rights and responsibilities under IDEA, obtain and evaluate resources and services for your child, and fully participate as a team member with professionals in planning services for your child.

PATH Project – Partners Resource Network (prntexas.org): The PATH Project is one of four federally funded Parent Training and Information Centers (PTI) serving Texas parents of children and youth with disabilities ages 0-26. We serve families living in ESC regions 2-6. PATH Regional Coordinators are here for you! We can help you understand your child's disability, understand your rights and responsibilities under IDEA, obtain and evaluate resources and services for your child, and fully participate as a team member with professionals in planning services for your child.

PACT Project – Partners Resource Network (prntexas.org): The PACT Project is one of four federally funded Parent Training and Information Centers (PTI) serving Texas parents of children and youth with disabilities ages 0-26. We serve families living in ESC regions 7, 8, 10, and 11. PACT Regional Coordinators are here for you! We can help you understand your child's disability, understand your rights and responsibilities under IDEA, obtain and evaluate resources and services for your child, and fully participate as a team member with professionals in planning services for your child.

Home - Any Baby Can San Antonio: Providing direction and guidance for families of children and youth with special needs is at the heart of this organization. The impact the birth of a child with special needs has on the family is immense. Instantly, the family's dreams are altered and their lives are changed forever. The stress has the potential to tear even the strongest families apart. Any Baby Can believes that the child can be saved without losing the family. Any Baby Can of San Antonio is a non-profit agency and all services are provided at no cost – regardless of income – to families who have a child birth through 17 years of age with a chronic illness, disability, developmental delay or health risk. The child must reside in Bexar, Atascosa, Bandera, Blanco, Caldwell, Comal, Edwards, Frio, Gillespie, Gonzales, Guadalupe, Hays, Kendall, Kerr, Kimble, Medina, Real, Uvalde or Wilson County.

Sibling Support - Any Baby Can San Antonio: or young children growing up is hard enough, especially where there is a sibling whose special needs require a great deal of time and attention. Sometimes siblings feel alone and left out, as we have seen happen over the years at Any Baby Can. Because of this, we have a Sibling Support Group.

Local Resources - Any Baby Can San Antonio: Any Baby Can strives to provide the most comprehensive Resource Guides for families with children and youth facing serious health or developmental challenges. Please contact Any Baby Can to access the assistance of a case manager who can provide useful service coordination to guide you and your family through the many available resources.

KidsCanSeq | CSER (cser-consortium.org): Evaluating Utility and Improving Implementation Of Genomic Sequencing For Pediatric Cancer Patients In The Diverse Population And Healthcare Settings Of Texas: The KidsCanSeq Study.

Resources & Services for Families & Parents of Children with Disabilities or Special Health-Care Needs in Texas | Navigate Life Texas: RESOURCES & SUPPORT For families raising children with disabilities.

Morgan's Wonderland - The World's First Ultra-Accessible™ Theme Park (morganswonderland.com)

Texas | RareAction Network: The mission of the RareAction Network® (RAN) is to connect and empower a unified network of individuals and organizations with tools, training, and resources to become effective advocates for rare diseases through national and state-based initiatives across the United States.

April 28, 20011 (rareaction.org): Emergency Relief Resources for Families with Rare Diseases in Texas

DFW DME Exchange of Dallas, Inc. | Recycling Durable Medical Equipment: We are distributing medical equipment to individuals in need throughout Dallas County.

Comprehensive Pediatric Home Health Care | Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

Year 6 Genetic Navigator Outreach Presentation (canva.com)

Created by: Sierra Phillips @mrs.phillijt
Genetic Ambassador Program - Mountain States GeneticsMountain States Genetics

Mending Hearts Grief Center: The MHGC was established to help children and families grieving the death of a loved one. In a culture that does not talk about grief and bereavement, and in a world that doesn't "get it," we do. The Mending Hearts Grief Center is here in the Brazos Valley area to provide grief support programs for children through young adulthood. We believe that each person's journey through grief is unique and therefore deserving of a distinctive approach to healing. Our goal is to help children and their caregivers understand the depth of their grief, stabilize and preserve family relationships, and develop healthy coping skills after the death of a loved one.

Texas School for the Blind and Visually Impaired | TSBVI: We serve as a leading center of expertise and resources, working in partnership with schools, families, communities, and organizations to transform outcomes for students, ages birth to 22, who are blind, visually impaired, or deafblind.

Cheyanna's Champions 4 Children | CC4C: CC4C enhances the lives of children battling rare and undiagnosed medical conditions in Texas. We achieve this by giving children and families access to mental health and wellness programs, providing financial assistance, and giving them access to events and experiences that would otherwise be impossible. Together, we can Champion these children and their families out of the darkness of isolation, into the light.

Family Transition Tool- TexasYouth2Adult (TY2A) – BridgingApps

Home - Camp Agape Grief Recovery | (campagapetexas.org)

Home - Children's Bereavement Center of South Texas (cbcst.org)

austingrief.org | The Austin Center for Grief & Loss

austingrief.org | CAMPREDBIRD

UTAH RESOURCES:

Kids On The Move - About Kids On The Move | Autism Center, Early Intervention, Child Care (kotm.org): Kids On The Move provides services throughout Utah to support families with young children with special needs. Kids On The Move has an umbrella of independent operating pillar programs. Our programs are: Autism Center, Child Care, Early Head Start, Early Intervention, and Respite Care.

Now I Can Foundation: Now I Can stands apart from other physical therapy centers in many ways, including the use of the Intensive Model of Therapy (IMOT). Our therapists treat patients 4 hours a day, five days a week for intensive sessions, Now I Can physical therapists design a tailored program for each patient to help them reach their greatest level of independence. Over the course of a three-week intensive session, children reach their goals and gain developmental skills as therapists have the needed time to use repetition and all the tools at their disposal to help kids meet their potential. It's very common for patients to make more progress in three weeks of intensive therapy than they do in 12 months of traditional therapy!

The Autism After 21 Utah Project - Madison House Autism Foundation: Autism After 21 Utah (AA21Utah) is a 3-year,
Genetic Ambassador Program - Mountain States GeneticsMountain States Genetics
first-ever statewide partnership comprised of the Beehive State's preeminent organizations, autism advocates, and industry leaders in all sectors. The goal of the collaboration is to prevent displacement, foster inclusivity, and ensure adults with autism—and their families— have a place in our communities.

Rocky Mountain ADA: The Rocky Mountain ADA Center is proud to serve individuals and organizations throughout Colorado, Utah, Montana, Wyoming, North Dakota, and South Dakota.

Pediatric Comprehensive Care | University of Utah Health | University of Utah Health: The comprehensive care program helps children between the ages of 0 and 21 years with complex chronic conditions associated with disabilities.

Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

Year 6 Genetic Navigator Outreach Presentation (canva.com)

Created by: Sierra Phillips @mrs.phillijt

VERMONT RESOURCES:

Joey's Fund Grant Program | Spectrum for Hope Fund | Flutie Foundation: Today, Joey's Fund serves as a crucial funding bridge for autism families who are advocating, promoting, supporting and seeking out opportunities for their loved ones. Since its inception, 193 families have received over $375,000 in financial support, making their journey just a little bit easier. Must have one family member medically diagnosed with Autism Spectrum Disorder and reside in New England (Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire & Maine). Families are only eligible to apply if they have not received funding in the previous year.

New England | Autism Speaks: Serving all communities in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism, and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

Adaptive At Snow | Adaptive At Snow

Easterseals New Hampshire | Home: Easterseals NH, VT & Farnum is a community of care for all ages, for all abilities, for life. We welcome your support and participation in making our programs the best they can be for those who depend on them to live life to the fullest.

VIRGINIA RESOURCES:

2022 Directory of Services for Deaf and Hard of Hearing

Commonwealth Catholic Charities | Developmental Disability Waiver: Commonwealth Catholic Charities provides case management services for individuals with a developmental disability under the Family and Individual supports (FIS) and Community Living (CL) Waivers. Services are available to Medicaid recipients aged six and older who are diagnosed with a developmental disability prior to the age of 22.

VA Family Special Education Connection | Local Disability Services: What services are available to support your needs? Please select the beginning letter of your county and then your county name to locate services available in your area.

Virginia Smiles Inc.: Virginia Smiles, a 501(c)3 non-profit organization, was founded in 2002 to provide an essential link between families who are touched by cleft lip and/or cleft palate and the medical community that serves these patients.

C.A.R.A Therapy | Midlothian VA: The C.A.R.A. in CARA Therapy stands for Children Are Really Active and we are dedicated to helping children through FUN and FUNCTIONAL Learning. Our mission is to provide the best in pediatric therapy services to every child we treat. We strive to foster opportunities for growth and independence while helping others see and celebrate each child's unique gifts. We provide Pediatric OT/PT.

Lindsay Institute for Innovations in Caregiving: The Lindsay Institute, named after one of its co-founders, Dr. Richard W. Lindsay, is led by public/private partnership non-profit VirginiaNavigator and an Advisory Committee made up of energetic, experienced and passionate partners—working collaboratively to create and implement inventive and award-winning new initiatives aimed at improving caregivers' health, wellbeing and stability.

Yellow Door Foundation: Yellow Door was born to provide free, long-term "sanctuary" lodging for the families of pediatric patients undergoing cancer and transplant treatment at UVA Children's hospital. Our single-family apartments offer families convenient, comfortable "homes" as they fight to maintain as normal a life as possible when confronting severe pediatric illness. Your support allows families to concentrate fully on their child's treatment and recovery, helping to ensure positive outcomes.

The Doorways**:** Based in Richmond, VA, The Doorways is a registered 501(c)(3) nonprofit that provides lodging and support for patients and their loved ones who need to be close to the hospital but not far from the feeling of "home."

National Genetics Education and Family Support Center: The National Genetics Education and Family Support Center (Family Center) works to increase access to genetic services by promoting and strengthening family engagement in the genetic healthcare delivery system.

The Laurent Clerc National Deaf Education Center: provides resources and teaching to the deaf and hearing impaired. The Clerc Center has two separate schools, the Kendall Demonstration Elementary School (KDES) and the Model Secondary School for the Deaf (MSSD). Both schools are tuition-free, accredited ay schools for deaf and hard of hearing students. The elementary school serves students age birth through grade 8 from the Washington DC metropolitan area. The secondary school has a residential component and serves students from all over the US and its territories. Students living outside of a 12-mile radius of the school campus may live in the dormitories during the week. Students living outside of a 60 mile radius may stay in the dormitories during weekends that the school is open.

Evelyn D. Reinhart Guest House - Bon Secours: Located on the Libbie Avenue side of the St. Mary's campus, the 14,000-square-foot Evelyn D. Reinhart Guest House has 16 guest rooms and common areas for families to eat, relax, play, work and pray. This home away from home brings patients' families together in a place where they can experience healing and community together.

TTAC Online | State + National Organizations: This section accesses a multitude of State and National Organizations that provide information, support and research on a wide range of disabilities and medical conditions.

Northern Virginia Resource Center for Deaf & Hard of Hearing Persons: To empower deaf and hard of hearing individuals and their families through education, advocacy and community involvement.

DSANV | The Down Syndrome Association of Northern Virginia: The mission of this organization is to ensure all individuals with Down syndrome in the Northern Virginia area, and their families, receive the support necessary to participate in, contribute to and achieve fulfillment of life in their communities.

DSANV | DADS: In 2011, DSANV launched a Dads Appreciating Down Syndrome group. The purpose of D.A.D.S. is to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome.

DSANV | Family Resources: One service DSANV members consistently request is information about community resources for people with Down Syndrome and their families. These resources can be challenging to identify, but they have the potential to sustain a lasting positive impact on members of the Down Syndrome community. In order to address this need, DSANV has compiled a list of community services in northern Virginia that may be relevant to our members.

The Hampton-Newport News Community Services Board: The Hampton-Newport News Community Services Board is the premier provider of behavioral health and intellectual and developmental disability services. We are recognized throughout Virginia for our leadership, excellence and commitment to service. We earn this distinction by creating a community where people can find their own strength and become self-determining.

THE EPILEPSY FOUNDATION OF VIRGINIA: The Epilepsy Foundation of Virginia leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. The foundation was established in 1978 to promote awareness about epilepsy and provide assistance to those with the disorder.

Neighborhood and Community Services | Fairfax VA: Neighborhood and Community Services (NCS) promotes the well-being of individuals, families and communities by providing a variety of recreation, educational and developmental programs and services; by facilitating community engagement to identify areas of need and enhance countywide capacity for serving those needs; and by connecting residents with a continuum of county- and community-based resources that promote equity and create positive outcomes for people of all ages and abilities.

Therapeutic Recreation Activities Centralized Electronic System | TRACERS: Therapeutic Recreation Services' aim is to provide opportunities for children and adults with disabilities so they may acquire the skills that enable them to participate in the recreation and leisure programs of their choice. Staff is committed to providing services, education, and resources that meet our participants' interests, needs, and abilities on the road toward lifelong participation and enjoyment in recreation and leisure activities. Staff also provides support and advocacy to individuals who wish to participate in general recreation activities

Easterseals Child Development Center | Falls Church: The Child Development Center in Falls Church has been serving the community for over 40 years, moving to its newly built location in 2013. This state-of-the-art, environmentally green center is the only provider within a five-mile radius that accepts children under the age of two and the only center within a ten-mile radius that enrolls children with disabilities for all age groups. This inclusive early care and education center is accredited by the National Association for the Education of Young Children (NAEYC) and provides exceptional services for children with and without disabilities and their families.

POAC-NOVA – Parents of Autistic Children of Northern Virginia: Families Helping Families: Education. Community. Support.

POAC-NoVA | Resources

Adapted Sports, Recreation and Travel Opportunities for Individuals with Disabilities | NOVA

Microsoft Word - POAC-NoVA Newly Diagnosed Handout logo.docx

Formed Families Forward | Resource Directory: This Northern Virginia Family Resource Directory is provided as a free service to families and professionals by Formed Families Forward with financial support of SCAN of Northern Virginia. The Directory provides information and contact information for organizations, agencies and private practices offering programs, services and other resources for children, youth and families. There is a special focus on providers who serve families formed by adoption, foster care and kinship care who are raising children and youth with disabilities and other special needs. This Directory primarily covers the areas of Alexandria city, Arlington County, Fairfax County, Falls Church city, Loudoun County, and Prince William County. Some listings for residential and other programs outside of northern Virginia are included.

Formed Families Forward | FFF: We are a non-profit organization dedicated to supporting foster, kinship, and adoptive families of children and youth with disabilities and other special needs. We serve families, educators and child welfare professionals in the Northern Virginia area.

VCLD – Virginia Council for Learning Disabilities: The Virginia Council for Learning Disabilities (VCLD) is a statewide organization that promotes evidence-based teaching, collaboration, research, leadership, and advocacy within the Commonwealth. VCLD is composed of professionals who represent diverse disciplines and are committed to enhancing the education and quality of life for individuals with learning disabilities and others who experience challenges in learning.

Commonwealth Autism Human Services: We're working towards equitability in our community by reimagining human service systems. CA Human Services collaborates to innovate, operate, and model services that support community inclusion for Virginians with developmental disabilities such as autism through advocacy that builds awareness and creates engagement. We provide resources to individuals, families, and professionals across the Commonwealth.

Autism Database – CA Human Services: Our Autism Resource Database includes everything from camps for children with ASD to training opportunities for ABAs.

2-1-1 Virginia: 2-1-1 Virginia is a free service that can help you find the local resources you need. We're here for you 24 hours a day, seven days a week.

A Dream Come True Playground | Harrisonburg, VA: A Dream Come True Playground is a totally accessible/inclusive playground with many unique and one-of-a-kind features. The playground has separate equipment for 2-5 year olds and 5-12 year olds plus more fun and exciting equipment. Features include a rock, rainbow arches, shade structures, roadway, hammock swing, draw wall, pavilion, and family comfort stations that are fully accessible.

VCU Center on Transition Innovations: CTI is a leader in providing resources and innovative models to support students with disabilities in their transition to adulthood. We help keep transition stakeholders updated on evidence-based practices that will assist students to reach their goals after high school.

In-House Clinics - School of Law - University of Richmond: Richmond Law operates three in-house clinics, in which students work on real legal matters for real clients, under the supervision of law school faculty members. The clinics offer an invaluable capstone experience for upper-level students as they transition from learning the law to practicing the law, allowing them to represent clients in a wide variety of matters—disability rights, trademark registration, wrongful conviction, and more. As part of the law school's integrated skills program, the clinics build upon and reinforce work done in both simulation-based and traditional course work. In addition to receiving advanced skills training, clinic students apply these skills in real-life situations and examine both the real-world impact of social and political policies and the assumptions underlying the practice of law.

VHEAP – Virginia Higher Education Accessibility Partners: Virginia Higher Education Accessibility Partners, or VHEAP, was established in 2018 to promote collaboration and partnership between accessibility-focused professionals throughout the Commonwealth of Virginia. Looking at accessibility from a holistic perspective, events and resources supported and offered by VHEAP are broad, encouraging collaborative solutions. Our focus is on offering shared opportunities for those who are tasked with improving access to information and communications technology resources, those who focus on the built environment, and those who provide services for Virginians with disabilities.

Virginia Early Childhood Foundation - Virginia Early Childhood Foundation (vecf.org)

Resources | Virginia Tech Autism Clinic & Center for Autism Research | Virginia Tech (vt.edu)

VTCAR Autism Resource Guide Winter 2023.pdf

PELE Special Education Advocacy Clinic | William & Mary Law School: The Special Education Advocacy Clinic was formed to assist students with disabilities and their families with eligibility or Individualized Education Program meetings, discipline matters, mediation, and administrative hearings. The clinic is designed to bolster the partnership between families and schools and is part of the Law School's Parents Engaged for Learning Equality (PELE) Initiative.

Start on Success Replication Guide | CTI: designed to provide guidance in replicating the components of this highly successful school-to-work model. The information, strategies, and tips are based on the development and implementation.

LibraryWorld OPAC Home Page: Welcome to the VDOE's T/TAC library at VCU! Our library hours are 8:30 AM to 4:30 PM, Monday through Friday. You can check out materials from our lending libraries by LibraryWorld online request. Materials are now available for a longer checkout period. These materials and include assistive technology, augmentative communication devices, books, videos, assessment instruments, curricula, and more! Use the LibraryWorld search bar and find the item you would like to borrow and then click on the "Request Hold" button. Please make sure you put your first and last name along with your email address. We will contact you once we receive your request. If you don't find what you're looking for, please give us a call at 804-828-6947 we'll be happy to assist with your search.

Project SEARCH - VCU Center on Transition Innovations: through a collaboration with the business community, Project SEARCH provides a one-year work training experience for young adults aged 18-21 with intellectual and/or developmental disabilities. Through three unpaid, individualized internships, students learn the job and social skills they need to become successfully employed. Project SEARCH serves students at 21 sites across Virginia. In Virginia, the project has an eighty-five percent success rate in helping students find meaningful jobs after graduation.

Discovering ME Implementation Guide | CTI: This implementation guide provides the “equipment” necessary to engage in the Discovering ME! process. This equipment includes an overview of recruitment, a description of all meetings for a Discovering ME! team, and all the documents necessary to facilitate and evaluate the process. The model has been piloted and refined throughout Virginia by experienced facilitators from VCU’s Center on Transition Innovations (CTI).

TTAC Online: A web-based community linking people and resources to help children and youth with disabilities (birth to 22). Virginia Department of Education's (VDOE’s) state-wide projects with Training & Technical Assistance Centers (TTACs) provide professional development and support designed to assist schools in addressing accountability and improvement goals for students with disabilities.

TTAC Online | Regional TTACs: There are eight TTAC Regions across the Commonwealth of Virginia that serve professionals in their local areas

The Advocacy Institute: The Advocacy Institute is a non-profit, tax-exempt organization dedicated to the development of products, projects and services that work to improve the lives of people with disabilities.

Legal Aid Justice Center: The Legal Aid Justice Center partners with communities and clients to achieve justice by dismantling systems that create and perpetuate poverty. Justice means racial justice, social justice, and economic justice.

Ability Center of Virginia: Ability Center of Virginia provides superior programs and services to support the needs of individuals with different abilities throughout Hampton Roads. ACVA is a family, where EVERYONE is welcome, no one is ever turned away. The programs provide a wide range of activities that encourage community inclusion, personal independence, healthy life choices, and social skill development.

ACE-IT in College: VCU’s ACE-IT in College is an inclusive learning and training program for transition-age adults with intellectual disabilities. With individualized support, ACE-IT in College students participate in employment, college classes, and campus activities. These college experiences create opportunity and prepare students to pursue self-determined futures.

Fact Sheet for Virginia's Professionals: Working with Families of Students with Disabilities (peatc.org)

Mommas & Poppas Connection | MPC: We are Powerful Parent leaders offering compassionate peer to peer support to empower, educate and connect families, building an inclusive community, and improving the lives of all families through their journey as caregivers of a child ages 0-5 who is, or at risk of, a developmental disability/delay in Virginia.

Adagio House | Therapy: Founded with the intent to care for caregivers and their disabled loved ones.

Adagio House Respite: We understand all that it takes to be a caregiver and want to provide you with an opportunity to rest. Adagio House offers scheduled, quality care with a trained companion who will keep your disabled loved one safe and happy until you return.

Adaptive Dance Classes - Charlottesville Ballet: Adaptive dance classes provide an opportunity for children with Autism, Down Syndrome, Cerebral Palsy, or any other developmental and intellectual disabilities to explore the joy of dance with a supportive and knowledgeable team. Charlottesville Ballet follows the guidance of the Boston Ballet Adaptive Dance Teacher training program as well as from pediatric physical and occupational therapists from Vanderbilt Children's Hospital.

Aid Another: Aid Another provides inclusion programs that exclusively considers special needs families. Our purpose is to promote awareness of special needs families in our community, to empower special needs children with opportunities for social integration and to create an environment of acceptance, support and advocacy. Aid Another provides inclusive educational, cultural and recreational programs that are designed to improve quality of life, reduce isolation and enhance social settings. Aid Another is committed to building a network of support, advocacy and inclusion within our community that exclusively focuses on solving the challenges of special needs families. Based in VA Beach.

All Blessings Flow All Blessings Flow is a local faith-based non-profit founded to improve the quality of life of families living with disabilities and serious health conditions. Our primary mission is to promote health equity by providing healthcare items to those in need in Charlottesville, Albemarle, and surrounding counties. For families in need, obtaining the necessary items to care for their loved one can be a life-changing blessing.

ArcPark – RARC – Assistance, Resources, and Community (richmondarc.org): ArcPark is a yearly camping adventure hosted by Richmond ARC, a center that provides services for individuals with disabilities. It is located in the beautiful and scenic setting of Pocahontas State Park in Virginia, USA. The purpose of ArcPark is to provide an inclusive and accessible camping experience for people with disabilities and their families. There are a variety of fun activities and events throughout the weekend, including swimming, fishing, crafts, and live music.

Asperger's and Neurodiversity Support and Information of RVA | Facebook: The Asperger's and Neurodiversity Information Support group of Richmond Va (ANSIRVa)is designed to provide information and be a medium for supportive conversation and information sharing between individuals in the Richmond Va area diagnosed with Asperger's, "high functioning" autism, and/or who experience neurodivergent thinking. We do not believe autism and/or neurodivergent thinking is "bad" or "wrong" or something to be recovered from, but rather diagnoses and conditions that can and should be better understood, supported, and accepted by society. It is meant to be a safe, supportive, and accepting environment for parents, individuals, and professionals.

Autism Society Central Virginia: For over 40 years, the Autism Society of Central Virginia (ASCV) has been proud to serve as one of the region's premier sources of education, advocacy, services, and support for individuals with autism, their families and friends, and professionals.

Autism Therapy Specialists in Virginia - Acorn Health: Acorn is moving autism therapy forward, offering new hope for this generation of children. To find the Acorn Health ABA provider nearest you, enter your zip code in the field below.

Ballet Virginia | Adaptive Dance: At Ballet Virginia, we believe that dance should be accessible to anyone who wants to dance. So, we've created ballet-based creative movement program for children with disabilities and their caregiver/parent for ages 3 to 9 years. The program is under the direction of Ballet Virginia's Children's Program Director, Lisa McCarty. Ms. McCarty has completed the Boston Ballet's Adaptive Dance Teacher Training course and has taught children's dance classes for over 25 years.

Beyond Boundaries RVA: Beyond Boundaries is a non-profit based in Richmond, Virginia specializing in guiding participants with disabilities, veterans, at risk youth, and recovery programs on outdoor adventures.

Bridge2Resources VA: Search and connect to support. Financial assistance, food pantries, medical care, and other free or reduced-cost help starts here.

Calvert Kids: Calvert Kids, an Alliance Kids Network partner, is a pediatric hospice program that provides expert and compassionate care to children of all ages (infants through young adults) who are living with a life-limiting illness and their families. Children are cared for in their own home, surrounded by the people and things they love. Each child and family is treated as the unique individual they are, and the Calvert Kids team respects each family's individual needs and wishes.

Camp Easterseals: Camp Easterseals UCP is an overnight camp near Roanoke, Virginia for children and adults living with physical and intellectual disabilities.

CampLIGHT: Camp LIGHT is a summer day camp program for individuals with special needs and at-risk youth. Our mission is to show kids with special needs and circumstances that life is only limited by their imagination, and to give them new tools and skills, along with love and support, to inspire them to become anything they can dream.

Capital Caring: For nearly two decades, Capital Caring has embraced grieving children and teens by offering grief support through specialized bereavement programs held in individual Capital Caring neighborhoods across the MD, VA and the D.C. metropolitan region. At Capital Caring Kids, we offer grief counseling, support groups and special bereavement programs to not only help our Capital Caring families, but to assist anyone in the community who is struggling with loss in safe and supportive environment.

Care Connections: Care Connection for Children (CCC) is a collaborative partnership with VCU and sponsored by the Virginia Department of Health. CCC is a statewide network of six regional programs that coordinates the health care, community support services and resources to children with special health care needs.

Caregiver Resource Guide: This guide was created by the Virginia Caregiver Coalition (VCC). It is composed of public, private and non-profit organizations and individual caregivers. The VCC is dedicated to improving the caregiving experience through education and resource accessibility so that caregivers are valued and supported. The VCC meets every odd month for networking, training, education, project brainstorming, and resource sharing.

Center For Family Involvement: The Center for Family Involvement works with families to increase their skills as advocates, mentors and leaders so that families, children and young adults with disabilities can lead the lives they want.

Chai Lifeline Midatlantic Region: Founded in 2016, the Mid-Atlantic Region of Chai Lifeline supports over 120 families impacted by pediatric illness living in Maryland, Virginia, Delaware, and Washington, DC. We offer professional case management coupled with revolutionary therapeutic programming in an unprecedented creative modality.

Child Development Services: A professional team consisting of a pediatrician, nurse, social worker, educational consultant, and psychologist provides services. Core services include diagnostic assessment and care planning, follow-up care coordination and referral. Consultations are available from other pediatric specialists as needed.

Children's Assistive Technology Service | CATS: C.A.T.S. accepts donations of gently used pediatric adaptive equipment, cleans and refurbishes it, and provides it to children with disabilities that need it at no cost.

Comfort for Caregivers: Comfort for Caregivers is a place to find support, encouragement, and hope for those of you who find yourselves in a caregiving role. These resources are provided by Laura Beth DeHority (California LMFT #114979, Virginia LMFT #0717001987).

Comfort Zone Camp: Comfort Zone Camp is a nonprofit 501(c)3 bereavement organization that transforms the lives of children who have experienced the death of a parent, sibling, primary caregiver, or significant person. Our programs are free of charge and include trust-building activities and age-based support groups that break the emotional isolation grief often brings. Comfort Zone's programs are offered to children ages 7-17, and their families for the family programs, plus we offer young adult programs for 18-25-year-olds.

Communication Access Fund – Northern Virginia Resource Center for Deaf & Hard of Hearing Persons (nvrc.org): NVRC created the Communication Access Fund to provide organizations and low income individuals with CART services and Sign Language Interpreters on a sliding scale basis. Backed by donations, this fund provides support to ensure the Deaf and hard of hearing Community of Northern Virginia have interpreters or CART when needed.

Crossover Healthcare Ministry: CrossOver is a non-profit organization that provides high-quality, compassionate healthcare to uninsured and Medicaid patients.

DEAF/HARD OF HEARING: 1-3-6 FAMILY EDUCATOR PROGRAM: The day parents learn that their child is deaf or hard of hearing is a day they will never forget. It is also the beginning of a journey of discovery. They are not alone in this journey. There are parents and professionals who will support them and share experiences and insights along the way.

disAbility Law Center of Virginia: The disAbility Law Center of Virginia (dLCV) is the designated Protection and Advocacy organization for the Commonwealth of Virginia. Using funding received from federal grants, we help clients with disability-related problems like abuse, neglect, and discrimination. We work with individuals who are living in institutions and in the community. We provide legal services and direct representation as resources allow. We provide everyone who contacts us with some basic information and tools, when possible.

DMV | A Kid Again: A Kid Again serves families with life-threatening conditions and is excited to announce its expansion into DMV area. As part of this expansion, A Kid Again is partnering with Cedar Fair's Kings Dominion Amusement Park to offer cost-free, care-free Adventures for families with medically complex children.

Easterseals UCP North Carolina & Virginia: Easterseals UCP offers a wide variety of services across multiple service categories to help children, adults and families living with intellectual and/or developmental disabilities (IDD) and mental health challenges live their best possible life.

Families To Families

Family Events | Jacob's Chance: Join the Jacob's Chance family for Spring Family Fest 2023! The festival will take place at RF&P Park on the Raven's football field. Enjoy great music, fun, snacks, games, live performances, food trucks, and family relays! Visit community partners as you complete activities around the event. All ages welcome - bring the whole family!

FAMILY NAVIGATOR PROGRAM – Center For Family Involvement (centerforfamilyinvolvementblog.org)

Formed Families Forward

Friendship Circle of Virginia: Friendship Circle of Virginia (FCVA) is a non-profit organization that aims to create an inclusive community by facilitating friendships and social opportunities for people with and without disabilities to connect through meaningful social experiences at home and throughout the community.

Full Circle: Full Circle provides support for grieving children, families, adults, and communities through support groups, individual counseling services, remembrance programs, and grief education support.

Genetic Navigator Program of Virginia: A new statewide effort is helping Virginians navigate and access genetic services. The Virginia Department of Health and the Center for Family Involvement @ VCU have launched a Genetic Navigator program to provide support at no charge to families in collaboration with the NYMAC Regional Genetics Network. Genetic Navigators have lived experience and training to provide 1:1 emotional, informational and systems navigational support for children and adults with disabilities or special health care needs and their family members. They also receive additional genetic systems training through NYMAC.

Healing Strides of Virginia | Equine Therapy: To promote wellness for people with personal challenges who can benefit from equine assisted activities and therapies in a safe and supportive environment.

Hear Our Voices: Hear Our Voices, Inc. is a Delaware non-profit, member corporation established for the benefit of disabled and special needs children. Currently fighting for rights for students in Virginia.

Hospice Care for Children: To help families cope, pediatric palliative/hospice care offers a broad range of services to address the physical and emotional needs of the child as well as the multidimensional needs of the family. It is a comprehensive system of care for children with life-threatening illnesses and their families from the time of diagnosis, with hope for cure through bereavement follow-up if cure is not attained.

Hospice of the Piedmont: We're here for more than the end. We're here to care for patients and their families as they navigate serious illness and death, and offer grief and bereavement services to the entire community.

Inclusive Health and Fitness | Jacob's Chance: nclusive Fitness and Health (I.F.H.) is a Program created by Jacob's Chance and the VCU Kinesiology and Health Science (KHS) Department's current instructor and Exercise Physiologist, Matthew Scott. Matthew Scott and the KHS department are working in conjunction with Jacobs Chance, meaning the two organizations are working together to create the best possible experience for any member! IFH is designed to generate fun fitness programs that are individualized to each member needs! On top of trying to improve fitness levels and have a fun social environment, the program also seeks to educate the importance of living a health lifestyle. This will be done within the program for each member, but will also be available for families/caretakers/friends/etc. through a series of health talks! This program will follow the successful "buddy" model that Jacob's Chance implements in all of their programs. Volunteers will be made up of current VCU KHS students who are studying how to properly implement fitness and health programs for various populations.

Individual and Family Support Program | IFSP: DBHDS established the Individuals and Family Support Community Coordination Program to assist families and individuals with developmental disabilities with making local connections to resources and supports that maintain community living. The effort is a partnership led by families that have formed councils covering the five DBHDS service regions. Together,

Created by: Sierra Phillips @mrs.phillijt
DBHDS and the IFSP State and Regional Councils have worked to establish Virginia's Individual and Family Support State Plan and to set local goals to support its implementation.

Infant & Toddler Connection of Virginia

INSIDE OUT LEARNERS: Inside Out Learners provides social-emotional learning groups, academic tutoring, summer camps, social clubs, Kids & Teens Night Out, a special kind of book club, and more through a variety of engaging activities for both, neurodiverse AND neurotypical learners. Our learning center is a sensory-conscious setting for individuals ages 6 and up to help strengthen their ability to interact more effectively with others via our social-emotional learning programs. We provide cutting edge, research-supported curricula and interventions that address essential skills needed to support social development and academic performance, regardless of the presence or absence of a formal diagnosis.

Jacob's Chance: Jacob's Chance enriches lives by empowering individuals 5-40 years old with developmental, intellectual, and/or physical disabilities through inclusive programs that promote personal development and positive relationships.

Jewish Family Service Hampton Roads: non-profit organization providing a full spectrum of social and health services to meet the needs of Hampton Roads residents.

Jill's House | Overnight Care for Families of Children with Special Needs: Jill's House is a Christian non-profit that provides short-term, overnight respite care for families raising kids ages 6-17 with intellectual disabilities in the DC metro area, and around the country. Parents regularly receive 24-48 hours to rest and recharge, while their kids are engaged in fun activities, tailored to their interests and abilities.

JT Walk: For the past 13 years we have come together to support individuals and families in the fight against ALS and we have helped our community become a place where people with disabilities, including our wounded veterans, can experience a life without limits.

JT's Grommet Island Park: JT's Grommet Island Beach Park & Playground for EveryBODY stands on the Virginia Beach oceanfront as a testament to the power of people determined to make a difference in the lives of others. The first ever accessible beach park for disabled children.

Kids' Haven Lynchburg: We serve grieving children and their families through support and education.

KulCreations - Etsy: maker of tubie pals from Newport News Virginia.

Let's Move Mountains: I founded Let's Move Mountains in Fall 2021 in an effort to try and bring CME and intensive style therapy to more people in a more convenient manner. At this time it is a in the client's home style of therapy. For 2023 I will no longe be offering my traveling intensives. I will also be switching to a more intensive based schedule versus a mix of weekly and intensives. I am able to offer intensives to local to me DMV families as well as those who have the ability to travel to the greater metro DC area.

List of Special Education Attorneys and Advocates

My Life My Community: My Life, My Community is an online tool that helps people with developmental disabilities (DD) and their families answer basic questions about services and supports.

National Core Indicators in Virginia: Virginia's National Core Indicators Project gathers information from people with disabilities, their families, and providers. Welcome to our website that tells you more about this project and what we have learned about supports and services in Virginia. This initiative is one way that Virginia is examining quality and provides a means to track progress and changes in systems of support for people with intellectual and developmental disabilities.

New Path: New Path is a program of The Arc of Virginia. New Path provides understanding and compassionate peer to peer support to empower, educate and connect families through Early Intervention, transition from Part C to Part B or until other services in community have provided support to the family and child(ren). New Path is a family support network to guide you on this new journey to help your child(ren) meet their developmental milestones. At times, this journey can become overwhelming, but we are here to help. New Path is here to provide you with individualized resources and support that may improve your family's quality of life.

New Path's Resource Book

No Wrong Door Virginia: No Wrong Door is a person-centered system and statewide network of partners supporting older adults, caregivers, individuals with disabilities, veterans and their families. It uses secure technology to link providers together, collaboratively supporting individuals and families seeking long-term services and supports. There is literally no wrong door to access the resources you need.

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Noah's Children Palliative Care: The goal of Noah's Children, Central Virginia's pediatric palliative care program of Bon Secours is to deliver holistic, compassionate and comprehensive care. Our interdisciplinary team provides for the physical, emotional, social and spiritual needs of our patients and their families in the environment they feel most comfortable.

Northern Virginia Resource Center for Deaf & Hard of Hearing Persons: To empower deaf and hard of hearing individuals and their families through education, advocacy and community involvement.

Occupational Therapy On the Go: The OT bus is fully equipped with a sensory gym. It is used for individual and small group therapy. Imagine the convenience of not having to travel to an outpatient clinic. Ideally, OT on the Go can reach rural areas, communities that homeschool, serve children within private schools or daycare, families with multiples, and busy schedules. Based in Salem VA.

Parent to Parent of Virginia: We have a philosophy that our services should affirm parents' strengths and enable parents to obtain for themselves the services and supports their families need. We believe that professionals can give a family direction and ideas, but in order for families to become empowered, they need to be confident to explore and discover their own personal strengths. Parents need support from other parents so that they can carry on with their lives. Parents can help other parents develop positive self-esteem, pride in themselves and in their families, and the ability to seek the services and supports they need.

Partnership for People with Disabilities | Faculty & Staff Contacts

Partnership for People with Disabilities | VCU: To partner with stakeholders in the intellectual and developmental disability community and faculty and staff throughout Virginia Commonwealth University to provide culturally competent and engaged research, education, direct services, and information sharing to ensure people with disabilities and their families can live, learn, work and play together as a part of their community.

PEATC – Parent Educational Advocacy Training Center: The Parent Educational Advocacy Training Center builds positive futures for Virginia's children by working collaboratively with families, schools and communities in order to improve opportunities for excellence in education and success in school and community life. Our special focus is children with disabilities.

Precious Time | Respite Care: Precious Time is a pediatric respite care program that provides the families of children with disabilities/special needs an opportunity to take a break from the demands of caregiving. JMU nursing students provide respite care as part of a student learning experience. Precious Time serves families who live within a one-hour radius of Harrisonburg, VA.

Rainy Day Program: The Rainy Day Program helps Raindancer families with: House payments, utilities and other crucial (non-medical) bills, Gas, restaurant, and grocery store gift cards, Housing, lodging and travel needs required while traveling to specialized care, Other unexpected expenses that may arise during a crisis, Emergency support & other related needs related to the COVID-19 crisis. SJGF also sends Raindancer families meals through food delivery services like Uber Eats! The Sweet Julia Grace Foundation serves Raindancers within an hours drive of Bristow, VA, and the surrounding areas of Hurricane, WV.

Rappahannock-Rapidan Community Services

RARC | Assistance, Resources, and Community: We are a small nonprofit organization dedicated to empowering individuals with mental disabilities to lead fulfilling lives located in Richmond, Virginia. Our comprehensive support services, advocacy, and community engagement strive to create a society that values and includes people of all abilities.

Resources For Families of Infants and Toddlers with Special Health Care Needs: Resources For Families of Infants and Toddlers with Special Health Care Needs.

Richmond Hope Therapy Center | Bon Secours: Richmond Hope Therapy Center is the first clinic in Virginia to offer highly effective intensive therapy. Originally inspired by Eastern European methods, intensive therapy has been growing in the US since 2002. Children receive 3-4 hours of therapy a day, 5 days a week, for 3 consecutive weeks in our individualized programs. With the increased time utilizing a variety of innovative tools, our therapists work with children to gain maximum strength, flexibility and balance for increased independence and greater functionality.

River City Inclusive Gym: Improve the lives of individuals with disabilities through fitness and fun!

RVAccess : The primary objectives of RVAccess are to facilitate the sport of soccer for athletes with special needs, to encourage the formation of relationships between teenage volunteers (buddies) and athletes with special needs, and to create a positive environment for an hour of fun. Our goal is to provide a safe environment in which an athlete may engage in soccer related activities while playing with peers. With the transition from TOPSoccer to RVAccess, the program focuses upon each athletes' individual needs in a fun, flexible approach.

Sara Camak Coaching: Life coaching for moms of children with rare genetic disorders. Based in Virginia, but providing support to moms in all states.

Service Dogs of Virginia

Shooting Stars: To increase the opportunities, perception, acceptance, and quality of life for people with Down Syndrome as well as all those touched by them.

Signs of Fun Camp: Signs of Fun Camp is a day camp that runs for one week each summer. Signs of Fun relies solely on donations from people like you — people who believe in the importance of providing programs to children who are Deaf or hard of hearing. It was established in 1995 by Arlene VanHorn for the Deaf and hard of hearing youth in Virginia.

SOAR365

Special Needs Resource Project: Virginia Resource Links

Sportable: Sportable creates opportunities by making sports accessible and inclusive for individuals with physical disabilities and visual impairments. Sportable transforms lives and frees you to see beyond your disabilities, enhances your peer relationships, and helps you to reach your personal finish line.

St. Mary's Home: St. Mary's Home in Norfolk is a special place full of love and laughter, where children and young adults from all across Virginia live, play, go to school and receive complex, professional, around-the-clock care in a nurturing, comfortable environment to help them achieve their fullest potential.

Summer Camps | Jacob's Chance

SunnyDays Pediatric Therapy: Pediatric physical therapy for your little one. Individually customized treatment plans designed to empower your unique child to overcome their physical impairments and succeed in achieving big gross motor milestones.

Sweet Julia Grace Foundation: To Bless, Celebrate, and Love children who are seriously ill, have special needs, or are currently facing a medical crisis. We grant wishes that bring joy and change lives, fill in gaps other services are unable to fill, and provide support with day-to-day needs for families going through the unimaginable with their child. The Sweet Julia Grace Foundation serves Raindancers within an hours drive of Bristow, VA, and the surrounding areas of Hurricane, WV.

Technical Assistance Center for Children Who Are Deaf and Hard of Hearing | TAC-DHH: The Technical Assistance Center for Children Who Are Deaf and Hard of Hearing is funded by the Virginia Department of Education (VDOE) to provide training and technical assistance in the area of deafness and hearing loss. Assistance is available to local public school systems as well as state-operated programs including early intervention through the Virginia Network of Consultants for Professionals Working with Children Who are Deaf and Hard of Hearing (VNOC) in areas such as: identification, assessment (educational, psychological), communication of children across the spectrum of modalities (listening and spoken language, American Sign Language, Signed English, etc.), specific needs of children with cochlear implants, instructional strategies and amplification.

The Arc of Loudoun: At The Arc of Loudoun, we strive to bring about a just, equitable world for people with disabilities.

The Arc of Virginia

The Faison Center: At The Faison Center, our mission is to give children and adults with autism and related challenges the best opportunity to improve their life's journey through evidence-based practice. We provide world-class services and programs through our unique lifespan model, which offers enriching opportunities from early diagnosis to adulthood. No matter when our services are needed, we are committed to improving the lives of the individuals we serve.

The Hospice Alliance: Alliance Kids is the Mid-Atlantic regions collaborative voice and provider of high quality, compassionate pediatric hospice care serving children and young adults in the place they call home. Through our website, we can help anyone with a life-limiting illness to a pediatric palliative and hospice expert. Our vast provider network includes experts across Maryland, Delaware, Washington D.C. and Northern Virginia

The Motherhood Collective: The Motherhood Collective offers FREE year round programming to women from preconception to postpartum.

Therapeutic Riding Programs

ThisABILITY: The Mission of ThisABILITY is to offer support and encouragement to families who have or are expecting children with special needs, to ensure they have the Resources and Information they need available to them, to Educate and Advocate, and to create Awareness and Acceptance.

Created by: Sierra Phillips @mrs.phillijt
TotallyTubularCo: Patterned or Custom Tubie Tape from Virginia.

VA Family Special Education Connection: This website provides a one-stop-shop for parents, families and caregivers of children with special needs. Parents and families can and do make a difference in their child's education.

VA Sibling Network: As the Virginia's chapter of The National Sibling Leadership Network, our vision is for siblings with disabilities to form connections, share lived experiences, access information, utilize resources, and advocate collectively.

Veterans Park: Veterans Park is home to the Vietnam Veterans Memorial monument donated by local resident David Hooker in 1993 to honor residents who gave their lives in the Vietnam War. The 19-acre park is also home to Kidsburg, a 30,000-square-foot lighted playground that features separate play areas for children ages 2-5 and 5-12, a ship replica, swing areas, and 2 zip lines. Other park amenities include an indoor multipurpose room, 0.6-mile paved ADA accessible multiuse trail, sand volleyball courts, lighted basketball courts and pickleball courts, Wi-Fi connectivity, an off-leash dog area and lots of open space.

Virginia | RareAction Network

Virginia Assistive Technology System: The mission of the Virginia Assistive Technology System (VATS) is to ensure that Virginians of all ages and abilities can acquire the appropriate, affordable assistive and information technologies and services they need to participate in society as active citizens.

Virginia Beach Crisis Nursery: Our mission is to provide safety for children, to strengthen families, and to create a healthier community through an environment of unconditional love. To support our mission we currently offer Diaper and Formula Assistance. We also try to connect you with resources that may already be available in the community.

State Special Education Advisory Committee (SSEAC) | Virginia Department of Education: The State Special Education Advisory Committee (SSEAC) is organized and functions in accordance with state and federal requirements.

Virginia Board for People with Disabilities: VBPD serves as Virginia's Developmental Disabilities (DD) Council. DD Councils are in every state and territory of the United States. They work for the benefit of individuals with DD and their families to identify needs and help develop policies, programs and services that will meet these needs in a manner that respects dignity and independence.

Virginia Caregiver Coalition: The VCC will work passionately to improve the experience of caregiving through education, advocacy and access to resources.

Virginia Home for Boys and Girls | VHBG: Virginia Home for Boys and Girls (VHBG) is a nonprofit organization that has been serving youth in crisis since 1846. In the 1960's, we stopped operating as an orphanage and now provide transitional living services, specialized education, and therapeutic resources to youth with emotional and behavioral health concerns.

Virginia Kids' Waivers

Virginia Lifespan Respite Voucher Program: The Virginia Lifespan Respite Voucher Program (VLRVP) provides reimbursement vouchers to Virginia caregivers for the cost of temporary, short-term respite care provided to individuals of any age, with a documented disability or medical condition. The goal of this program is to increase access and reduce barriers to respite care, as well as enhance education and awareness about respite care. Respite funding is limited to $595.00 per family through June 30, 2026, or until funds are exhausted.

Virginia Navigator | Your Nonprofit Guide to Veterans' Benefits, Caregiving Resources, and Disability and Aging Services in Virginia

Virginia Organizing: Virginia Organizing is a non-partisan statewide grassroots organization dedicated to challenging injustice by empowering people in local communities to address issues that affect the quality of their lives. Virginia Organizing especially encourages the participation of those who have traditionally had little or no voice in our society. By building relationships with individuals and groups throughout the state, Virginia Organizing strives to get them to work together, democratically and non-violently, for change.

Virginia Statewide Independent Living Council: The Statewide Independent Living Council (SILC) is an independent planning body working with the Centers for Independent Living (CILs) and Department for Aging and Rehabilitative Services to increase the impact of Independent Living (IL) services in Virginia. The SILC is composed of gubernatorial appointees who represent people with significant disabilities across the state, the interests of CILs, and Independent Living programs and services.

Virginia LEND | VCU: The Va-LEND program is committed to the preparation of professionals, family members and people with disabilities statewide in the field of childhood neurodevelopmental disabilities who will assume leadership roles within health care and disability service systems. The interdisciplinary program provides a 12-24 month curriculum of interactive seminars, clinical and community-based practica, planned grassroots and systems level policy activities, and for most trainees, a family mentorship experience. The curriculum emphasizes all aspects of neurodevelopmental and related disabilities, social and family environments across the life course, the interdisciplinary approach, leadership and research.

Voices for Virginia's Kids: Voices for Virginia's Children champions public policies and legislation that achieve positive and equitable outcomes for young people.

Weinstein JCC | Special Needs & Inclusion: The Weinstein JCC Early Childhood Department strives to create a successful experience for every child by offering a unique, inclusive setting in our Preschool and Childcare Programs.

YMCA at JT's Camp Grom | YMCA of South Hampton Roads: YMCA at JT's Camp Grom is a day retreat developed especially for wounded veterans and their families, the families of fallen war heroes and children and adults with and without disabilities. It is a special place where everyone in the family can spend time and participate, together. Unlike traditional camps, JT's Camp Grom delivers a unique, integrated and adaptive day of activities surrounded by family and friends.

WASHINGTON RESOURCES:

CMG - Home (uwcmg.org): The UW-CMG is one of several centers supported by the National Human Genome Research Institute and the National Heart, Lung, and Blood Institute of the National Institutes of Health with an overall goal of identifying the genetic basis of Mendelian conditions for which the underlying cause is unknown. The UW-CMG performs exome sequencing (ES), whole genome genome sequencing (WGS), and /or analysis of ES/WGS data at NO COST (i.e., FREE) for qualified investigators and Mendelian phenotypes. The UW-CMG also accepts ES/WGS data and clinical information from families with Mendelian conditions who have undergone clinical testing but no responsible gene has been identified.

State Resources - Dads Move: A list of resources for the state of Washington compiled by Dads Move.

Community Resources | Washington State Department of Children, Youth, and Families: A list of resources compiled by Washington State Department of Children, Youth, and Families.

Early Support for Infants & Toddlers | Washington State Department of Children, Youth, and Families: Early intervention services are designed to enable children birth to 3 with developmental delays or disabilities to be active and successful during the early childhood years and in the future in a variety of settings—in their homes, in child care, in preschool or school programs, and in their communities.

Current Registered Providers - Lifespan Respite Washington: All of our current registered respite providers are listed below. To have a more specific list of providers based on your needs, you can search by county, type of respite service, ages served, type of disability or condition. To search click on the plus sign next to each section. When the section expands, click on the items you want or need for a provider.

Washington Sensory Disabilities Services – Every child is a child first.: WSDS partners with schools, families and agencies to support children and youth who are deaf/hard of hearing, blind/low vision, or deafblind, by providing assessment services, training and consultation.

Clinics and Programs (seattlechildrens.org)

Washington State Hands & Voices (wahandsandvoices.org): We are a parent driven organization dedicated to supporting families with children who are Deaf or Hard of Hearing (DHH) regardless of language or communication mode.

Home | Washington State School for the Blind: Every blind and low vision student in Washington has the supports and services they need to succeed.

Special Education Support Center | Washington Education Association: Our purpose is to provide professional development opportunities for all special education stakeholders including educators (both general and special education personnel), school administrators, paraprofessionals, ESA staff, parents and community members.

Created by: Sierra Phillips @mrs.phillijt

Washington State DeafBlind Citizens, Inc. (wsdbc.org): The mission of WSDBC is to promote, protect, and preserve leadership, independence, communication access, and to advocate DeafBlind individuals in the state of Washington.

Northwest – Helen Keller Services: Whether you're interested in learning about support services near your home, would like to take advantage of the technology available through the National Deaf-Blind Equipment Distribution Program or want to explore the possibility of training at our national headquarters, your regional representative is your link to all that HKNC has to offer — consultation, advocacy, assessment, training, referrals and more.

Washington School for the Deaf – Bilingual-Empowered-Successful for Today and Tomorrow—the BEST!: Washington School for the Deaf is the state of Washington's only ASL-English bilingual school serving deaf and hard or hearing students in Pre-K through 12th grade.

Washington Center for Deaf and Hard of Hearing Youth: The Washington Center for Deaf & Hard of Hearing Youth (CDHY), formerly the Center for Childhood Deafness and He:aring Loss (CDHL), is a statewide resource committed to ensuring all deaf and hard of hearing students in Washington reach their full potential regardless of where they live or attend school.

Washington DeafBlind Program – Washington State Services for Children with Deaf-Blindness: Serving early development and educational needs for children and youth from birth through age 21 who have combined hearing and vision challenges, including those with complex health needs.

STOMP - PAVE (wapave.org): To provide information and resources so that military parents, individuals with disabilities and military personal access services. We hope as a result of the workshops to enhance the connections and knowledge of all attendees and foster collaborative environments to further enhance family and professional partnerships.

Home : OPTION Schools, Inc. (optionlsl.org): OPTION Schools, Inc. is an international, non-profit organization comprised of listening and spoken language programs and schools for children who are deaf or hard of hearing in Canada, South America, and the U.S. OPTION Schools, Inc. advances excellence in listening and spoken language education by providing information and support to programs and school leaders. Member schools and programs, both individually and collectively, educate the public, professionals and policy makers as to what is possible for children who are deaf and hard of hearing in the 21st century.

Spokane HOPE | Hearing Oral Program of Excellence: With the right equipment, early intervention, and loving instruction; deaf and hard-of-hearing children can now learn to listen and speak. Spokane HOPE is the only program in eastern Washington that offers this vital instruction with services and classes from birth to preschool. With the ability to hear and speak, our students are empowered to chase their dreams and amplify their impact on the world around them.

Northwest School for Deaf and Hard-of-Hearing Children | WA

Family Conversations at NWSDHH - Northwest School for Deaf and Hard-of-Hearing Children: Family Conversations is a program for families with children from birth to age three who are deaf or hard-of-hearing. Our program offers a total communication approach which integrates Signing Exact English (S.E.E.), speaking and listening. The children we serve through Family Conversations have a variety of hearing levels.

Hearing, Speech & Deaf Center – Hearing, Speech & Deaf Center serving western Washington communities. (hsdc.org): The mission of Hearing, Speech & Deaf Center (HSDC) is to foster inclusive and accessible communities through communication, advocacy, and education. We envision an inclusive, accessible world where everyone is understood and respected. We offer a comprehensive array of programs that foster effective communication for individuals and families affected by hearing or speech differences.

Listen and Talk - No Child Is Limited By Hearing Loss (listentalk.org): Listening and Spoken Language is an approach that relies on newborn hearing screenings, supportive intervention, and hearing technology to empower children with hearing loss to listen and communicate verbally with the surrounding world. Listen and Talk families partner with highly-specialized providers to utilize auditory-verbal strategies that support their child's language development.

Parent Training and Information Program - PAVE (wapave.org): PAVE's program called Parent Training and Information (PTI) helps family caregivers, youth, and professionals with questions about services for children and young people with disabilities, ages 0-26. PTI provides direct help, training for groups, and access to resources. Click Get Help to fill out the form, and PTI staff will contact you to talk through your situation and provide information, resources, and coaching. For example, PTI staff might help you understand how to refer a student to be evaluated for school-based services. We might help you organize your concerns for a meeting to discuss a student's Section 504 Plan or Individualized Education Program (IEP). PTI empowers parents and students to help them understand their rights, and we provide coaching about special education vocabulary.

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Self-Care is Critical for Caregivers with Unique Challenges - PAVE (wapave.org)

Parent to Parent - Washington State (arcwa.org): Parents may have questions and concerns as they learn about new information and services that can help their child and family. Parents also need time and support to navigate their own emotions and adjust to raising a child with special needs. Personal support from another parent, who has a child with similar needs, can help. You are not alone. We have been there. Volunteer Helping Parents are available to provide support and information. Helping Parent volunteers have completed a training program and are available to provide support and information to other parents. All information is kept confidential. There is no cost for this service.

The Family Mentor Project: The Family Mentor Project (FMP) is a resource to support families and guardians through the process of moving a family member to the community from a Residential Habilitation Center (RHC) operated by the Developmental Disabilities Administration of Washington (DDA) or from a skilled nursing facility.

Journey with us... - Washington State (arcwa.org): The Arc of Washington State has been a leader in the development of services and programs for people with intellectual and developmental disabilities of all ages and in providing support to their families. As a non-profit 501(c)(3) organization, The Arc of Washington State is composed of individuals with intellectual and developmental disabilities, their families, professionals, and concerned members of the community.

A website for families and individuals in Washington state - Parenthelp123

Special & Developmental Needs - Parenthelp123: As a parent, you are the most important person in your child's life. You want to give your family the best care you can. There are early intervention services available as well as other kinds of support that can be of help. Finding information and resources to help your child with special needs can be a challenge. This site may give you a starting point for your search.

Families - Parent and Caregiver Support Resources - Parenthelp123

Empowering Strides: Empowering Strides is a non-profit organization providing therapeutic horsemanship to neurodiverse youth who face behavioral, emotional and/or cognitive challenges. Through the use of horses we can offer youth a different perspective. Horses often mirror the emotions of their handler which allows the horse to teach a child far easier than an authoritative figure. Horses gently encourage a new awareness and connection in people that grows a person's self-awareness and leadership abilities.

Families - Child Care Aware WA: Child Care Aware of Washington seeks to help every child receive high-quality child care.

Military Family Respite Care Program - LCSNW: Exceptional Family Member (EFM) Respite Care helps military families who have children with special needs by providing a few hours of respite care per month. The services allow parents temporary relief to attend appointments or gather some much-needed rest, without having to worry about the well being of their child. Eligible members receive up to 40 hours of respite care per month at no cost.

Olympic Neighbors: Olympic Neighbors' mission is to create home and community for people with intellectual and developmental disabilities (IDD).

Center for Child and Family Therapy: Center for Child and Family Therapy is an organization of therapists and specialists dedicated to providing therapeutic assessments and treatment for children, adolescents, adults and families in Kitsap County. We have been in business for over 25 years. Our staff, associates and consultants offer integrated services, working together and with the community resources such as schools, physicians and DSHS.

Stephens Neighborhood – Fostering Support for Young Adults with Special Needs in North Kitsap: We are a grassroots gathering of people in North Kitsap who love kids and are concerned about helping Special Needs young adults have full and rewarding lives.

Home | Bainbridge Island | Stephens House (bispecialneedsfoundation.org): We are a community-based organization that provides activities to help guide individuals with intellectual disabilities (i.e. learning disabilities, autism spectrum disorder, Down syndrome, etc) towards meaningful relationships within their community while building upon each individual's unique strengths. We are happy to announce that we are fully staffed and operating again! We are still at Eagle Harbor Congregational Church in downtown Winslow.

Easterseals Washington | Camp Stand By Me: Since 1974, Easterseals Camp Stand By Me has been an inclusive, barrier-free environment for children and adults with disabilities to experience all the joys of camp without limitations. Camp is about all the things children and adults CAN do: swim, canoe, sing, eat s'mores, build lifelong friendships and more. We offer week-long sessions in the summer, and weekend respite in the fall, winter, and spring. With low staff to camper ratios and an on-site registered nurse, we can serve children and adults of any ability level.

Easterseals Washington | Olympic Peninsula Autism Center: Easterseals Washington Olympic Peninsula Autism Center (OPAC) provides Applied Behavior Analysis (ABA) therapy for children with autism in home and in the clinic. We provide services throughout Kitsap County and nearby Jefferson and Mason Counties, with a special emphasis on the Intensive Verbal Behavior Approach. OPAC is located in central Silverdale — convenient to the mall and other amenities.

BKAT Association: The BKAT Association is organized for the charitable, religious, and educational purposes along with promoting recreational (amateur) athletic sports participation, development, and competition opportunities for developmentally disabled youth and adults.

Home | Tiny Notes (tinynotesmm.org): Tiny Notes Enrichment Center is an enrichment program that was created with the vision to educate children with developmentally appropriate concepts, reinforced through the joys of play and music.

Harbor Speech Pathology: Harbor Speech Pathology is unique in our ability to bring you the best speech, language and cognitive resources that set us apart from other providers in the Pacific Northwest. HSP is proud to offer an array of services to patients of all ages and abilities. We strive to apply the latest scientific evidence and technology to each patient's unique situation.

Grow Behavior Services: Play-based, child-led behavioral therapy services for kids with autism diagnoses, serving Bainbridge Island and North Kitsap County. Building individualized skills and reaching goals with a compassionate, connection-based, neurodiversity-affirming approach.

Consumer Direct Care Network Washington: For three decades and across the country, Consumer Direct Care Network (CDCN) has worked in the home as a provider of managed long-term services and supports. We are now in Washington state where we are Washington's Department of Social and Health Services (DSHS) Consumer Directed Employer (CDE). Consumer Direct Care Network Washington (CDWA) draws on more than 30 years' experience supporting innovative home care for individuals, families, and caregivers. CDCN specializes in solutions that make it easier for Clients to get the care they need. Our services and supports help people and families of all ages including children, older adults and people with disabilities, remain safe, healthy and independent in their own homes. We have extensive experience with Medicaid, private insurance, and supporting people to be independent and active in their communities.

Apple Tree Therapy LLC (appletreeot.com): provides revolutionary occupational therapy treatments for children with special needs (autism, sensory processing disorders, ADHD, learning disabilities, developmental delays and more). It empowers parents with knowledge, training and tools that bring peace of mind. And the kids love it!

Northwest ADA Center | ADANW (nwadacenter.org): he Northwest ADA Center is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and is part of the ADA National Network(link is external). The ADA National Network Centers are a national platform of ten centers comprised of ADA professionals and experts charged with assisting businesses, state and local governments, and people with disabilities as they manage the process of changing our culture to be user friendly to disability and the effect the variety of health conditions can have on society. The regional advisory committee and our state partners are premier leaders in ADA compliance in each of the states served--Alaska, Idaho, Oregon, and Washington.

Our Creative Minds (ourcreativemindsinc.com): Established in 2006, Our Creative Minds is dedicated to support the special needs of your family. Several of our family members have multiple disabilities, giving us a close, heartfelt connection, helping our clients get the specialty items so desperately needed, processed and shipped to you quickly. Currently Our Creative Minds holds state contracts with the Department of Developmental Disabilities in Washington and Hawaii. As a contracted state vendor, we can help with accessing the funds to purchase items not covered by insurance, including but not limited to assistive technology, adaptive clothing, sensory items, home modification equipment, indoor gyms and adapted bikes.

Developmental Disabilities Endowment Trust Fund | Protect today, Provide for tomorrow (wa.gov): The DD Endowment Trust Fund is a supplemental special needs trust program. It was established in 1999 by the Washington State Legislature and opened for enrollments in July of 2002. The DD Endowment Trust Fund allows individuals with developmental disabilities, or their families, to set aside funds for future use without affecting their eligibility for government services and benefits, such as Supplemental Security Income (SSI) and Medicaid. Funds can be withdrawn from the trust and used for many services not covered by other benefits, including recreation, therapy, clothing and transportation. The DD Endowment Trust Fund is an easy and effective way to prepare for the future (and life's unexpected expenses) without risking financial eligibility for needed benefits and services.

Benefit U | Your resource for Social Security Benefits info in the State of Washington: Whether you'd like to explore our training content on your own, or get help from a Certified Benefits Planner, we can connect you with the information you need. For information and resources related to specific benefit topics such as Medicaid, Medicare, SSI, and Title II benefits, please click the icons below or use this Individuals and Families link, or drop-down in the menu at the top of the page.

Northwest Down Syndrome Association (nwdsa.org): NWDSA has been a parent-driven family support network since 1997. NWDSA's mission is to create and nurture a loving and inclusive community celebrating every person with a disability including Down syndrome.

CHDD - Haring Center (washington.edu): The Norris and Dorothy Haring Center for Research and Training in Inclusive Education provides early childhood education to children with and without disabilities, conducts leading-edge research to advance inclusive learning, and champions the best practices we develop beyond our walls so that every child can reach their full potential. Through our unique integrated model we create inclusive communities that empower all children to learn, play and grow together, guided by the vision that every child has meaningful opportunities to learn, to engage with others, and to live in an inclusive community that values all its members.

CHDD - Genetics Program (washington.edu): The Genetics Program comprises clinics that serve individuals at risk for or with a genetic disorder or disability. Clinics offer diagnosis, assessment, treatment, and counseling services to meet the needs of these clients. Clinics also provide information on current research, support groups, and other community resources to help individuals and family members understand and manage the condition. Disorders diagnosed and treated by the Genetics Program include neurological, metabolic, and biochemical disorders. Genetic counselors also provide information about the heritability of a particular disorder to inform and support parents in preventing developmental and other disabilities in their future children.

Washington Speech-Language - Hearing Association | WSLHA: Washington Speech-Language - Hearing Association (WSLHA) is an organization which promotes professional excellence in speech-Language pathology and audiology. Empowering our members through collaboration, professional and leadership development, advocacy, and support to provide equitable and inclusive care to our diverse populations.

The Center on Human Development and Disability | CHDD: The Center on Human Development and Disability (CHDD) at the University of Washington makes important contributions to the lives of people with developmental disabilities and their families through a comprehensive array of research, clinical services, training, community outreach, and dissemination activities.

The Washington Assistive Technology Act Program | WATAP: provides resources and services to persons who face challenges related to disability and aging to help in the selection and use of assistive technology, also known as AT. AT helps make tasks easier or possible in school, at work, at home, and in the community. WATAP serves seniors and persons with disabilities, and their circle of support, including family members, caregivers, employers, service provider professionals, educators, and others seeking AT expertise.

Cerebral Palsy Program – Seattle Children's: Seattle Children's takes an active approach to caring for children with cerebral palsy (CP) so they can be as healthy and functional as possible. The Cerebral Palsy Program offers a full range of nonsurgical and surgical treatment options. Our program includes experts in every field your child might need, working together on a personalized care plan for your child.

Washington State Cerebral Palsy Resources | MyCPChild.org (mycerebralpalsychild.org)

Washington Connection (Your Link to Services): Washington Connection offers a fast and easy way for families and individuals to apply for a variety of services such as Food, Cash, Child Care, Long-Term Care, and Medicare Savings Programs. Individuals that are age 65 or older, blind or disabled may also apply for medical assistance.

Holly Ridge Center: Holly Ridge Center's mission is to enable children and adults with differing abilities to reach their fullest potential, creating a positive and lasting impact on the community.

Autism Resources Navigator - Holly Ridge: Holly Ridge Center's ARN, Debra Dineen, is a licensed behavior analyst who has worked with young children with autism and their families for over twenty years, including several years on the Infant Toddler Program team of ABA providers. Debra provides the same sensitive, high-quality care families experience from all Holly Ridge Center staff and it's her privilege to accompany families as they begin their journey with autism.

Disability Rights Washington: Disability Rights Washington is a private non-profit organization that protects the rights of people with disabilities statewide. Our mission is to advance the dignity, equality, and self-determination of people with disabilities. We work to pursue justice on matters related to human and legal rights.

Learning Disabilities Association of Washington | (ldawa.org): Learning Disabilities Association of Washington (LDA WA) promotes and provides service and support to improve the quality of life for individuals and families affected by learning and attentional disabilities.

Directory | Learning Disabilities Association of Washington (ldawa.org): These listings are intended solely to help users find a resource that can fulfill a specific need. The resources listed in the Directory are made without any guarantee by the Learning Disabilities Association of Washington (LDAWA) and users should independently assess the services offered by the listed resources. LDAWA does not recommend or endorse any specific person or organization, or diagnostic or therapeutic method.

Autism Guidebook for Washington State: A Resource for Individuals, Families, and Professionals

Autism Resources | AS360: AS360 aims to ensure people with ASD in Washington State have healthier, happier lives. We do this by sharing how to access providers, resources, information and community.

Washington Autism Alliance: We expand access to healthcare, education and services for people with autism and other intellectual and developmental disabilities in Washington State.

Myths & Facts about Inclusionary Practices | OSPI (www.k12.wa.us): Special education has its fair share of myths and facts about the inclusion of students receiving special education services, especially those with significant cognitive disabilities. These common misconceptions often lead to situations where students are denied their right to spend the maximum amount of time in general education settings and doing work aligned to the state learning standards. OSPI Special Education, the TIES Center, and UW Haring Center developed this resource to challenge those myths and highlight the facts of why inclusionary practices work for each and every student.

KC Resource Guide 2020-2021.pdf (kitsapgov.com): The following guide lists the essential services for people with developmental disabilities in Kitsap County.

Kitsap Resource Fair | Wise (gowise.org): Holly Ridge Center, the Washington Initiative for Supported Employment (WISE), Kitsap County Parent Coalition, and Kitsap County Developmental Disabilities collaborated to bring you this year's Resource Fair. It will be live from April 3rd through June 30th. Check out the many partner agencies serving individuals with disabilities and their families. Explore services in our community in the areas of Education, Advocacy, Support, Employment, Care, Housing, Recreation, Leisure, and more!

Resources – Kitsap County Parent Coalition: The Kitsap County Community Resource Guide lists the essential services for people with developmental disabilities in Kitsap County. It includes information ranging from Advocacy to Volunteering as well as an acronym listing and glossary. Also has state-wide resources too.

Camp Fire Central Puget Sound: Camp Fire believes in the dignity and the intrinsic worth of every human being. We welcome, affirm, and support young people and adults of all abilities and disabilities, experiences, races, ethnicities, socio-economic backgrounds, sexual orientations, gender identities and expressions, religion and non-religion, citizenship and immigration status, and any other category people use to define themselves or others.

Kitsap County Parent Coalition: The Kitsap County Parent Coalition (KCPC) is a free service providing education, advocacy and referrals to help people with developmental disabilities get the support and services they need to improve their lives. The Kitsap County Parent Coalition (KCPC) is a free service providing education, advocacy and referrals to help people with developmental disabilities get the support and services they need to improve their lives.

Easterseals Washington | Inclusive Child Development Centers: We are committed to providing a diverse, inclusive environment where parents can be sure their children are well cared for and will be encouraged to reach their full potential. We support the needs of children of all abilities.

Easterseals Washington | Home: Easterseals Washington has been helping children and adults with disabilities and their families reach their full potential for over 70 years. At our programs across the state, we serve people of any age—and any ability—and give them the support they need to live, learn, work and play in their community. Our purpose is to change the way the world defines and views disabilities by making profound, positive differences in people's lives every day.

Camp Fire Inland Northwest: Youth of all backgrounds and abilities are welcome in Camp Fire programs. Our staff works with parents to ensure a successful experience, whether it's in a school-year program, day camp or overnight camp. We encourage parents to be open with us about their child's needs, so that we can determine how best to support your child. Camp Fire is open to everyone and we embrace the uniqueness of every individual and family. Our inclusive program focuses on building skills and gaining self-esteem as part of the outdoor experience. We want every child to have the opportunity to participate in camp.

Camp Beausite Northwest: Camp Beausite Northwest (CBNW) is a place where everyone has the opportunity to be all they can be in an inclusive and welcoming residential camp environment. Our annual offerings include weeklong camp sessions during the summer and weekend respite programs during the rest of the year. We serve youth and adults with special needs ages 7–99+. CBNW is a proud certified respite provider and we work hard year-round to be able to provide the camp experience and respite opportunities for over 350 campers and 1,000 caregivers annually. We also rent the camp out to the public for lodging, workshops, retreats, and other types of gatherings.

Adaptive Life Coaches: Our program is a respite support service for those with disabilities but is open to anyone in need of a life coach. Our mission is to teach life, social, and communication skills with a focus on movement and activity in a one on one. Autism Life Coaches LLC (dba Adaptive Life Coaches) is based in Whatcom County, Washington. We also serve Skagit County.

Informing Families | Navigating the future: Informing Families is a resource provided by the Washington State Developmental Disabilities Council, in partnership with the Developmental Disabilities Administration. We offer trusted news and information to individuals and families that empowers them to be active participants in planning and building a network of support and opportunities.

Statewide Caregiver Support Group - Lifespan Respite Washington: A time to connect, share, learn, and support one another. All family caregivers caring for people of any age are welcome. These educational sessions focus on supporting and learning from one another. You can attend by phone, or online with any device and anonymously if you wish. Support groups are hosted on the HeyPeers website.

Dads Move - Home: Dads M.O.V.E. seeks to provide every parent/caregiver (especially dads) with the tools, support, and training needed to be fully engaged in the recovery of their children.

Lifespan Respite - Lifespan Respite Washington: Lifespan Respite WA offers support in the form of a voucher (financial award) for unpaid caregivers who support a family member, friend, or neighbor who has a special need or condition. The voucher is used to pay for services or programs that allow the caregiver to have respite, or "short breaks". Lifespan Respite vouchers are for short-term respite.

Parent Trust – Parent Trust for Washington Children: We equip parents and caregivers to raise safe, healthy and strong children.

FOCS - Families of Color Seattle (focseattle.org): Families of Color Seattle (FOCS- pronounced "folks") connects families, caregivers, and children of color through peer-led parent support groups; spaces to share culture, skills, and resources; and racial justice education and advocacy.

Community Engagement Program (DDA) - Dads Move: This service helps connect individuals to resources in their community and supports them to participate, engage, and integrate into the community. This service is available in the Individual and Family Services waiver.

Home - Family to Family Health Information Center (familyvoicesofwashington.org): The Family-to-Family Health Information Center helps families of children and youth with special health care needs, and the professionals who serve them, to find healthcare funding. Because children with special health care needs issues are chronic and complex, parents and caregivers are often challenged with finding the resources to finance health care for their children. The Family-to-Family Health Information Center understands the issues that families face; they provide advice, offer a multitude of resources, and tap into a network of other families and professionals for support and information. Family Voices, through the National Center for Family / Professional Partnerships, provides technical assistance, training, and connections to other Family-to-Family partnering organizations.

Special Education | OSPI (www.k12.wa.us)

Center for Change in Transition Services | Seattle University: CCTS works to empower educators and administrators to improve transition services for youth with disabilities through partnerships, research, and training.

Resources | Center for Change in Transition Services | Seattle University: Use the map or links below to navigate to a list of agencies in your county. Agencies are organized by areas of employment, healthcare, housing, postsecondary education, and transportation.

Inclusionary Practices Professional Development Project | OSPI (www.k12.wa.us): All students have a right to meaningfully participate in the general education setting, both academically and socially to the fullest extent possible. Inclusion is realized when all students, regardless of their designation to receive special education services, are provided with targeted services, supports, and accommodations; allowing them to learn in the general education classroom, interact with peers, and engage the core curriculum. To support more inclusive schools in Washington, the State Legislature provided OSPI with $25M for the 2019–21 biennium and $12M for the 2021–23 biennium to provide educators with professional development opportunities in support of inclusionary practices across the state.

PAVE: Partnerships for Action, Voices for Empowerment (wapave.org): PAVE provides support, training, information and resources to empower and give voice to individuals, youth and families impacted by disabilities.

Wheel to Walk Foundation: Wheel to Walk Foundation is a non-profit organization that helps children with disabilities, 20 years and younger, obtain medical & adaptive equipment or therapy services not provided by insurance. Our organization strongly believes that no child or young adult with special needs go without items that could improve the quality of their daily life. If you live in Oregon, Washington, Idaho or California and need assistance, please contact us and we will send you an application.

The Western States Regional Genetics Network: The Western States Regional Genetics Network, formerly known as the Western States Genetic Services Collaborative, is a federally-funded, multi-state project that seeks to increase access to genetic services and education for medically underserved populations. The participating states and territory are Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. The Western States Regional Genetics Network, formally known as the Western States Genetic Services Collaborative, is a federally-funded project that seeks to improve access to genetic services and education for medically underserved populations. By working together as a region to increase access to and reduce disparities in clinical genetic and newborn screening services, the participating states/territory seek to improve the health of individuals with or at risk for heritable disorders.

PROVAIL: PROVAIL is one of Washington State's largest, multi-service agencies dedicated to meeting the needs of children, youth, and adults with disabilities who need an integrated, complex set of services to live life according to their own choices. Serving primarily King and Snohomish Counties, PROVAIL offers a comprehensive range of services to support people, with even the most severe disabilities, in all major areas of life so they can live, work, play, and fully participate in the community of their choice.

WEST VIRGINIA RESOURCES:

Developmental Therapy Center | Developmental Therapy Center (dtchuntington.org)

About SFC | Center for Excellence in Disabilities (cedwvu.org)

Sweet Julia Grace Foundation | Learn to Dance in the Rain: To Bless, Celebrate, and Love children who are seriously ill, have special needs, or are currently facing a medical crisis. We grant wishes that bring joy and change lives, fill in gaps other services are unable to fill, and provide support with day-to-day needs for families going through the unimaginable with their child. The Sweet Julia Grace Foundation serves Raindancers within an hours drive of Bristow, VA, and the surrounding areas of Hurricane, WV.

Rainy Day Program | Sunshine on a Rainy Day (sweetjuliagrace.org): The Rainy Day Program helps Raindancer families with: House payments, utilities and other crucial (non-medical) bills, Gas, restaurant, and grocery store gift cards, Housing, lodging and travel needs required while traveling to specialized care, Other unexpected expenses that may arise during a crisis, Emergency support & other related needs related to the COVID-19 crisis. SJGF also sends Raindancer families meals through food delivery services like Uber Eats! The Sweet Julia Grace Foundation serves Raindancers within an hours drive of Bristow, VA, and the surrounding areas of Hurricane, WV.

WISCONSIN RESOURCES:

UW Undiagnosed Disease Program: The goal of the UW-Undiagnosed Disease Program (UW-UDP) is to improve the health and well-being of individuals with undiagnosed disorders. The program's objectives are to shorten the diagnostic odyssey for patients with rare diseases, discover new disease genes, develop novel diagnostic techniques, improve our understanding of the relationships between genomic variants and disease, and share our discoveries with the global genomic medicine community.

Act Early Wisconsin – Learn the Signs. Act Early. – UW–Madison: The Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), in collaboration with a number of national partners, launched a public awareness campaign called "Learn the Signs. Act Early." The campaign aims to educate parents about childhood development, including early warning signs of autism and other developmental disorders, and encourages developmental screening and intervention.

Wisconsin Surveillance of Autism and Other Developmental Disabilities System – WISADDS – UW–Madison: The Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) is part of the Autism and Developmental Disabilities Monitoring (ADDM) Network funded through the Centers for Disease Control and Prevention (CDC). WISADDS is a multi-source public health surveillance project that monitors the prevalence of autism spectrums disorders (ASDs), cerebral palsy (CP), and co-occurring intellectual disability (ID) in 4- and 8-year-old children within an 8-county area in southeastern Wisconsin.

United Way of Wisconsin: The United Way of Wisconsin (UWWi) is the statewide organization providing member support services to the local and independent United Ways in Wisconsin. Through UWWi member support services, local United Ways in Wisconsin have capacity to individually and collectively build stronger communities.

Autism Hub Page – Waisman Center – UW–Madison (wisc.edu): The scope of the Waisman Center's autism-related activities continues to expand as we actively pursue research into the causes, consequences and treatments of this complex disorder.

Find Your Local Wisconsin United Ways: United Way fights for the health, education, and financial stability of every person in every community. Each local United Way is governed by a board of local volunteers who convene partners to determine local needs, set priorities, and make local investment decisions. There are 40 UnitedWays in Wisconsin. Find yours using the map on this page.

Children's Theatre – Waisman Center – UW–Madison (wisc.edu): Waisman Center Children's Theatre (WCCT) enhances the arts for young children in Dane County by providing high quality, diverse, educational, and interactive live theatrical performances at a modest cost and in fully accessible settings. The Friends of the Waisman Center Auditorium is the indoor setting for the majority of the Children's Theatre performances. With a formal stage and individual seats accommodating up to 250 people, the fully accessible auditorium provides an intimate yet informal traditional theatre experience.

WI LEND Program – Wisconsin Leadership Education in Neurodevelopmental and Related Disabilities – UW–Madison: Developing leaders to improve services and supports for children with or at risk for neurodevelopmental disabilities.

Day with Experts – Waisman Center – UW–Madison (wisc.edu): The Waisman Center presents six community "Day with the Experts" educational events focused on autism, augmentative and alternative communication (AAC), cerebral palsy, cochlear implants, fragile X syndrome, and Down syndrome.

CYSHCN – Children and Youth with Special Health Care Needs – UW–Madison (wisc.edu): The Southern Regional Center (SRC) is dedicated to supporting all families with children and youth with special health care needs/disabilities and the providers who serve them. The SRC is staffed by specialists who can help get answers, find services, connect you to community resources, provide trainings and support you on your journey. Our Center serves the following counties: Adams, Columbia, Crawford, Dane, Dodge, Grant, Green, Iowa, Juneau, Lafayette, Richland, Rock, Sauk and Vernon, shown in orange on the map.

The Grandparents' Network – Waisman Center – UW–Madison (wisc.edu): The Grandparents' Network provides a context for grandparents and other family members to increase their understanding of developmental disabilities, learn how other families cope with the challenge of disability, and contribute expertise, wisdom, and experience.

Elevations: Elevating children with special needs to reach their full potential by providing access to the resources and support they need to improve their family's overall quality of life.

Center for Pediatric Therapy: We serve children birth to 18 years of age who present with delays in development and/or who are in need of specific therapy needs. We offer services to include physical, occupational, and speech therapy services. Some of the sub-specialties include addressing alignment issues, sensory processing difficulties, feeding and oral motor difficulties.

Jordan Fund: We are a grant making organization providing assistance to individual families, as well as 501(c)(3) organizations. We help families with respite, therapy, and equipment costs that are not covered by their insurance.

Faith's Lodge: As the first dedicated retreat facility, Faith's Lodge provides hope, connection, and support to parents and families coping with the death of a child.

FamilyMeans: FamilyMeans is a multi-service, nonprofit organization that was founded in 1963. We are funded by grants, donations, and client fees. FamilyMeans is headquartered in Stillwater, Minnesota, with branch offices located throughout the Twin Cities metro area, southeastern Minnesota and western Wisconsin.

Joshua's Camp: Joshua's Camp serves families that have a child 17 years of age or younger being treated for cancer or out of treatment less than three years…Free of Charge. Families must be referred to Joshua's Camp by an Oncology Professional and have a Medical Clearance.

Pediatric Home Service: An independent children's home health care agency, PHS is here for one reason: helping kids with medical complexities live as fully as possible – at home, with their families, where they belong. We do this by providing comprehensive pediatric home care services across Minnesota, Wisconsin, Iowa, Kentucky, Ohio, Indiana, Missouri, Nebraska, Kansas, and Texas.

Youthful Horizons: Youthful Horizons is a fun and caring therapy clinic dedicated to the wellbeing of your health. At Youthful Horizons Therapy, you'll find highly trained, compassionate, and dedicated professionals who are sincere in their efforts to provide you with the absolute best in personalized care. It is our goal to ensure your time with us exceeds your expectations.

Guiding Star | Family Grieving & Rebuilding Retreat: For families under such constant stress, Guiding Star is a very special retreat for these families. We offer a safe haven where a small number of families in the same circumstance are given the opportunity to talk with therapists and each other, and relax and rebuild the foundation of family support that we all need to carry on. Guiding Star is available to these families free of charge.

Halos of the St. Croix Valley: Halos of the St. Croix Valley is a recognized 501(c)(3)non-profit foundation in the State of Wisconsin that provides emotional and financial support to bereaved parents who have lost a child from miscarriage through age 20 and reside in Minnesota or Wisconsin.

Stepping Stones Pediatric Therapy: Dedicated to providing the highest quality therapy by using a family centered approach to maximize each child's ability to participate in life's adventures.

Milestones Pediatric Therapy, PLLC: To provide outstanding evidence-based speech, occupational, physical, and behavioral intervention services to children and adolescents while building strong intervention teams through collaboration with caregivers and community professionals.

Our Grants | Smith-Barbieri

https://www.citherapies.com/

WYOMING RESOURCES:

Genetic Navigator Program - Mountain States GeneticsMountain States Genetics: The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of residence.

Year 6 Genetic Navigator Outreach Presentation (canva.com)

Genetic Ambassador Program - Mountain States GeneticsMountain States Genetics

Rocky Mountain ADA: The Rocky Mountain ADA Center is proud to serve individuals and organizations throughout Colorado, Utah, Montana, Wyoming, North Dakota, and South Dakota.