

DSACT

Down Syndrome Association of Central Texas

Asociacion de Sindrome Down del Centro de Texas

Down in the *Heart* of Texas

Volume 7, Issue 4

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Historic Hire for Down Syndrome Community of Central Texas

After an extensive search process for the Down Syndrome Association of Central Texas' first Executive Director, the Board has selected Cleofas Rodriguez Jr., an outstanding individual who fits not only our current needs, but our vision of growth for the future.

Mr. Rodriguez has 15 years experience in non-profit management of organizations, including support for high-risk children, children with disabilities, youth, families, and their communities. Most recently he served as Program Director for the Austin Travis County Advocate Program, where he was responsible for administering all aspects of local programming, organization management, and the recruitment and management of staff, volunteers, and interns. Additionally, Mr. Rodriguez served 6 years as Executive Director of Texas Head Start Association, Inc., where he initiated membership growth, increased revenue, and worked efficiently with a state-wide Board of Directors.

Through Mr. Rodriguez's extensive non-profit experience and community activism, he has developed skills that have crafted him to become a focused and effective leader. With comprehensive knowledge of program development, special event coordination, community outreach, and fund donations, Mr. Rodriguez can lead DSACT from a 100% volunteer-run organization into the new phase of its existence.

There has never been a better time to be born with Down syndrome. Today, people with Down syndrome are becoming more and more included in their communities. As expectations, research, and medical treatments improve, many are able to attend college, live independently, get married, or otherwise become productive members of society. However, there are still many unmet needs here in Central Texas, and our families need quality support and services from the time of diagnosis throughout the life span. The Board is confident that Mr. Rodriguez is the competent and compassionate leader who will ensure our members and their families have a great quality of life and are treated with the dignity and respect they deserve.

"I am pleased to be working with this group of focused and dedicated board members," states Mr. Rodriguez. "I look forward to merging my passion with that of DSACT and growing a partnership with the board, its members and community stakeholders. We are poised to create great things for our children, youth, adults and their families."

As Executive Director, Mr. Rodriguez's responsibilities will include program expansion and development, fundraising, and community and donor relations. He will build upon DSACT's nationally-recognized success in the field of special education by strengthening and growing The Learning Program (an early childhood literacy and mathematics program), working with the Board to create an Advocacy Academy

for parents, and managing the Parents and Schools in Partnership program (through which DSACT partners with school districts and provides training to over 200 educators each year). In addition, he will work with the Board to expand other crucial programs for members, including the cooking, swim, self-defense, art, and music classes, as well as the upcoming Lose the Training Wheels Bike Camp (through which nearly 40 individuals with disabilities will be taught to ride a bike). He will work closely with the fundraising committee to secure grants and corporate sponsorships, as well as plan the organizations fund- and awareness raising events. He will report directly to the DSACT Board of Directors, provide necessary support for the Board to achieve the mission and vision of our organization, and help the Board raise the visibility of DSACT.

Most importantly, he will work with and meet our members to determine how DSACT can best meet the many and diverse needs of individuals with Down syndrome in the Central Texas area.

We hope you will join us in welcoming Cleo to the DSACT family. Please feel free to call the DSACT office at 323-0808 or set up an appointment to speak with him if you would like to volunteer, get involved, or share your ideas about how DSACT can better serve our diverse community.

New Parent Corner

Need support? READY, SET, PLAY!

Whether you have an infant, a toddler or a young child in Kindergarten, you probably have a million questions about raising a child with Down syndrome. Who better to talk to than other parents who are experiencing a similar journey? Regardless of whether you are an introvert or an extrovert, socializing with other parents of children with Down syndrome is helpful to all of us. Not only does it benefit our kids to get together and play, but as parents we share experiences, swap stories, celebrate milestones and support each other through the challenges. Mainly, social networks remind us that we are not alone.

Many of you with young children are involved in InkDots which is a fun social group for children with DS from 0-5 years old and their siblings. We get together once a month in varying venues ranging from North to South Austin. It is a great opportunity for our children to get together and for parents to meet and socialize.

For more information, please contact Jeanette Holahan at **Jeanette@randallh.com** with your contact information. READY, SET, PLAY!

Using Play to Encourage Speech

Adapted from The New Language of Toys & It Takes Two to Talk

Teaching time becomes FUN time when you use the concepts in the books DSACT profiles below!

It Takes Two to Talk Guidebook: A Practical Guide for Parents of Children with Language Delays

Written in simple language by the Hanen Program for Parents, this guidebook shows parents how to help their child communicate and learn language during everyday activities like mealtime, bath time, playtime and book reading. The book is premised on the idea that parents need to get down on their child's level, figure out their interests, and follow their lead.

Another core concept is to "O.W.L." That doesn't mean you should start "hooting" at your child, but rather that you should:

- Observe closely to figure out what child is interested in about the toy & start a dialogue about it;
- <u>Wait</u> for child to respond/communicate (words, laughing, pointing, etc.); and
- **Listen** to determine what your child is trying to communicate back to you. Show that you're interested in what he or she has to say by leaning in and waiting for a response. React to your child's response with enthusiasm & praise!

Other good tips include:

Repeat concepts or words at least 3-5 times in conversation. Use a single concept at a time. For example, if you're playing with blocks, stick to talking about one concept (color, shape, direction) and then move on to another activity.

Vary your communication. Use two (2) statements for each question. Turn questions into comments. ("Do you like that banana? Mmmm. Good banana!). Vary your tone of voice. Occasionally pause an activity and wait for a reaction. Use fun sounds, such as animal or car noises or other sounds effects. Sing!

Remember the FOUR S's:

- **S**ay Less
- Stress the important words
- Go Slow.
- Show (picture, object, etc.)

And finally, *get your own toys!* You can't join in and play if your child has the only toy.

The New Language of Toys -- Teaching Communication Skills to Children with Special Needs: A Guide for Parents and Teachers

Many young children with special needs experience language delays and need additional help to build language skills. What better way to encourage communication development than through play? This book presents 65 toys and accompanying conversations you can use to play purposefully with your child, provide language learning opportunities, and stimulate language development.

Here are a few tips for you to try until you can purchase your own copy of this great book!

TOY	INSTRUCTIONS: Choose one toy from the column on the left. While playing with your toy, you can encourage language and teach vocabulary using the suggestions in this column! Just be sure to repeat each concept 3-5 times and have fun!
ANIMALS (Books, stuffed animals, puppets, See N' Say)	Animal Names & Sounds Repeat animal names 3-5 times. "Look at this duck! It's a yellow duck. What sound does a duck make? Quack." Sing Old Mac Donald Sing for 1 animal only and show child a picture of the animal or a stuffed animal. Big & Little Compare stuffed animals or pictures. Repeat concept 3-5 times in conversation. See N' Say (arrow, animal name, lever, animal sound) "Let's turn the arrow. Oh, the arrow is pointing to the cow. It's a brown cow! Can you pull the lever (help child)? Good job! You pulled the lever! What do you hear? Mooooo. The cow says Moo. Mooo. Let's put the arrow on the cow again. Moooo." Sing Animal Songs that Correspond to Toy Duck: "5 Little Ducks", "Quack quack (cock-a-doodle-doo)" Monkey: "No More Monkeys Jumpin' on the Bed," Wiggles' "Do the Monkey" Pig/Cow: "Laurie's Got a Pig on her Head"
BLOCKS	Up & down Stack blocks & count as you stack. "We're building it UP, UP, UP. Let's put another block UP on top. Look UP at the top. Oh, no. It's falling DOWN. You knocked it DOWN. All the blocks fell DOWN." Counting or Colors Count as you stack. Sort by color or say colors as you pull out of bag. Do sign language for colors. Peek-a-blocks Talk about shape inside. Have your child touch, bang or shake it. Repeat name of shape 5 times in conversation.
BODY PARTS Music therapy	Reinforce body parts through song: • "This Little Piggy" • "Head, Shoulders, Knees & Toes" • "Do Your Ears Hang Low?" • "If You're Happy & You Know It." • Laurie Berkner Songs: "I've Got a Song in My Head/ Tummy/ Nose/ Bones/ Heart," "Laurie's Got a Pig on her Head"
BUS, CARS, TRUCKS	Colors, Car Sounds, Make Believe about School First pull out the bus, car, truck and talk about it – color, sounds it makes, Little People who ride on it, etc. Then SING! "Wheels on the Bus" Let your child hold your hands to make you do the actions. PAUSE frequently to see if he or she will do the action alone without you prompting with actions or words.
CHANGING CLOTHES OR DIAPERS	Body Parts "Where's your head? There it is! Let's put the shirt over your head. We did it! Where are your arms? Let's put your left arm in your shirt, etc." Name articles of clothing; Talk about Color Pants, shirt, diaper, dress (repeat 3-5 times)
KITCHEN (Pretend or Real)	Food names "What is Mommy cooking for us? Look, it's a banana. I'm taking a bite of the banana. What a yummy banana! Do you want a bite of banana? Let's give the dog a bite of this banana." Kitchen Items Plate, cup, spoon, etc.
MUSICAL INSTRUMENTS	Instrument Name & Sound Take out instruments one at a time & discuss name & sound 3-5 times in conversation. "Look, it's a DRUM! Let's take the DRUM out of the box. What sound does a DRUM make? A DRUM goes BOOM, BOOM! Hit the DRUM! BOOM, BOOM! Good job! Let's put the DRUM back in the basket." Tambourine & Maracas "shake, shake" Bells "Ring or ring-a-ling" Rainbow Shakers "Swish"

Rx for Health

The Use of Ginko, Prozac, and Focalin as a "Treatment" for Down Syndrome

We are a group of healthcare professionals, scientists and support organizations who care for and about people with Down syndrome. We wish to provide families with information about a proposed "treatment" for Down syndrome. We recognize that all parents wish to improve the lives of their children with Down syndrome and are interested in treatments, therapies and interventions that can help. We respect these wishes. At the same time, we are concerned that these "treatments" are potentially dangerous. We are all aware of the advances that have been made in the basic science of memory and cognition in animal models of Down syndrome and are hopeful that these studies may lead to new ways to improve the lives of people who live with the condition. Physicians and biomedical scientists evaluate potential interventions on the basis of safety and benefits to patients. As we describe below, the "treatments" that the Changing Minds Foundation recommends have not passed either test: there is no information whether these compounds are safe for children, especially young children. Furthermore, there is no evidence to support the claims for benefits that have been made. Because we care about your children, we strongly urge families to consider this information when considering the claims for this "treatment."

The protocol

An organization called the Changing Minds Foundation is promoting a "new treatment for Down syndrome" that leads to "life changing" results. The "treatment" includes regular doses of Fluoxetine (Prozac), Dexmethylphenidate (Focalin XR) and Ginkgo biloba, Phosphatidylcholine, 'Body Bio Balanced Oil' and folinic acid. Some of these substances are associated with potential harmful sideeffects.

Some of these side-effects are of particular concern for people with Down syndrome and younger children. Fluoxetine (Prozac) is used to treat depression, obsessive-compulsive disorder, bulimia nervosa and panic disorder. Dexmethylphenidate (Focalin XR) is used for the treatment of attention deficit and hyperactivity disorder (ADHD). Their use should be initiated and monitored by an appropriately qualified physician and should be limited to applications and treatments formally reviewed and approved by appropriate governmental and medical drug regulatory agencies.

Evidence of effects and safety

There is no scientific evidence to support the use of any of this protocol with people with Down syndrome of any age in order to improve memory or any other aspect of cognition. Nor is there any evidence that this protocol is safe for routine use with people who have Down syndrome. The few studies referenced in support of this protocol are studies of mice. These mice have been engineered to carry extra copies of some genes similar to genes found on human chromosome 21. (People who have Down syndrome have an additional copy of this chromosome). These studies may or may not be good indicators of aspects of memory and learning for people

who have Down syndrome. Studies in mice alone are not sufficient to support use of this (or any) protocol in children or adults with Down syndrome. The Changing Minds Foundation promotional videos do not prove the claims of benefit from the protocol. While the people shown are clearly doing well, none of the individuals shown are functioning beyond the wide range seen in others with the syndrome. Claimed changes following 'treatment' could be the result of many factors. Only a controlled trial can give clear evidence of treatment effects.

Scientific progress

Scientific research has improved our understanding of Down syndrome considerably over the past 30 years. This has led to the better healthcare and education received by many people with Down syndrome today. Many scientists and organizations continue to work to improve our knowledge and understanding of effective ways to improve quality of life for people who live with Down syndrome. Although the pace of further progress is often slow and this can be frustrating, only careful research and rigorous controlled trials can provide the evidence necessary to demonstrate that a therapy is useful and safe.

Further Information

Ginkgo – Although bilobalide, a component of Ginkgo Biloba, has been shown to be a GABA antagonist, the activity has been tested only in isolated cells and in only one subtype of GABA receptors. No controlled studies have been done in animals or humans to establish safe doses, or to prove the claimed benefits.

www.nlm.nih.gov/medlineplus/druginfo/natural/patient-ginkgo.html

Fluoxetine (Prozac) – The action of fluoxetine on the growth of new nerve cells seen in one part of the brain of Ts65Dn mice has not been replicated in humans. Published case reports suggest that medications like Prozac used in pregnancy can harm the fetus. The potential impact on developing minds of babies and young children is unknown. A general, or uncontrolled, increase in nerve cell growth is not necessarily a good thing, especially over long periods of time. www.nlm.nih.gov/medlineplus/druginfo/meds/a689006.html

Dexmethylphenidate (Focalin XR) – The use of stimulant medication should be carefully considered for children with unusual heart structures, which includes about half of children with Down syndrome. Again, use is not recommended for babies or very young children. www.nlm.nih.gov/medlineplus/druginfo/meds/a603014.html

Folinic acid – Folinic acid supplementation has been shown to have no significant effects for infants and children with Down syndrome on a range of developmental measures.

www.nlm.nih.gov/medlineplus/druginfo/natural/patient-folate.html www.bmj.com/cgi/content/full/336/7644/594

DSACT respects the right of every family to pursue treatments for their loved one with Down syndrome and encourages all families to consult a physician before starting any medication protocol. 'Off label' use – Families and healthcare professionals should understand that use of the protocol at this time is essentially experimental, with none of the benefits of a controlled trial. Monitoring for adverse effects would be the responsibility of the prescribing physician, with no one collecting that information to determine real risks. Similarly, positive effects would not be collected in a credible way that could be used by healthcare professionals to gauge the value of the treatments. While there is no current evidence of the treatment's effectiveness for people with Down syndrome, there are significant risks of harm.

This statement is endorsed by the following scientists and clinicians:

- Joel Borstlap, Paediatrican n.p., Stichting Downsyndroom, TheNetherlands.
- Sue Buckley OBE. Director of Science and Research, Down Syndrome Education International and Emeritus Professor of Developmental Disability, University of Portsmouth, UK.
- William I Cohen, MD. Developmental-Behavioral Pediatrician, Director, Down Syndrome Center of Western PA Children's Hospital of Pittsburgh of UPMC, Professor of Pediatrics and Psychiatry, University of Pittsburgh School of Medicine, USA.
- Sindoor S Desai, BDS, Cleveland, New York, USA.
- Jesús Flórez, MD, PhD. Professor of Pharmacology, University of Cantabria School of Medicine, Santander, Spain.
- Sallie Freeman, Ph.D. Professor Emeritus. Down Syndrome Clinic Advisor, Department of Human Genetics, Emory University School of Medicine, Georgia, USA.
- Edward J Goldson, MD. Pediatrician, The Children's Hospital, Aurora, Colorado, USA.
- Lilliam Gonzalez de Pijem, MD. Pediatric Endocrinologist. Puerto Rico Down Syndrome Association, San Juan, Puerto Rico.
- Joan E Guthrie Medlen, RD, LD. Vice President Down Syndrome Education USA, Director, Disability Compass, Publisher, Phronesis Publishing, Author, The Down Syndrome Nutrition Handbook.
- Rob Hanson, MD, PhD. Pediatric Cancer and Hematology Center, St. John's Mercy Medical Center, St. Louis, Missouri, USA.
- Michael M Harpold, PhD, Chief Executive Officer, Down Syndrome Research and Treatment Foundation, USA.
- Jacqueline London, Professor of Molecular and Pathological Biochemistry, University Paris-Diderot, Paris, France.
- Acisclo M Marxuach, MD. Fundación Puertorriqueña Síndrome Down, San Juan, Puerto Rico.
- Philip J Mattheis, MD. Associate Professor, Cincinnati Children's Hospital Medical Center, Ohio, USA.

- William C Mobley MD, PhD. Professor, Department of Neurology and Neurological Sciences and Director, Center for Research and Treatment of Down Syndrome, Stanford University, California, USA.
- David Patterson, PhD. Professor, Department of Biological Sciences, Eleanor Roosevelt Institute, University of Denver, Colorado, USA.
- Alberto Rasore-Quartino, Professor, Unit of Neonatology, Galliera Hospital, Genoa, Italy.
- David S Smith, MD. Program Director, Down Syndrome Clinic of Wisconsin Children's Hospital, Wisconsin, USA.
- Dr Renaud Touraine, CHU-Hôpital Nord, Service de Génétique, Saint Etienne, France
- Jeannie Visootsak, MD, FAAP. Assistant Professor, Developmental-Behavioral Pediatrics, Department of Human Genetics & Pediatrics, Emory University School of Medicine, Georgia, USA.
- Patricia White, MD, Chair, Board of Directors, Down Syndrome Research and Treatment Foundation, USA.

This statement is endorsed by the following organizations:

- Association Française pour la Recherche sur la Trisomie 21, France.
- Association of Parents and Friends of Children with Down Syndrome, Prague, Czech Republic.
- Centrul de Resurse Sindrom Down, Bucharest, Romania.
- Deutsches Down-Syndrom InfoCenter, Hammerhöhe, Lauf, Germany.
- Down Syndrome Education International.
- Down Syndrome Education USA.
- Down Syndrome International.
- Down Syndrome New South Wales, Australia.
- Down Syndrome Research and Treatment Foundation, USA.
- Down Syndrome Research Foundation, Vancouver, Canada.
- European Down Syndrome Association.
- Fundación Iberoamericana Down21, Spain.
- Fundación Síndrome de Down de Cantabria, Spain.
- National Down Syndrome Congress, USA.
- National Down Syndrome Society, USA.
- Stichting Downsyndroom, The Netherlands.
- Trisomie 21 France

Education Exclusive

Back to School Tools

Education! Empowerment!

Saturday, August 29th

8:00 to 3:30 p.m. First Evangelical Free Church 4220 Monterey Oaks Blvd Austin, TX 78749

Attendees will be inspired by Keynote Address "Dwell In the Possibilities" by Bridget Brown. Bridget is a national public speaker, a lifelong learner, and a young woman with Down Syndrome. She was the first person fully included in her school district and has had a remarkable educational experience. The keynote address will be followed by national expert Nancy Brown, who will present "Honey I Blew Up the Curriculum." Workshop participants will learn how to adapt curriculum, help children at home, and make easy adaptations that will help children with Down syndrome access the general education curriculum and be full participants in the educational process.

The day will also include breakout sessions for parents of children with Down syndrome of all ages, including tips on advocacy, literacy, behavior, self-determination, and transitioning out of the public education system.

Registration form: Back to School Tools

Saturday, August 29, 2009		
Spanish interpretation provided with advance request.		
Name:		
Email:		
Address:		
City, State, Zip:		
Phone:		
I am a (circle all that apply): Parent • Educator • Administrator Attorney/ Advocate • Other School District: Campus:		
Grade: Age of Child: % Inclusion:		
Payment (\$35/ registration) I would like to request financial aid I am enclosing a check made payable to DSACT. Total Enclosed:		
Mail payment and registration form to: DSACT, 3710 Cedar Street Box 3, Austin, TX 78705		

Contact DSACT at (512) 323-0808 or email: cleojr@dsact.com

Registration now open for 2009–2010 Learning Program!

"Eyes open when a child with Down syndrome enters kindergarten able to read."

- Dana Halle, The Learning Program creator

What: The Learning Program

Early childhood literacy and mathematics for children

aged 2 through 7

When: September 2009 through June 2010

2nd Saturday morning of each month Attendance at all sessions is mandatory.

Where: First Evangelical Free Church

4220 Monterrey Oaks Blvd.

Fee: \$40/ semester supply fee (financial aid available)



After giving birth to your child with Down syndrome, one of the first things most parents do is call an early childhood intervention (ECI) agency to set up therapy services. Speech pathologists, occupational therapists, and physical therapists are then assigned to work with our children on a regular basis and instruct us

on ways to improve our children's communication and motor skills. Sometimes, we may even pursue music, play therapy, yoga, or other programs to maximize our children's potential.

But no one ever tells us what we can do in early childhood to improve our child's cognitive functioning. How do we teach our children to read? What does the research say about how children with Down syndrome learn best? Where can we find quality materials that are proven to work with children who have Down syndrome? How do we go about teaching them to add and subtract or tell time?

Years ago, Learning Program creator Dana Halle asked these critical questions. She then teamed up with experts like Patricia Oelwein author of Teaching Reading to Children with Down Syndrome and Literacy Skill Development for Children With Special Learning Needs) and Professor Sue Buckley (DownsEd International founder and chief scientist) to create an answer: the Learning Program.

The Learning Program is an early childhood literacy and mathematics program that meets monthly to deliver parent instruction about how to teach children with Down syndrome reading, writing, and





math, as well as techniques to improve speech and memory. Parent lectures for the 2010 -2011 Learning Program may include introduction to literacy, personalized books, alphabet/ sounds, sentence building, spelling strategies, pre- and early number

concepts, addition and subtraction, time, money, effective learning sessions, accommodations & modifications, writing, speech, memory, and more. In addition, parents will receive meaningful, high interest materials to develop their children's sight word reading, vocabulary, comprehension, and number sense at home.

While parents are attending the workshop, children between the ages of 4 and 7 will spend their time (1 ½ hours) in class with their peers. They will start their morning with a short group social time (similar to circle time)



and then rotate through specific learning centers (reading, math, speech, and occupational therapy). Children between the ages of 2 and 3 will remain with their parent or caregiver for 1 hour of hands-on instruction in literacy and pre-number skills.

Here is a general outline of the program and family commitments:

- We will begin in September 2009 and will meet on the second Saturday of each month through June 2010.
- There are 30 seats available for children between the ages of 4 and 7, and a limited number of spaces available for children aged 2-3.
- There is a \$ 40 fee per child per semester, which includes take-home materials, classroom materials/ supplies, and take-home parent instructions. If the fee is cost prohibitive, but you want to be involved in the program, please contact DSACT as soon as possible to request a financial assistance.
- The success of this program is dependent upon your level of parental commitment. Program participants must commit to attend all monthly meetings, and agree to work with your child on a daily basis. Program participants will be removed from the roster after missing two (2) monthly sessions.

Inscripcion abierta para el Programa de Aprendizaje 2009-2010!!!

"Los ojos se abren cuando un nino con Sindrome de Down ingresa a pre-escolar y aprende a leer."

- Dana Halle, creadora del Programa de Aprendizaje

Que: El Programa de Aprendizaje

Lectura, Escritura y Matematicas para ninos con

edades de 2 a 7

Cuando: Septiembre 2009 Junio 2010

2do Sabado por la manana de cada mes Asistencia es mandatoria a todas las sesiones.

Donde: First Evangelical Free Church

4220 Monterrey Oaks Blvd.

Costo: \$40/ costo utiles escolares por semestre

(ayuda financiera disponible)

Despues de dar a luz a un nino con syndrome de Down, una de las primeras cosas que los padres hacemos es llamar a un Programa de Intervencion Temprana (ECI) para arreglar servicios de terapias. Terapistas de lenguaje, ocupacionales, terapia fisica son asignadas a trabajar con nuestros hijos en una forma regular e instruirnos para mejorar la comunicacion con nuestros hijos, asi como sus habilidades motrices. Algunas veces, algunos hasta buscamos musica, terapia de juego, yoga, u otros programas para maximizar el potencial de nuestros ninos.

Pero nunca nadie nos dice lo que podemos hacer en sus edades mas tempranas para mejorar el funcionamiento cognocitivo. Como ensenamos a nuestros ninos a leer? Que dicen las investigaciones acerca de como pueden leer mejor los ninos con syndrome de Down? Donde podemos encontrar materiales de calidad que sean aprobados para trabajar con ninos con sindrome de Down? Como le hacemos para ensenarlos a sumar, a restar o saber la hora del dia.

Anos atras, la creadora del Programa de Aprendizaje Dana Halle se preguntaba estas cuestiones. Entonces se organizo con los expertos como Paricia Oelwein autora de Ensenando Lectura a ninos con syndrome de Down y el desarrollo de la Literatura para ninos con Necesidades Especiales de Aprendizaje) y la profesora Sue Buckley (DownsEd fundadora Internacional y cientifica) para crear una respuesta: El Programa de Aprendizaje.

El Programa de Aprendizaje ensena lectura, escritura y matematicas, el cual se lleva a cabo mensualmente para llevar instruccion a los padres acerca de como ensenar a ninos con syndrome de Down a leer, escribir, y matematicas, asi como tambien las tecnicas para mejorar el lenguaje y la memoria. El Programa de Aprendizaje para el ano 2010- 2011 podria incluir introduccion a las letras, libros personalizados, sonidos alfabeticos, construccion de enunciados, estrategias de deletreado, conceptos de numeros, sumas y restas, tiempo, dinero, sesiones de lectura efectivas, escritura, lenguaje, memoria y mas. Ademas, los padres recibiran materials valiosos y de alto interes para desarrollar la lectura de sus ninos, vocabulario, comprension, y el sentido de numeros en casa.

Mientras los padres estan atendiendo al taller de aprendizaje, los ninos entre las edades de 4 a 7 pasaran el tiempo (hora y media) en clase con sus companeros. Ellos empezaran su manana con un pequeno grupo para socializar (similar al tiempo en circulo) y entonces se rotaran hacia especificos centros de aprendizaje (lectura, matematicas, lenguaje, y terapia ocupacional). Los ninos entre las edades de 2 a 3 permaneceran con sus padres o tutores por una hora para instruccion de lectura y habilidades con numeros.

Aqui esta una idea general del programa y las obligaciones familiares:

- Empezaremos en Septiembre 2009 y nos reuniremos el segundo Sabado de cada mes hasta Junio 2010.
- Hay 30 asientos disponibles para ninos de edades entre 4 a 7, y un numero limitado de espacios disponibles para ninos entre 2 a 3.
- Hay un costo de 40 dlls por nino por semestre, el cual incluye materiales para llevar a casa, materiales de clase, e instrucciones para los padres para llevar a casa. Si no puedes cubrir el costo, pero quieres estar envuelto en el programa, por favor contacta DSACT tan pronto como sea possible para solicitar asistencia financiera.
- El exito de este programa depende del nivel de compromiso de los padres. Los participantes al programa deberan obligarse a participar mensualmente a todas las reuniones, y acordar trabajar con su nino a diario. Los participantes del programa seran removidos del mismo despues de no asistir a dos sesiones mensuales.

Las familias del Programa de Aprendizaje han visto a sus ninos brincar de no lectores a lectores en menos de un ano. Por favor contactanos TAN PRONTO COMO SEA POSIBLE si estas interesado en participar en el programa. Tambien queremos que tomes en serio el compromiso de estar envuelto en el programa. Si aun no lo has hecho, revisa nuestra pagina en internet www.dsfoc.org. Estamos muy

contentos de poder brindar esta oportunidad para nuestros miembros. Esperamos poder ayudar a nuestros miembros mas jovenes y convertirlos en avidos lectores.

Get a good baseline, give your child a great start

by Jana Palcer, DSACT Education Committee Chair

Summer fun is something wonderful to look forward to, but so is sending your child back to class with an impressive new level of skills and knowledge. The hot days that now lie ahead of you and your child can be used for more than playing in the pool or skipping town on vacation...they can be taken advantage of by preparing your child for significant and meaningful success.

So school is out, but learning is still in session. When your child left their Individualized Education Plan (IEP) behind at the end of the year, they did not leave behind their need to successfully accomplish all of its goals. When school reconvenes in the fall, educators will pick

back up where they left off, and it is best for everyone involved if your child is able to jump back in without having missed a beat. It's even better if they come back having set a whole new pace.

Your child's IEP is based a great deal upon a section of the paperwork which addresses present levels of performance. Present levels of performance are the baselines found in your child's education. Baselines measure exactly what knowledge your child has acquired to that point in time, and what skills they have already mastered. Goals and ongoing work plans will be determined using these baselines as starting points, so the accuracy and validity of the baselines is of extreme importance. You do not want work done on your child's goals to be directed toward concepts they have already conquered, as time spent continually toiling on previously-learned skills is precious time your child does not have to waste. Precise data-taking on your part and the part of the educator is imperative for effectively staying on track while tackling the long list of educational needs your child has before them. Stay "in the know" about what your child can and cannot do, so that you can be their biggest advocate for moving forward instead of unknowingly taking part in them spinning their wheels.

If your child can enter class in the fall having made tangible progress on their IEP goals, they are that much closer to filling in the gaps between their modified curriculum plan and the curriculum that will be set forth for their typical aged peers. Also, if you can pass the torch back to the school by being able to explain exactly where your child stands and what staff will need to do to catch up with them, your child will receive a jump start on learning that can mean weeks or months worth of NEW victories instead of wasted focus on old ones. Keep in mind that at anytime when your child has met the goals outlined in their IEP, a new ARD can be held to create updated and more accurately challenging ones. And don't fear...ARDs can actually be fun when their purpose is to place your child one step closer to becoming the star achiever you know they can be.

Your task for the summer should be this:

- Know precisely what your child's IEP goals are.
- Work on your child's goals and raise their baselines of academic performance.
- Gain confident knowledge of your child's baselines before school begins again and notify educators of them immediately.

Obten una buena base, dale a tu nino un fabuloso inicio

por Jana Palcer, DSACT Comite Educativo

La diversion del verano es algo por lo que estar esperando, pero tambien lo es enviar a tu nino de regreso a clase con un impresionante nivel de habilidades y conocimientos. Los dias tan calientes que seguiran en adelante para ti y tu nino pueden ser usados para algo mas que estar jugando en la alberca o salir fuera de la ciudad por algunas vacaciones . . . estos pueden ser tomados como una ventaja para preparar a tu nino hacia un exito significativo.

Asi que la escuela ha terminado, pero el aprendizaje esta aun en sesion. Cuando tu nino deje su Plan Educativo Individualizado (IEP) atras al fin del ano, ellos no dejan atras sus necesidades para alcanzar el exito y todas sus metas. Cuando vuelva el ciclo escolar en el Otono, los maestros volveran al punto en donde se quedaron, y lo mejor para todos los que estan envueltos con tu nino es que el este preparado para empezar en ese mismo escalon sin haber brincado alguno. Y es aun mucho mejor si ellos regresan a la escuela teniendo un nuevo y completo paso.

El Plan Educativo Individualizado (IEP) de tu hijo se basa enormemente en una seccion de trabajos los cuales se dirigen hacia el nivel de evaluacion de tu hijo. Los niveles presentes de lo bien o mal que hace tu nino los trabajos son las bases en que se encuentra la educacion de tu nino. Las bases miden exactamente que conocimiento ha adquirido tu hijo hasta ese punto en el tiempo, y que habilidades han sobrepasado. Objetivos y planes futuros de trabajo seran determinados usando estas bases como puntos para el comienzo, así que la exactitud y validez de esas bases son de extrema importancia. Tu no querras que se trabaje en objetivos que se dirijan directamente hacia algo que tu nino ya sabe e incluso es un master en ello. Porque el tiempo gastado jugando con habilidades previamente aprendidas es tiempo valioso que tu nino no debe desperdiciar.

Precisos puntos de partida de tu parte y del maestro son indispensables para estar efectivamente en el camino correcto de lo que tu nino puede y no puede hacer., así que tu puedes ser su mas grande y efectivo protector para moverse hacia adelante en lugar de ir por un camino equivocado sin saberlo y desperdiciando el tiempo tan valioso de tu hijo.

Si tu hijo puede entrar a clase en el otono habiendo hecho un progreso tangible y visible en los objetivos del IEP, los maestros estaran mas cerca de llenar tanto los vacios entre su curriculum modificado para tu hijo, asi como el plan de curriculum de sus companeros regulares; que es el que deseamos alcance tambien No solamente su plan individualizado, sino tambien el que realizan sus companeros de clase. Tambien si puedes pasar la estafeta a los de la escuela sabiendo exactamente en que punto se encuentra tu hijo y lo que el personal escolar necesitara hacer para obtener mejores resultados, tu nino recibira un salto para empezar en algo que pudiera significar semanas o meses de trabajo de NUEVAS victorias en lugar de enfocarse en objetivos viejos. Manten en mente que en cualquier momento cuando tu nino haya alcanzado los objetivos establecidos en su IEP, un nuevo ARD puede ser llevado a cabo para crear un plan mas actualizado y alcanzar nuevos retos. Y no tengas miedo . . . ARDs pueden ser divertidos cuando su intencion es poner a tu nino a un paso mas cercano de convertirse en el realizador estrella que sabes que el puede ser.

Tu tarea para el verano debera ser la siguiente:

- Saber precisamente cuales son las metas del IEP.
- Trabajar en los objetivos de tu hijo y elevar las bases de realización academica.
- Obtener conocimiento seguro de las bases de tu nino antes de que la escuela comience de nuevo y notificar a los maestros de ellos inmediatamente.

Learn about SMART IEPs

An excerpt from "Wrightslaw Game Plan: SMART IEPs" by Pete Wright and Pam Wright (http://www.wrightslaw.com/info/iep. goals.plan.htm)

The term SMART IEPs describes IEPs that are specific, measurable, use action words, are realistic and relevant, and time-limited.

S Specific

M Measurable

A Use Action Words

R Realistic and relevant

T Time-limited

Let's look at these terms.

Specific

SMART IEPs have specific goals and objectives. Specific goals target areas of academic achievement and functional performance. They include clear descriptions of the knowledge and skills that will be taught and how the child's progress will be measured.

Measurable

SMART IEPs have measurable goals and objectives. Measurable means you can count or observe it.

Measurable goals allow parents and teachers to know how much progress the child has made since the performance was last measured. With measurable goals, you will know when the child reaches the goal.

Action Words

IEP goals include three components that must be stated in measurable terms:

- (a) direction of behavior (increase, decrease, maintain, etc.)
- (b) area of need (i.e., reading, writing, social skills, transition, communication, etc.)
- (c) level of attainment (i.e., to age level, without assistance, etc.)

SMART IEPs use action words like: "The child will be able to . . ."

Realistic and Relevant

SMART IEPs have realistic, relevant goals and objectives that address the child's unique needs that result from the disability.

SMART IEP goals are not based on district curricula, state or district tests, or other external standards.

Time-limited

SMART IEP goals and objectives are time-limited. What does the child need to know and be able to do after one year of special education? What is the starting point for each of the child's needs (present levels of academic achievement and functional performance)?

Time-limited goals and objectives enable you to monitor progress at regular intervals.

Aprende acerca de IEPs INTELIGENTES

Un extracto de "Wrightslaw Game Plan: SMART IEPs" por Pete Wright y Pam Wright (www.wrightslaw.com/info/iep.goals.plan.htm)

El termino IEPs INTELIGENTES describe IEPs que son especificos, medibles, uso de palabras de accion, son realistas y relevantes en un tiempo limite.

Veamos estos terminos.

Especifico

IEPs INTELIGENTES tienen metas y objetivos. Metas especificas se dirigen hacia la realizacion en areas academicas y funcionales. Estos incluyen descripciones claras del conocimiento y habilidades que seran ensenados y como sera medido el progreso del nino.

Medible

IEPs INTELIGENTES tienen metas y objetivos que son medibles. Medible significa que tu puedes contar u observer el avance.

Las metas medibles permiten a los padres y maestros el conocer que tanto progreso ha hecho el nino desde que esa tarea o trabajo fue medida la ultima vez. Con metas medibles, tu sabras cuando el nino alcance el objetivo.

Palabras de Accion

Las metas del IEP incluyen tres components que deben ser establecidos en terminos medibles:

- (a) direccion de comportamiento (incremento, decremento, mantener, etc.)
- (b) area de necesidad (ej. lectura, escritura, habilidades sociales, trancision, comunicacion, etc.)
- (c) nivel de exito (ej. nivel de su edad, sin asistencia, etc.)

IEPs INTELIGENTES usan palabras de accion como: "El nino va a poder . . . "

Realistas y Relevantes

IEPs INTELIGENTES tienen realistas, y relevantes metas y objetivos que se dirijen hacia las necesidades unicas que resultan de la disabilidad.

Las metas de los IEPs INTELIGENTES no son basados en el curriculum del distrito escolar, examenes estatales o del distrito, u otros estandares externos.

Tiempo Limite

Las metas y objetivos de los IEPs INTELIGENTES tienen un tiempo limite. Que es lo que el nino necesita saber y poder hacer despues de un ano de educacion especial? Cual es el punto de partida para cada una de las necesidades del nino (niveles presentes de realizacion academica y la realizacion functional)?

El tiempo limite de metas y objetivos te obliga a monitorear el progreso en intervalos regulares.

Basic Life Planning Steps

"Who will care when you are no longer there?" is an overwhelming concern people with disabilities and their families must address. A well thought-out life plan is essential for long-term quality of life for your loved one with Down syndrome. Physical, social, financial and legal issues, among others must be considered. The life plan is evolving and ever-changing; it is a process, not an end result. It will require that different needs be addressed as your loved one ages. Below are some suggested steps to get started in the right direction:

Prepare a life plan. Decide what you want regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements.

Write a letter of intent. Put your hopes and desires in a written document. Include information regarding care providers and assistants, attending physicians, dentists, medicine, functioning abilities, types of activities enjoyed, daily living skills, and rights and values. Make a videotape during daily activities, such as bathing, dressing, eating, and recreation. A commentary accompanying the video is also useful.

Decide on a type of supervision. Guardianship and conservatorship are legal appointments requiring court-ordered mandates. Powers of Attorney are other, less restrictive options. Choose for today and tomorrow. Select capable individuals in the event you become unable to make decisions in the future.

Determine the cost. Make a list of current and anticipated monthly expenses. When you have established this amount, decide on a reasonable return on your investments, and calculate how much will be needed to provide enough funds to support his or her lifestyle. Don't forget to include disability income, Social Security, etc.

Find resources. Possible resources to fund your plan include government benefits, family assistance, inheritances, savings, life insurance, and investments.

Prepare legal documents. Choose a qualified attorney to assist in preparing wills, trusts, power of attorney, guardianship, living will, etc.

Consider a "Special Needs Trust." A Special Needs Trust holds assets for the benefit of people with disabilities and uses the income to provide for their supplemental needs. Appoint a trustee and successor trustees (individuals or corporate entities, such as banks).

Use a life-plan binder. Place all documents in a single binder and notify caregivers/family where they can find it.

Hold a meeting. Give copies of relevant documents and instructions to family/caregivers. Review everyone's responsibilities.

Review your plan. At least once a year, review and update the plan. Modify legal documents as necessary.

President's Column July 2009



As this newsletter goes to print, Down Syndrome Association leaders across the United States are working together to share best practices that will improve your children's lives!

Through the 2009 Affiliates in Action Public Education Committee, co-chaired by the Down Syndrome Association of Central Texas and the Red River Valley Down Syndrome Society (also of Texas), we will focus on three areas:

- Parent trainings and materials;
- Direct educational services to individuals with Down Syndrome; and
- Educator Outreach.

Groups from across the U.S. will upload information about their most successful member or educator programs to a central repository. From there, DSACT and groups like ours will be able to access and easily adapt the best materials and programs for our members, freeing up valuable time and resources for program implementation!

DSACT has also taken the lead in creating two new resources that will help parents of children with Down syndrome across the nation. As you read this, our new Executive Director and a summer intern are creating a side-by-side document of common obstacles parents encounter during the educational process, helpful responses, and the law. They will be assisted by the Down Syndrome Association of Cinncinnati. This fall, DSACT will begin to create a national IEP goal bank, so that when parents head into an IEP meeting next year, they will be free to peruse a national database of goals, choose from those goals that might pertain to their children, and feel more confident in their meetings!

In the past two years, DSACT has successfully adapted three programs from other associations: the Learning Program (early childhood literacy and mathematics program from the Down Syndrome Foundation of Orange County); Down Syndrome Specialist Program (educator outreach, Kansas City Down Syndrome Guild); and Inclusion Solutions (newsletter for educators, Kansas City Down Syndrome Guild). In return, two DSACT programs have been shared and implemented by other Down syndrome groups across the United States: the Educator Packet: Working Together to Educate and Include Students with Down Syndrome and the DSACT Inclusive Congregation Initiative.

We are excited about the programs we have learned about this year, such as the Denver Adult Down Syndrome Clinic's ALIVE! Program for adults, Louisville's Lifetime Learning Center and employment resources, Central Florida's "Teen Talk," Cincinnati's Post-Secondary Education Collaborative!

Founded in 2006, Down Syndrome Affiliates in Action started as a conference bringing together outstanding leadership from Down syndrome organizations around the country. After consecutive years of explosive growth, the conference has extended its reach internationally and is currently in the process of forming a trade association to continue its mission. The purpose and mission was, and continues to be, serving Down syndrome affiliates through collaboration, resource sharing, and networking.

As the DSACT Board of Directors plans strategically for next year, we will continue to utilize this wonderful resource.

What's Up at DSACT?

Join us for the Share the Passion 2010 DSACT Calendar Gallery Exhibition on September 19th

A celebration and gallery exhibition of photographs showcasing individuals with Down syndrome and celebrities sharing the same passions.

DSACT invites you to be our guest in the celebration of the 2010 Share the Passion calendar exhibition and gala. Through our awareness calendar, we educate the Central Texas community about the talents and abilities of all individuals with Down syndrome. Come join us for this grand celebration and view the beautiful photos on display. You can purchase your calendar at the event and even get your calendar autographed by some of DSACT's own celebrities!

Photographer Jean Louis captured some very special moments for the Share the Passion Exhibit and Calendar. Participating celebrities include Adam Yauch (Beastie Boys) Jim Spencer (KXAN), Jimmy Vaughan (Musician), Stephen Mills (Ballet Austin), JB & Sandy (Mix 94.7), and Jay Pearce (Reunion Ranch), among others.

When: Saturday, September 19, 2009

Time: 5:00 to 9:00pm

Where: Rough Hollow Yacht Club, Lake Travis

Drinks and Hors D'oeuvres served

FOR MORE INFORMATION & TO RSVP:

Contact Teana Ross at 484-3112, Stefanie Martinez at 293-5503 or Irene Myers at 238-1877.

DSACT Special Needs Aquatic Program (SNAP) teaches individuals with Down syndrome a valuable skill for life

Imagine yourself as a parent of a young child with Down syndrome. When summer rolls around, you call your local community pool to enroll your child in swim class. Unfortunately, all too often, you find that the instructor lacks experience teaching children with disabilities, and/or the other children and parents in the class display a lack of acceptance for your child.

Research in the recreation and leisure field has shown swimming to be one of the most popular community leisure activities pursued. Despite growing interests and benefits of aquatic activities, a number of children with disabilities continue to experience barriers accessing swim programs.

The Special Needs Aquatic Program (SNAP) is a fun and beneficial weekly, year-round program for our members with Down syndrome. SNAP meets the need for alternative physical therapy and recreational services for children with Down syndrome. Programs are tailored to address the physical, cognitive, and psychosocial needs of each participant. Young children are introduced to the aquatic environment, and basic safety. Skills include blowing bubbles, floating, kicking, social interaction through songs and play, and basic aquatic safety skills for parents. It's a lot of fun and does a great job of preparing your child for future swim classes by helping them to learn in a structured environment in the pool. Older individuals with Down syndrome learn the basics like holding their breath underwater, and the leg and arm movements that necessary to swim while in a fun, safe and nurturing environment. They will learn how to swim free style, backstroke, frog-kick, swimming laps with and without a kick-board or noodles, and how to jump into the pool properly. Pool safety is emphasized and independence from parent is encouraged and nurtured.

To obtain more information, register, or donate to the DSACT SNAP program, please contact Executive Director Cleo Rodriguez at the DSACT office at (512) 323-0808 or cleojr@dsact.com.

If you can't fit the DSACT program into your scheudle or would like more intense instruction, you might want to try these other community resources who may offer swimming instruction to children with special needs:

- Nitroswim (Cedar Park) http://www.nitroswi m.com/
- West Austin Athletic Club
- Northwest Family Branch YMCA 5807 McNeil Dr. (Mark Olmstead, Executive Director, at 335-9622)
- Lifetime Fitness (South Austin)

DSACT Night at the Austin Outlaws

On Saturday June 6th, the Austin Outlaws, a professional women's football team dedicated their game to DSACT. Now don't be fooled: this is full-contact real football! The evening was a lot of fun! We had a blast! The Outlaws blew away the Houston Cyclones 42-20 and the stands were packed with enthusiastic fans! Annie Outlaw, the mascot, had the crowd cheering all night long. The kids were brought down on the field during half-time to take turns at a piñata and about 30 kids all dove in for the candy when it broke.

Just before the end of half-time, some of the players graciously came out early from half-time to pose for pictures with DSACT member Sydney Holahan. The evening was a LOT of fun! They honored DSACT by waiving the entrance fee for all DSACT members under 18, and charge half-price for accompanying adults. They made a series of announcements about DSACT and the upcoming Buddy Walk, and highlighted us in their programs. Thank you Outlaws!

If you didn't get a chance to make it to the game, you can look for the Outlaws to be at the Buddy Walk this year. If you like football and get a chance to catch a game, we highly recommend it! You can check out the Austin outlaws at www.austinoutlaws.com.

Caption(left to right: Justine Wolfanger, Lorin Smith, Lily Messina, Wendy Salter, front:Sydney Holahan)





10th Annual Buddy Walk Sunday, October 25th 12:00 p.m. ro 4:00 p.m. Reunion Ranch



Help us cross the finish line at the 10th Annual Buddy Walk on Sunday, October 25, 2009 from 12:00 p.m. to 4:00 p.m. at Reunion Ranch. The Buddy Walk is a one- mile walk created to promote awareness about Down syndrome, build team spirit, and raise funds for services and programs. It is one of the largest celebrations for Down syndrome awareness in the nation. All participants help in spreading the message of acceptance and inclusion for children and adults with Down syndrome - a message which will last long after the Buddy Walk.

Form your Family or Corporate Team Today!

Buddy Walk makes "FUN" draising enjoyable!

The Buddy Walk is one of the most enjoyable ways to raise funds. Last year, over 80 teams walked to support their loved ones with Down syndrome. Together, these families and friends raised over \$50,000 which was used to create some wonderful new programs for all ages!

By participating in the Buddy Walk, you will help make a difference in the lives of individuals with Down syndrome. Every step you take and each dollar you raise will help the Down Syndrome Association of Central Texas provide the important services that enhance the quality of life for individuals with Down syndrome and their families.

If you would like to be involved in the Buddy Walk, you can do so by registering yourself or your team on our website at www.dsact.com. Come ready for a one-mile walk, entertainment, and fun for the whole family! If you are not able to physically make it to the Buddy Walk, you can still head over to the above website and financially support our cause. Membership in DSACT is free of cost, and we strive to provide all services at little or no cost to members. We are sustained by fundraising activities and private donations. Financial contributions are vital in creating, promoting, and developing activities and programs in our priority areas: programming, education, caregiver support, inclusion, awareness, communication, and advocacy.



BUDDY WALK TEAMS - FORM YOUR TEAM TODAY

Forming a Buddy Walk team helps us raise awareness. More importantly, it gives our loved ones with Down syndrome a day to shine and be recognized by the Central Texas community for their unique contributions. The success of Buddy Walk 2008 was a direct result of the efforts of our teams: we had about 75 family and corporate teams, who raised over \$50,000 and countless awareness for Down syndrome. This year we hope to have 100 teams!

Why Form A Team?

- To raise awareness about the amazing individuals with Down syndrome who bring so much joy to our lives.
- To enhance the quality of life for all individuals with Down syndrome in the Central Texas area by raising money for programs and services

Six Steps To A Successful Team:

 Select a Team Name (Examples include: Patrick's Pack, Tyler's Tiara's, Sabine's Soldiers, Alejandro's Amigos)

2. Get a copy of the 2009 Team Packet

The 2009 Team Packet includes entry forms, tips for building a successful team and a sample letter to use to recruit team members. You can download a 2009 Team Packet and register your team online!

3. Recruit Team Members

A team is made of 5 or more people. You can recruit team members from your family, friends, co-workers, schools, neighbors, and church.

4. Collect Registration Forms & Donations (optional)

Though the Buddy Walk is our primary fundraiser of the year, collecting donations is optional. We want people to come and have fun! You can register your team, recruit members and accept donations online at www.dsact.com. Make sure that your team name is indicated on each members' form. For corporate teams, ask your employer about matching your donation.

- 5. Return Forms & Pick-up T-shirts
- 6. Show Your Team Spirit! Be Creative!

For More Information, A Team Packet Or Support:

For information on forming a family team, visit our website at www.dsact.com. You will find all the materials you need for successful fundraising!

Family team coordinator

Elizabeth Bradley elizabethbradley20@gmail.com (512) 479-0265

Corporate team coordinator

Bill Ebs bebs@austin.rr.com (512) 461-3677

Team Captain Commitment Form

Please sign me up to be a Team Captain!

Name:		
Team Name:		
Address:		
City, State, Zip:		
Home Phone: Work		
E-mail:		
Check One: Family Team Corporate Team		
Please tell us about your team:		
This is my year to do the Buddy Walk.		
I Hope to recruit a team of members.		
My goal is to raise \$ for Down Syndrome		
My inspiration:		
I want to receive information by emailor mail		
Designary on line or mail/amail your		

Register online or mail/email your Team Captain Commitment Form to:

Down Syndrome Association of Central Texas (DSACT)

Attn: Buddy Walk Team Coordinator Elizabeth Bradley 3710 Cedar Street, Box 3 Austin, Texas 78705



Corporate Sponsorship Search

Buddy Walk 2009

Dear DSACT Family and Friends:

The DSACT Buddy Walk committee is searching for sponsors who believe in our mission and want to contribute to make Central Texas a better place for all people with Down syndrome, including your loved one.

Do you know someone that would like to become a sponsor?

Membership in DSACT is free to all individuals with Down syndrome and their families, and we strive to provide all services at little or no cost to members. We are sustained by fundraising activities and private donations. Financial contributions are vital in creating, promoting, and developing activities and programs such as our new parent packets, physician trainings, speaker events, recreational programming (art, dance, music, cooking, self-defense, and more), educational programs and materials (the Learning Program, our nationally-recognized Educator Packet, and parent and educator trainings), member events (monthly playgroups, social events), and much more!

CONTACT US FOR A SPONSORSHIP PACKET:

If you are aware of a company or individual who would be willing to make a financial commitment to support our mission, please have them contact Stefanie Martinez at 293-5503 or email: mikeandstef2000@aol.com

If you work for a company that you think might be interested in becoming a corporate sponsor or forming a Buddy Walk Team to help raise pledges, we would be happy to contact them or give you a sponsorship packet to present to your employer.

MATCHING GIFT PROGRAMS

Ask your employer about Matching Gift Programs that they may have in place. Most companies will match your donation.

All donations to DSACT are tax deductible and will directly benefit individuals with Down syndrome in Central Texas.

Thank you for your help!

Júntese con nosotros para la 10ma Caminata de Amigos Anual!

Un evento familiar super divertido!

La Asociación del Síndrome Down del Centro de Texas Domingo, 25 de octubre de 2009 Rancho de Reunión, Georgetown, Texas 12:00 – 4:00 p.m.

Agarren sus amigos y váyanse al Rancho de Reunión – Las posibilidades no tienen límites!

La Asociación del Síndrome Down del Centro de Texas organiza este gran evento familiar para promover la comprensión y aceptancia de la gente con el Síndrome Down.

ENTRETENIMIENTO MUSICAL POR: Joe McDermott, Monte Warden y Elvis por Randy Hinson! Vengan y disfrutan de inflatables, paseos a caballo, una laguna con botes de pedaleo, nadar, golf en miniatura, pintores de la cara, paseos en carro de heno y mucho más para toda la familia!

Cada paso que se toma y cada dólar que se levanta ayuda a La Asociación del Síndrome Down del Centro de Texas a proveer programas y servicios que mejoran la calidad de vida para individuos con el Síndrome Down y sus familias.

Regístrese a: www.dsact.com

Forme un equipo para la caminata, sea voluntario o patrocinador. Contacte a Stefanie Martinez en 512- 323-0808 para más información.





Jake Deforest placed 5th in Trail, 1st in Barrels, and 1st in English Equitation at the Golden Stirrup Horse Show at the Star of Texas Rodeo. Way to go! We are proud of you!



Share The Passion 2009 DSACT Calendars are *STILL AVAILABLE!*



Brad Pitt -pictured with Nasrine

Celebrities in the 2009 calendar included: Brad Pitt (Actor), Fiona Shaw (Actress), Judy Maggio (K-EYE TV), Dr. Susan Culp, DVM, Andy Roddick, Art Acevedo (Austin Police Chief), Brad Womack (ABC's "The Bachelor"), Chad Womack, Wes Womack & Jason Carrier, Nolan Ryan, Skydive San Marcos, Los Lonely Boys, Paul Corrozo (RunTex), and The Honorable Senator Kirk Watson

Buy your 2009 Share the Passion Calendar Today and help educate the public about the talents and abilities of all individuals with Down syndrome.

Share the Passion is a *PERFECT* gift for everyone, including your child's new teacher this fall!

Order online at www.dsact.com or by phone at: 512-323-0808

Spotlight on Service: DSACT needs you!

Buddy Walk Committee Meetings

We need your help on the planning committee

If you can give an hour or two a month we would greatly appreciate your help. Volunteer today and help make a difference! Call today if you would like to join the Buddy Walk committee, and help us plan the largest event of the year.

PLEASE CONTACT US TODAY!

Buddy Walk Chairs, 2009 Stefanie Martinez - mikeandstef2000@aol.com Randall Holahan - randall@randallh.com Cynthia Ochoa – manor038@hotmail.com

La luz principal al servicio: DSACT te necesita!

Juntas del Comite Buddy Walk

Necesitamos tu ayuda en la planeacion del Buddy Walk

Si puedes dar una hora o dos al mes nosotros agradeceriamos muy amablemente tu ayuda. Se voluntario ahora y ayuda a hacer la diferencia!!! Llama ahora si te gustaria reunirte al comite Buddy Walk, y ayudanos a planear el mas grande evento del ano.

POR FAVOR CONTACTANOS AHORA!

Buddy Walk Chairs, 2009 Stefanie Martinez - mikeandstef2000@aol.com Randall Holahan - randall@randallh.com Cynthia Ochoa – manor038@hotmail.com

In the News

Young Mesquite man with Down Syndrome earns Eagle Scout

By KAREL HOLLOWAY / The Dallas Morning News kholloway@dallasnews.com



MESQUITE – The pictures flashing on the wall told the story.

Adam Townsend (left) and Eagle Scout Keeton McWhorter, 19, were side-by-side for the Boy Scout

pledge during the award ceremony. The two have been friends and in the same Scouting troop since they were 6-year-old Tiger Cubs.

Adam Townsend in a kayak. Adam in a canoe. Adam swimming, fishing, cooking over a campfire.

In short, Adam, who has Down syndrome, doing everything a regular Boy Scout does.

Keith Townsend (left) gave son Adam a hug after giving him his Eagle Scout award as mom Barbara watched. 'For parents with children with disabilities, your child can do it,' she said. 'You just have to believe.'

On Sunday, Adam, 20, received the organization's highest honor – he was awarded his Eagle Scout.

It takes years to earn the Eagle. In addition to the traditional camping skills, boys learn communication and personal skills in finance and relationships. They must organize and oversee a project. Adam's project was refurbishing a church parking lot.

"It's just magical seeing him do this," said one of his best friends, 19-year-old Keeton McWhorter.

Keeton, also an Eagle Scout from Troop 856, stood with Adam during the ceremony. They joined Tiger Cubs together in the first grade and have been close since.

Adam speaks very slowly, so Keeton took the Eagle Challenge for him, promising to remember his Scout pledge to do his duty to God and country, and to continue contributing to Scouting.

"Adam has just got a personality that could charm Iraq," said Scout leader David Abshire. "You look forward to coming to the [Scout] meetings just to shake his hand."

Abshire choked up during the ceremony at Eastridge Park Christian Church when he talked of how important Adam has been to his son, also named Adam.

He said Adam inspired his son, now a Marine, to earn his Eagle Scout.

Adam Townsend has rarely missed an activity. His dad, Keith Townsend, has been his companion and protector, attending all the campouts with him.

Scoutmaster Kelly Rambo said that Adam and his dad have five times the hours canoeing, kayaking and camping of anyone else in the troop.

One by one, adult mentors and other boys from the troop took the stage to tell stories about Adam.

James Lewis, an adult troop leader, remembered Adam patiently helping other boys as they kayaked, waiting until all the others had gone.

One Scout said that Adam had taught one of the younger Scouts not to complain.

Another said: "He's the most determined Scout I've ever seen."

For Adam's determination, Sunday was declared Adam Keith Townsend Day in Mesquite by Mayor John Monaco, who attended the ceremony with about 75 others.

Adam's mother, Barbara Townsend, said she thinks it's important for others to hear about all that Adam has accomplished. In addition to earning his Eagle Scout, he graduated from Mesquite's John Horn High School and competes in Special Olympics basketball and track.

"For parents with children with disabilities, your child can do it," she said. "You just have to believe." Join the DSACT Yahoo Group to receive up-to-date notice of events!



Donate today

Yes, I would like to contribute to individuals with Down syndrome!

Name:		
Email:		
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 Please contact me! I'm interested in scheduling an awareness presentation at my school, business or civic organization so others can learn more about Down syndrome and DSACT. I have enclosed a check for / please charge my Visa or Mastercard for: 		
\$25\$50\$75\$100\$125		
Credit Card # Exp. Date Please remit donations or inquiries to: Down Syndrome Association of Central Texas 3010 Cedar Street, Box 3, Austin, TX 78705 512-323-0808 www.dsact.com • cleojr@dsact.com		

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Si, me gustaria contribuir para los

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Upcoming Dates, Socials, Meetings

Join a DSACT Yahoo Group to receive the latest news

DSACT Yahoo Group

For parents and caregivers only. Join by sending an email to DSACT-subscribe@yahoogroups.com with brief reason you want to join (e.g., your name and child's name).

DSACT Buddies Yahoo Group

For friends, educators, related service professionals, and others in the Central Texas area who care about people with Down syndrome. Join by sending an email to DSACTBuddies-subscribe@yahoogroups. com. Please include a brief description of your position or relationship to a person with Down syndrome in Central Texas (e.g., "I teach a 2nd grader with Down syndrome in Round Rock." Or "My niece, who lives in Austin, has Down syndrome.")

DSACT Social Groups

INKDOTS: AGES 0-5

Upcoming Playdates: June 13 (location TBD)

InkDots is a group for children with Down syndrome age 0-5. Through monthly social get-togethers, parents get a chance to meet each other, gain valuable insights, and make life-long friends. Children get to make friends and have fun. To be included on the email list and receive notices of upcoming dates, please email Jeanette Holahan at jeanette@randall.com or call the DSACT office at 323-0808. We look forward to seeing you at our next gathering!

KIDSACT: AGES 6-12

KIDSACT is a group for kids with DS age 6-12, with monthly social get-togethers to facilitate friendship and have fun. Please contact suzshepherd@sbcglobal.net to be included on our email list. We love new members!

TEENS AND ADULTS

DSACT hosts periodic social outings and events for teens and adults with Down syndrome. Recent events included an afternoon of bowling and free tickets to the Austin Toros! For more information, contact Melly Mendoza (mellymendoza@yahoo.com) or Glenda Shoghi (gshoghi@yahoo.com).

Upcoming events

Friday, July 24, 6:00 – 8:00 p.m. 2009 Fiesta Party/ Dance (15 years and up) Georgetown Community Center

\$ 5 admission (caregiver or family member is free)

Hosted by Georgetown Parks & Recreation

Food! Dancing! Photos! Prizes! Please contact Heather Schwan with questions at 512-930-3596 or hschwan@georgetowntx.org.

Saturday, August 1st

DSACT Indoor Beach Party Dance

2 p.m. to 5 p.m.

Twin Lakes YMCA, 204 E. Little Elm Trail, Cedar Park, TX 78613

Everyone loves the Holiday party in December, but who wants to wait for cold weather? Come have some summertime fun at the DSACT Summer party. It's an indoor Beach party for the whole family! There is no charge, it is free to DSACT families.

Contact Jeanette at jeanette@randallh.com or the DSACT office at 323-0808 to RSVP.

Saturday, August 29th

DSACT Back to School Tools conference

Annual education conference for parents of individuals with Down syndrome, educators, and related service professionals. More details and registration form to come in next newsletter. For more information or to volunteer on Education committee, please contact Jana Palcer at janap@austin.rr.com.

Friday, October 23, 6:00 – 8:00 pm 2009 Halloween Party / Dance (15 years and up) Georgetown Community Center

\$ 5 admission (caregiver or family member is free)

Hosted by Georgetown Parks & Recreation Food! Dancing! Photos! Prizes! Please contact Heather Schwan with questions at 512-930-3596 or hschwan@georgetowntx.org.

Summer Camps & Leagues

2009 SUMMER CAMP PROGRAMS:



Big Sky Pediatric Therapy

For more information, go to www.bigskyfriends.com/index.html or call 306-8007.

August 3-7 - Handwriting Rocks

July 20-24 - Yoga Groove

July 27-31 - Big Sky Friends

DSACT Programs

Classes are FREE to Central Texas residents with Down syndrome and family members. Individuals with Down syndrome will be given first priority. Available slots will be filled by family members based on the date application is received by DSACT. Pre-registration is required. Call DSACT at (512) 323-0808 to obtain the program brochure and registration form or more information.

Teens & Adults

ARC of the Arts Program
Creative Movement Dance
Cooking With Young Chef's Academy
Anti-predator Self Defense Class
Special Needs Aquatics Program (SNAP)

KiDSACT (ages 6-12)

Special Needs Aquatics Program (SNAP) Music & Me

InkDots (ages 0-5)

Special Needs Aquatics Program (SNAP)
Music & Me
Sign Language
Gymboree

Programas de la Asociacion del Sindrome de Down Central de Texas (DSACT)

Las clases son GRATIS para nuestros residentes en Texas con syndrome de Down y miembros de su familia. Se les da prioridad a los individuos con syndrome de Down. Si hay lugares disponibles, los miembros de la familia pueden llenarlos, esto basado en la fecha en que la DSACT haya recibido la forma de inscripcion. Se requiere previa inscripcion.

ADOLECENTES Y ADULTOS

ARC Programa de Arte Danza Creativa y Movimiento Cocinando en la Academia con el Chef Joven Clase de Anti-Depredadores Programa Acuatico de Necesidades Especiales (SNAP)

KIDSACT (edades 6 a 12)

Programa Acuatico de Necesidades Especiales (SNAP) La Musica y Yo

InkDots (edades 0 – 5)

Programa Acuatico de Necesidades Especiales (SNAP) La Musica y Yo Lenguaje con Senas Gymboree

Registi	ration Form
Parent Name:	
Address:	
Day phone: _	
Cell phone: _	
Email:	
	S (name, age):
	ants (name, age):
I want to regi	ister for (check all that apply):
InkDots	SNAP (swimming)
	Music & Me
	Sign language
KiDSACT	SNAP (swimming)
6 - 12	Music & Me
Teens &	SNAP (swimming)
Adults	Music & Me
	Creative Movement Dance
	Cooking
	The Art Project
Waiver/ Relea	ase from Liability
I certify that I	am the parent/ legal guardian of Participant.
	Participant is in good health and has no
	her impediment which would endanger him/
_	cicipating. I agree (on behalf of myself,
	cutors, administrators, and assigns) to release,
•	ive and relinquish DSACT (or its officers,
	yees, volunteers) from any and all liabilities,
	ons for personal injury, property damage, or
	h which may arise out of his/her participation.
	ssion to DSACT to use any/all photos or of participant for any DSACT promotional
	iding but not limited to the website, newsletter
	onsor letters, or other promotional items.

Return completed forms to dsact2008@yahoo.com or

DSACT, 3710 Cedar Street, Box 3, Austin, TX 78705.

Forma de Inscripcion

Nombre del Padre:		
Direccion:		
Telefono (dia):		
Telefono (celular):		
Email:		
Nombre y edad del nino con SD:		
Otros inscritos (nombre y edad):		
Quiero inscribir por (marca todos los que apliquen):		
InkDots SNAP (natacion)		
Musica & Yo		
Lenguaje con Senas		
KiDSACT SNAP (natacion)		
6 - 12 Musica & Yo		
Teens & SNAP (natacion)		
Adults Musica & Yo		
Danza Creativa y Movimiento		
Cocina		
El Proyecto de Arte		

Renuncia/ Liberación de Responsabilidad

Certifico que soy el padre/tutor del participante. Certifico que el participante goza de buena salud y no tiene incapacidad física o de otro tipo que lo ponga en peligro durante su participación. Me obligo (en mi nombre, el de mis herederos, albaceas, administradores y cesionarios) a liberar y eximir a DSACT (o sus funcionarios, agentes, empleados o voluntariado) de cualquier responsabilidad, reclamaciones o acciones por lesiones personales, daños a propiedades u homicidio culposo que pudieran darse con motivo de su participación. Autorizo a DSACT a usar cualquiera o todas las fotografías o videos tomados al participante para uso en campañas promocionales, incluyendo sin limitar sitios en internet, boletines, folletos, cartas a patrocinadores u otros materiales promocionales.

irma	
Nombre escrito	Fecha_/_/_

Envia la forma debidamente llenada a dsact2008@yahoo.com o DSACT, 3710 Cedar Street, Box 3, Austin, TX 78705

Signature _

Officers

President & Education - Lori Tullos Barta

512.771.6081 • lmtullos@yahoo.com

Vice-President - Elizabeth Bradley

512.479.0265 • elizabethbradley20@gmail.com

Secretary - Becky Clowers

512.255.8510 • bclowerstx@sbcglobal.net

Treasurer - Vacant

Board Members

Comite Latino - Melly Mendoza

512.447.5474 • mellymendoza@yahoo.com

Education - Jana Palcer

janap@austin.rr.com

Governmental Affairs - Gerard Jimenez

512.496.6100 • gerard@austin.rr.com

Health Care - Chris Simon

chris.simon@suddenlink.net

Health Care & KiDSACT (6-12 year olds)

Suzanne Shepherd

512.306.1561 • suzshepherd@sbcglobal.net

Outreach, New Parents, & InkDots (0-5 year olds)

Jeanette Holahan

512.484.0013 • jeanette@randallh.com

Programming - Chris Smyth

512.656.1199 • cdsmyth@austin.rr.com

Programming - Jim Farrell

512.470.2012 • jfarrell25@att.net

Fundraising - Stefanie Martinez

512.293.5503 • mikeandstef2000@aol.com

PR/Media - Kirsten Monson

kirsten.monson@gmail.com

Volunteer Coordinator - Hannah Hays

281.435.5458 • Hannah.hays83@yahoo.com

Webmaster - Cynthia Ochoa

512.413.7317 • cochoa@dsact.com

Williamson County - Tiffany Young

tifzachwynter@yahoo.com

Hays County - Vacant

Non-Board Member Committee Chairs

Comite Latino – Rebecca Tobias

512.447.6974

Comite Latino - Deborah Trejo

 $512.909.8359 \bullet DTrejo@kempsmith.com$

Social - Cindy Lopez

512.300.9261 • lopez_cm@yahoo.com

Staff

Executive Director - Now Hiring

Administrative Assistant - Carrie McGuire

512.323.0808 • info@dsact.com

Vision Statement

The Vision of the Down Syndrome Association of Central Texas is a world in which all members, including those with Down syndrome, are accepted, valued for their uniqueness, respected for their abilities and contributions, and assured the opportunity and choice to create their own path to fulfillment and success.

Mission Statement

The mission of DSACT is to provide support and resources to individuals with Down syndrome, their families, professionals, and the community to achieve our vision. We achieve this by:

- Promoting the development of programs that enrich the lives of individuals with Down syndrome;
- Increasing public awareness and understanding about the abilities of individuals with Down syndrome;
- Encouraging inclusion of individuals with Down syndrome in our neighborhoods, schools, places of worship, recreational activities, and places of employment;
- Providing education, resources and support to parents and educators to ensure quality education which will prepare individuals with Down syndrome for further education, employment and/or independent living; and
- Creating a forum for the exchange of ideas and experiences.

Nuestra Visión

La visión de DSACT (Asociación de Síndrome Down de la Zona Central de Texas) es un mundo en el que todos sus miembros, incluso aquellos con el Síndrome de Down, son aceptados, valorados por lo que son, respetados por sus habilidades y contribuciones, y cuya oportunidad de crear su propio camino al éxito y realización personal es asegurado.

Nuestra Misión

La misión de DSACT es proveer soporte y recursos a individuos con síndrome de Down, sus familias, profesionales, y la comunidad a obtener nuestra visión. Nosotros podemos cumplir ésto de la siguiente forma:

- Promoviendo el desarrollo de programas que enriquezcan las vidas de los individuos con síndrome de Down.
- Incrementando el conocimiento y el entendimiento público acerca de las familias y los individuos con síndrome de Down.
- Estimulando la inclución de individuos con síndrome de Down en nuestros vecindarios, escuelas, iglesias, actividades recreacionales, y lugares de empleo.
- Proveyendo educación, recursos y soporte a los padres y educadores para asegurar la calidad de educación que prepare a individuos con síndrome de Down para una mejor educación, empleo, y/o vida independiente.
- Crear un foro para el intercambio de ideas y experiencias.

The content of this newsletter is provided as a public service for informational purposes. DSACT does not promote any particular therapy, treatment, institution or professional system, etc. The opinions, beliefs, and viewpoints expressed in this newsletter do not necessarily represent those of the DSACT, its directors, members or the editors of this newsletter.

A huge Thank You to our 2009 Buddy Walk Sponsors







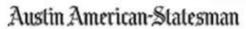
























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Monty Warden

















Christine Gaharan, OTR/L Pediatric Occupational Therapy 3109 W. Slaughter Lane, Bldg. B



Heidi Armendariz, MA CCC/SLP Pediatric Speech & Oral-Motor Services 3109 W. Slaughter Lane, Bidg. B Austin, Texas 78748

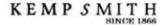


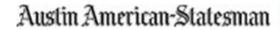
























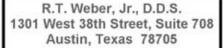


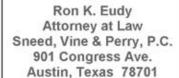


Starlyn Aurit









512-476-6955







Kuperman, Orr & Albers, P.C. David Kuperman



Down Syndrome Association of Central Texas

DSACT

3710 Cedar Street Box 3 Austin, TX 78705

Phone: 512.323.0808
Fax: 512.451.3110
Email: info@dsact.com
Newsletter Email:
cleojr@dsact.com



Moving? Don't miss and issue of the Heart of Texas due to an address change! Since the Post Office does not forward the newsletter, please call, write or e-mail us to update your information—thanks!