

Eliana's Light



Second Annual Report

Fiscal Year Two

April 1, 2018 – March 31, 2019

@elianaslight

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INTRODUCTION





LETTER FROM OUR FOUNDER

Dear Collaborators,

It is tremendous to be writing our second annual report. So much has transpired since this time last year. We are emerging out of our “start up” phase and moving into a stage of ever evolving growth, enhanced understandings, and deeper connections within our community.

We maintain profound connections with the families we support. In addition, we remain focused on maintaining and building genuine partnerships, and continue with our dedication to our vision of co-creating alongside collaborators a community-based system of integrated health care that addresses the whole health and well-being of families with children who have complex medical conditions. This vision provides opportunities for individuals, organizations, agencies, and businesses to come together *as a community* to help others feel better while they connect to each other. Together, we provide an approach to care that addresses the mind, body, and spirit while we promote integrative medicine (IM) and integrative care services within pediatrics.

Our inaugural year focused on forming a strong foundation for the future, a replicable and scalable model that creates *Constellations of Care* within a community to support families and caregivers who live and work there.

Through the support of our funders, collaborators and volunteers, we achieved the following in our second Fiscal Year:

- **Grew from working with six pediatric medical centers in our first Fiscal Year to collaborating with eight facilities** that support these children and families who live in Washington, DC, Maryland, and Virginia.
- **Donated another \$1,000 to Children’s National Medical Center** in addition to the more than \$20,000 Eliana’s Light previously raised to support the development of an Integrative Medicine and integrative care services division;
- **Posted an additional 25 resources** to our website to total 325 resources applicable to caregivers, medical professionals, and integrative care providers;
- **Participated in more than 25 knowledge exchange and advocacy meetings** to support whole health approaches to pediatric medical care;
- **Initiated collaborations with 20 additional organizations and businesses** to extend our reach and enhance our impact, building on our original 43 collaborations;
- **Organized 17 in-person and online learning events** to disseminate information and build awareness;
- **Engaged more than 2,300 volunteers** (1,000 more than last year) in contributing to our work and growth;

- **Gave more than 3,800 hand-made cards (1,000 more than last year) and more than 1,600 cookies (1,000 more than last year) to all pediatric patients and their caregivers** at seven local medical centers (one more than last year) on Valentine's Day 2019;
- **Delivered 600 gift bags to moms and 600 gift bags to dads** at seven participating medical centers on Mother's Day 2018 and Father's Day 2018, respectively;
- **Supported 17 families** who applied for support (10 more than last year), providing each family with a personalized gift bag, guidance on additional services and resources, and support in reducing their financial, emotional, mental, and physical stress; and
- **Contributed to five advisory committees and roundtables** to share learning and best practices.

You can read more about these activities in the section of this report titled "**What We've Accomplished**" (page 11), along with quotes from some families we've supported and individuals with whom we've collaborated. Together, these illustrate some of the tangible outcomes and impacts we made in our second Fiscal Year. We truly believe Eliana's Light is unique in how we **C.A.R.E.:** by **connecting with families** to support them where they are; **advocating for whole health** approaches to patient- and family-centered pediatric medical care and attention; **raising awareness** on whole health and related programming, approaches and strategies that help reduce stress, anxiety, pain, and fear, especially in regards to medical care and treatments; and **exchanging ideas and resources** with collaborators. We are excited to share our experiences with you in this report.

It is important to us that we build and maintain authentic connections and relationships in the work that we do. We hope you will join us during our next Fiscal Year to support local families with children who have complex medical conditions. Thank you for your interest and engagement.

With warm regards,
Whitney Ortiz

Founder and President of Eliana's Light

MESSAGE FROM OUR BOARD

Dear Collaborators,

We are supporters of integrative and integrated care who empower families of children with complex medical conditions while reducing the stress, pain, fear, trauma, anxiety, and depression that can accompany these difficult situations. We connect families to resources, information, specialists, and tools while advocating for whole health approaches to care. We raise awareness on holistic ways to address physical, mental, spiritual, and emotional health.

We are advocates, caregivers, health and wellness professionals, and parents. **We have been there**, and we believe in holistic health care that addresses the body, mind, and spirit in the hospital and at home. We're also profoundly dedicated to our community, and work to bring together members in meaningful volunteer opportunities that make a positive difference.

We invite you to join us in 2019 as we:

- bring more integrative care services and a whole health approach to care to more families in DC, Maryland, and Virginia while connecting them to essential resources, information, and specialists that can support them.
- raise awareness on and enhance understanding in integrative care services and holistic health care approaches that facilitate, support and promote whole health.
- connect to collaborators who want to work synergistically with us to build an evidence base of effective integrative care approaches for children with complex medical conditions and their caregivers.

Thank you for your consideration, and we look forward to hearing from you.

Sincerely,

Natalia Isaza Brando

Megan Dennis

Rhiannon Landesberg

Celinha Martins

Melissa Nussbaum

ELIANA'S STORY

Knowing where and how to share our story is difficult. Before starting Eliana's Light, we never shared much publicly about Eli's condition.

Everything started on a regular day when I put our three month-old twins down for a nap.

After a few minutes, I saw Eli's chest heaving. I rushed over to her and found her largely unresponsive. After a rush to the emergency room, we learned she was in heart failure. Her heart was not beating, only vibrating. The doctors didn't know if she would make it through the short trip across town from Georgetown Hospital to Children's National Medical Center, which has more life-saving machines and medicines for children in health crises.

The doctors at Children's National conducted many tests over the weeks that followed. She was in a coma, hooked up to multiple machines, and on life-saving medicines. Eli was diagnosed with dilated cardiomyopathy, which meant her heart was enlarged and not pumping sufficient blood to meet her body's needs. She had three open-heart surgeries, including one to attach a Berlin Heart and another to receive a heart transplant. Eli was the first child in the Washington, DC area to be on a Berlin Heart, which is a device that pumps blood for the heart while a child awaits heart transplantation. She also had dozens of cardiac catheterizations, was on dozens of medicines, and had dozens of hospitalizations, up to eight months at a time.

Eli spent the majority of her almost four years in the hospital, as both an inpatient and outpatient. Through it all, we did everything we could to give her joy, happiness, and fulfillment. When she was able to be at home and was feeling well, we took our girls to library story times, the playground, birthday parties, and our family members' houses. We got to see them play in the sand, kick soccer balls, twirl in tutus, dance to "Frozen" songs, and start pre-school. Each moment was precious and we hold onto all of them dearly.

Eli passed away March 28, 2016. Her light continues to shine and will always guide us.

With love,

Whitney Ortiz

Founder and President of Eliana's Light

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WHO WE ARE





OUR MISSION

Eliana's Light supports families with children who have complex medical conditions by providing a community-based collaborative approach to care that's focused on whole health and well-being. We connect directly with families through customized gift bags, learning events, and online communications; advocate for and raise awareness on whole health, integrative, and integrated approaches to care; and exchange information and resources with caregivers, practitioners, and researchers. We help children and their caregivers feel better while we contribute to a whole health and family-centered approach to pediatrics.

OUR PURPOSE: WHY WHOLE HEALTH & WELL-BEING

When a child is diagnosed with a complex medical condition, s/he can endure long and frequent hospitalizations, painful and traumatic procedures, and scary discussions. Caregivers and siblings may feel stressed, scared, and exhausted. Children and their families frequently experience medical trauma, Post-Traumatic Stress Disorder (PTSD), toxic and chronic stress, and feelings of helplessness, loneliness, and desperation, all of which can have a negative impact on both immediate and long-term health and wellbeing. Stress has been shown to exacerbate existing medical conditions, and can cause new conditions to form. This is particularly true when stress is constant or compounded by pain, fear, trauma, anxiety, and depression. Visit our [website \(www.elianaslight.org\)](http://www.elianaslight.org) to learn more about research on medical trauma and stress.

In our conversations with families dealing with complex medical conditions in our region, we found that many feel helpless in dealing with the stress of their situations. All too often, they find that medicine and medical treatments alone do not fully address the needs of their minds, bodies, and spirits. They are left searching for support and relief, often unaware of the many resources available in the Washington, DC metro area.

There are a wide variety of complementary and integrative care service providers interested in supporting children and their caregivers across the region. However, a number of factors limit access to these critical services. Few medical facilities offer significant integrative care services or have an Integrative Medicine (IM) program. Providers are not often associated with a local hospital, therefore lacking strong referral networks. Insurance companies do not tend to cover complementary and integrative care services, making the cost of care prohibitive for far too many families.

"Integrative medicine and health reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic and lifestyle approaches, healthcare professionals and disciplines to achieve optimal health and healing."

– Academic Consortium for Integrative Medicine & Health (ACIMH)

The medical, integrative, and complementary care specialists collaborating with Eliana's Light want to relieve these children's and families' suffering, improve their quality of life, and make their life experience easier. We believe in the importance of necessary medicine and medical procedures, and that complementary health care and integrative care services work alongside standard medical practice. **We want to make integrative care services more accessible as part of our efforts to improve the whole health of a family and its members.**

We also recognize that a key component of whole health is connection to community. Eliana's Light thus organizes three large community service activities, in which many smaller ones take place, each year. More than 2,250 volunteers engaged in initiatives we organized in our second Fiscal Year to give support to local caregivers and their family members. Our volunteers generously and graciously made Valentine's Day cards and cookies, and contributed to gift bags for Mother's Day and Father's Day. More than 2,000 children and their caregivers received the outpouring of support from these community members. Many recipients shared how they felt a greater sense of connection to their community and were uplifted by their support. The volunteers also benefited from the experience, with adults and children alike expressing gratitude for the chance to help others in their community feel better.

OUR VISION

Our vision is to become a go-to health and wellness support system and resource for families in the Washington, DC, Virginia, and Maryland region that have children with complex medical conditions. We envision being an active member of a local health and wellness system that supports and empowers a whole family with a child who has a complex medical condition, improving each family member's quality of life, wellness and well-being. A "Constellation of Care" addresses the physical, mental, emotional, and financial needs of each family member through referral processes; compassionate care; advocacy; information exchange; and the use of Integrative Medicine, integrative care services, and complementary care approaches and modalities. We recognize a regional team of collaborating medical professionals, hospitals, community health centers, specialists, integrative care providers, volunteers, donors, and other caring individuals will play an important role in the effort to transform today's health care system into one that focuses on whole health and wellness through community-based support.

OUR VALUES

Altruism, Collaboration, Community, Empowerment, Flexible, Grateful, Inquisitive, Immersed, Integrity, Participant-Centered, Personalization, Respect

OUR VALUE PROPOSITION

Eliana's Light recognizes the need to focus on the whole health of the whole family -- as well as each member's body, mind, and spirit -- in an effort to improve the health, wellness, and well-being of a family and each of its members. We accomplish this by building *Constellations of Care*: networks of committed specialists, organizations, companies, and individuals that work together in a community to support the unique needs of families with children who have complex medical conditions. Families become empowered while they feel better through the direct care they receive from Eliana's Light, and the specialists, organizations, businesses, and caring individuals who attend to the specific needs of each family member. Each family member will gain understandings and capacity to practice self-care and relaxation techniques that are safe and appropriate; and they also can access resources in the community that can help alleviate the stress, pain, fear, trauma, anxiety, and/or depression they are experiencing. **This collaborative, whole health approach to care builds on existing systems and services to promote greater quality of life during this immensely difficult time.**

OUR APPROACH

Eliana's Light uses a Policy, Systems and Environment (PSE) approach to helping families. This approach recognizes the reality in which families live, work, attend school, and receive medical attention, and addresses the policies (governmental and within institutions), systems (within institutions and a community), and the environment (within institutions and a community) that affect a person's whole health and well-being.

A PSE approach is a long-term approach that is designed to make a sustained improvement in community health, and builds on the cultural and social assets of the community. It has a greater chance of success, empowers communities to take part in the process and advocate for their own health, and fosters strategic public-private partnerships to improve the health of the community.

Our activities follow a structure we have come to call **C.A.R.E.**:

- **C= Connect:** We connect to families where they are through our Eliana's Light Constellation Kits, learning events, tip sheets, and communications channels. We also connect families to resources, specialists, other organizations, and information that can help reduce their physical, mental, emotional, spiritual, and/or financial stress. We build trusting, compassionate relationships through our shared humanity while we develop "Constellations of C.A.R.E." through the collaborative community service events we organize.

- **A= Advocate:** We advocate for whole health approaches, Integrative Medicine (IM) expertise, and integrative care services within pediatric medical facilities and as part of standard medical care, therapy programming and research initiatives.
- **R=Raise awareness:** We raise awareness on whole health and related programming, approaches and strategies that help reduce stress, anxiety, pain, and fear, especially in regards to medical care and treatments.
- **E=Exchange:** We manage and serve on advisory committees to exchange information and resources with local specialists and caregivers in areas relevant to our mission.

We invite you to read on to learn about our successes and growth in each of these areas throughout our second year!

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WHAT WE'VE ACCOMPLISHED





OUR PROGRAMMING: HOW WE C.A.R.E

C = CONNECT

We connect to families where they are through our Eliana's Light Constellation Kits, learning events, tip sheets, and communications channels. We also connect families to resources, specialists, other organizations, and information that can help reduce their physical, mental, emotional, spiritual, and/or financial stress. We build trusting, compassionate relationships with them through our shared humanity while we develop "Constellations of C.A.R.E." through the collaborative community service activities we organize. .

Highlights from Year Two:

- ✓ **We provided direct support to the seventeen new families that applied**, in addition to the 10 that applied last year, providing each with a signature *Eliana's Light Constellation Kit*, guidance on additional services and resources, and support in reducing their financial, emotional, mental, and physical stress.
- ✓ **We posted 25 new resources** on our website, in addition to the original 300. These include lists of relevant providers and organizations, current research on integrative medicine and integrative care services, and tips on financial and legal planning for parents of children with complex medical conditions.

Families living in Washington, DC, Maryland and Virginia find their way to Eliana's Light through referrals (from Child Life specialists, case managers, doctors, nurses, chaplains, social workers, and others), word of mouth, and Internet searches. We work with families of children with complex medical conditions who seek support in reducing their financial, emotional, physical, and/or mental stress and improving their quality of life, wellness, and sense of well-being. Our easy-to-complete application (<https://www.elianaslight.org/get-support-1/>) asks for basic information on a child's medical diagnosis and treatment as well as the type of support a family would find most useful, such as connections to specific specialists and organizations, gift cards for gas or groceries, and distraction toys to help children during difficult medical procedures. We accept applications in English, Spanish, and Portuguese at any time. We can accept applications in Arabic, Amharic, and French with the help of volunteer translators.

Our board reviews each family's application, and we contact families within 24 hours. Once the board approves an application, Whitney then arranges a time and place to meet with the child/ren's parent/guardian(s) to discuss the family's needs and concerns. Our experience and research have taught us that caregivers applying for support tend to face one or more of the following challenges:

- Finding and maintaining sufficient medical insurance coverage for their children and themselves;
- Finding and maintaining a job that accommodates the time demands of necessary doctor appointments and hospitalizations;
- Securing appropriate child care when the caregiver needs to work or rest;
- Maintaining a positive relationship with a spouse or other life partner;
- Securing reliable and low-cost transportation to get to and from doctor appointments;
- Coordinating the medical and therapeutic care their child/ren need;
- Staying with their child/ren during long-term hospital stays;
- Having positive interactions with members of their child's medical team;
- Navigating their child/ren's medical care, health insurance, and school system, particularly in cases where the caregiver does not speak English;
- Finding resources and expertise available to them in their community;
- Understanding how best to care for their child/ren at home;
- Reducing their overwhelming stress, pain, anxiety, fear, trauma, and depression.

We understand how stressful it can be to care for a child who has a complex medical condition, and want to support caregivers in mitigating the stress of the challenges they face. Importantly, we do not provide technical expertise or serve as a coordinator of care; instead, we help *connect* caregivers to relevant experts that form *Constellations of Care* within our communities. **In our second year, we worked with 17 families of children with complex medical conditions who applied to our organization for support.**

Once a family contacts Eliana's Light for support, we accompany a family in support for as long as they like. When the family's needs change, we help guide them to other support services that are relevant to their new needs and/or give them suggestions of possible solutions for the specific stresses they have. We check in with them, providing comfort, connection, and coaching as appropriate. We let them know they are not alone.

Eliana's Light Constellation Kits

As a bedrock of our programming, all families applying for support through our organization receive tailored gift packages designed to ease stress during this difficult time. We call these packages *Eliana's Light Constellation Kits*, because of the constellation of wellness and well-being that comes from complementing one's medical care with other appropriate and safe healing approaches and services.

Each of the 17 "kits" we created for the families we worked with was unique, designed to meet a family's specific needs and circumstances. Below are some examples of the resources and stress-relieving tools we have included in *Eliana's Light Constellation Kits*:



Ander, a local child with a rare genetic disorder, is an example of a child who received a personalized Eliana's Light Constellation Kit.

- Yoga mat for a caregiver who joined her child in relaxation stretches during the child's physical therapy sessions;
- Distraction toys for children who receive regular medical procedures;
- Age-appropriate children's books for the child with the medical condition, and also the child's siblings;
- Coloring books and art supplies for children, youth, and adults;
- Contact list of complementary care services available in our community;
- Tips on how to position a child for comfort at home, how to keep a family safe in the case of an emergency, how to achieve stress relief while in the hospital or at home, how to create a calming environment for therapy sessions, and how to financially plan for the future;
- Gift certificates to supermarkets, complementary care providers, and other frequented or desired locations; and
- Foot massagers, organic lavender sachets, and aromatherapy heat wraps for adults.

Online Resources

In addition to the in-person connections we make with families, we also connect caregivers - parents, guardians, and professionals - to resources on our website. **During the past two years, we added more than 325 entries to the *Resources* section of our website (www.elianaslight.org/resources).** These free resources provide critical information for anyone interested in tending to the whole health of families with children who have complex medical conditions. Examples of the resources we have compiled online include:

- **Lists of other organizations and companies** that can provide financial and in-kind support for families and children in Washington, DC, Maryland, and Virginia. This includes local non-profits with grant-making functions and expertise, government agencies that address mental health, and early childhood intervention programs that evaluate and provide appropriate therapies for children.
- **Names and contact information of local medical personnel and therapists** who take an integrative approach to the care of children and/or adults. These providers can share information on the safety, relevancy and benefits of this kind of care.
- **Names and contact information of local integrative and complementary care providers** who can provide additional support alongside a medical care plan, such as yoga, mindfulness, massage, and acupuncture therapists.
- **Links to up-to-date information** on research related to pediatric Integrative Medicine (IM); IM program models in operation throughout the U.S.; and books, apps and tip sheets for supporting mental and emotional health and wellbeing.

- **Information on associations** where practitioners can seek additional training and credentials.

Sandra's Story

We are grateful to have known Sandra, a beautiful young girl who passed away in December 2018. She had Epilepsy and couldn't sit or roll on her own. A gastronomy tube (G-tube) helped to provide her nutrition. Sandra faced frequent hospitalizations for necessary procedures, often due to illness contracted on top of her medical condition. Her parents primarily speak Spanish. Sandra's parents learned of Eliana's Light from a chaplain at a local hospital. Her father submitted an application through our website, which the board quickly approved.

Since the time Sandra's parents applied for support in November of 2017 through the present, Whitney has met with them five times and talked with them numerous times by phone. Whitney brought the family an *Eliana's Light Constellation Kit* filled with items to reduce their immediate sources of stress, spoke with her parents about their concerns, connected them to additional resources, and helped Sandra's parents complete an application for rent assistance through another organization.

Sandra's mother once wrote: *Thank you, Eliana's Light, for concerning yourselves about us and always keeping us in mind. We want to thank you infinitely for all you are doing for us, and especially for our daughter. Thank you for the gifts you brought her, which are going to be very useful for us.*

When Sandra passed away, we were so deeply saddened. We attended her funeral and check in with her parents regularly. Our love and thoughts remain with Sandra and her family always. Sandra's light will always shine in our hearts.



A = ADVOCATE

We advocate for whole health approaches, Integrative Medicine (IM) expertise, and integrative care services within pediatric medical facilities and as part of standard medical care, therapy programming, and research initiatives.

Highlights from Year Two:

- ✓ **We raised more than \$1,000 specifically for Children's National Medical Center** in support of the development of an Integrative medicine and integrative care services division. Some of the more than \$20,000 we have raised in total for this effort went this year to help start the development of a yoga program for caregivers (parents and staff members) at this hospital.
- ✓ **We participated in more than 25 knowledge exchanges and advocacy meetings** to support whole health approaches to pediatric medical care.
- ✓ **We managed the finances for the Healing Touch program at Children's National**, which a private donor is funding so nurses at the hospital can learn this approach for bringing greater relaxation to their pediatric patients.
- ✓ **We co-developed a tip sheet on mindfulness feeding therapy**, which is applicable to many types of at-home therapy sessions, along with feeding therapists in our region.

In addition to serving families living in Washington, DC, Maryland, and Virginia, we seek to advocate for and support whole health approaches, Integrative Medicine expertise, and integrative care services at major hospitals and medical centers. In our second year, we collaborated closely with the Child Life and social work team in the Cardiac Intensive Care Unit at Children's National Medical Center who developed a yoga program, which is now being accessed by caregivers and patients from other parts of the hospital as well. We continue to collaborate with members of this hospital's leadership team as they move forward on plans to increase the coordination and mainstreaming of a greater number of integrative care services to more patients and caregivers (staff included). The hospital's Executive Leadership is committed to integrative care, and to developing evidence-based programming that coordinates, prioritizes, tracks, and funds integrative care services. We're thrilled by other developments there, such as an integrative medicine sickle cell clinic, a Mindfulness-Based Stress Reduction program, and a physician wellness initiative, among other programs.

R = RAISE AWARENESS

We raise awareness on whole health and related programming, approaches and strategies that help reduce stress, anxiety, pain, and fear, especially in regards to medical care and treatments.

Highlights from Year Two:

- ✓ **We organized and participated in 20 in-person and online events** to disseminate information and build awareness.
- ✓ **We used four social media accounts and our email newsletter** to reach more than 1,000 followers and supporters (690 through social media and 480 via email).
- ✓ **We initiated collaborations with more than 50 organizations, networks, and businesses** to enhance our reach and impact.
- ✓ **We engaged more than 2,300 volunteers** to contribute to our mission.

Community Engagement and Learning Events

Throughout our second year, we organized a variety of in-person and online events designed to reach caregivers, children, and entire families while raising awareness on topics related to whole health and the realities of caring for a child who has a complex medical condition. Our primary target audience has been caregivers of children with complex medical conditions. These events are designed to be practical and informative while providing families opportunities to connect to each other. Examples of events from our second year include:

- **2019 Valentine's Day Cards for Kids & Cookies for Caregivers:** In 2017, we organized more than **80 volunteers** to make and deliver over **300 cards to children and 250 cookies to their caregivers** at Children's National Medical Center on Valentine's Day. By the next year, our reach and impact had expanded tremendously. With the help of **1,101 volunteers, we delivered 2,395 cards and 504 cookies to six hospitals** serving children with complex medical conditions in Washington, DC, Maryland, and Virginia on Valentine's Day 2018. **In 2019, 2,003 volunteers from 6 states plus the District of Columbia, made and delivered 3,883 cards and 1,655 cookies to 7 medical centers** in DC, MD, and VA. *That's an increase of 1,000 volunteers and 1,000 cards each year; and 1,000 cookies more than last year along with an additional medical center.*

- **#WeCareForMoms and #WeCareForDads:** Recognizing the tremendous love and support parents give to their children, as well as the stress that can come from caring for a child with a complex medical condition, we delivered more than **250 sachets of organic lavender to moms** staying at Children's National Medical Center on Mother's Day 2017, as well as **250 stress balls to dads** staying at Children's National Medical Center and the Children's Inn at NIH on Father's Day in 2017. **In 2018**, we delivered **600 gift bags to moms and 600 gift bags to dads for these holidays**. These bags were filled with donated self-care items (e.g. toiletries, lavender sachets, stress balls, etc.) and gift certificates from local businesses, organizations, and individuals. They reached moms and dads who needed to be at one of our six collaborating medical centers over Mother's Day and Father's Day in order to care for their hospitalized child. Not only did we increase our reach, but we were also able to give these caregivers more items to "give them a boost". We re-named this community service initiative "**Give a Boost to Moms for Mother's Day**" (<https://www.elianaslight.org/new-events/2019/3/2/giving-a-boost-to-moms-on-mothers-day>) and "**Give a Boost to Dads for Father's Day**" (<https://www.elianaslight.org/new-events/2019/4/20/giving-a-boost-to-dads-on-fathers-day>).
- "**In The Case of An Emergency: How To Keep Your Child Safe**". In June 2018 and March 2019, we collaborated with the Lollipop Kids Foundation and Montgomery County's Police Department and Fire and Rescue team to provide local families with a practical learning event and tip sheet to protect them in the case of an emergency. To read the latest version of the tip sheet we collaboratively developed, please visit: <https://static1.squarespace.com/static/5893aadedb29d6ce15167eb2/t/5c98bc9f71c10b6eca3b1ddf/1553513632258/EmergencyPreparednessTipsforCaregiversMar2019.pdf> (English) and <https://static1.squarespace.com/static/5893aadedb29d6ce15167eb2/t/5b7f062daa4a99d40b7166a8/1535051310368/Spain.EmergencyPreparednessTipsforCaregiversJune2018.pdf> (Spanish). We will be building on this and disseminating an updated version after an event we're planning to organize in Washington, DC during the fall of 2019.
- **Race for Every Child.** Eliana's Light organized a team again for Children's National's annual Race for Every Child. The 2018 Race took place October 20, 2018 in downtown Washington, DC. Eliana's Light specifically raises funds through this race to support the development of an integrative care services and Integrative Medicine division/department at Children's National that will mainstream a larger number of a greater range of integrative care services to patients and their caregivers, while providing expertise from those with training in Integrative Medicine and related care modalities. We were pleased to raise an additional \$1,000 for this effort in 2018, and with those funds, help launch a new yoga program in collaboration with a social worker who has training in this area and works at the hospital. Eliana's Light has raised more than \$20,000 to date for integrative care at Children's National.

- **Online Learning Series: Conversations With A Caregiver:** In October 2017, we **launched our online learning series, *Conversations With a Caregiver***. These short, videotaped conversations are designed to provide caregivers (parents/guardians and professionals) with access to information on caregiver realities, self-care, and whole health for the whole family. In Fiscal Year 1, we recorded two “Conversations”. In Fiscal Year 2, we recorded the following five:

 - **Conversation with LaJoy Johnson-Law, mom/primary caregiver of Abria, and intake coordinator at Advocates for Justice and Education (AJE)”:** March 27, 2019. Hear from LaJoy on the realities of being a mom and primary caregiver of a child who has a complex medical condition, the resources AJE provides, and the importance of organizations and individuals collaborating in a community to support these families." 13 minutes, 24 seconds.
<https://www.youtube.com/watch?v=XIBpdjUdAVc&feature=youtu.be>
 - **“Conversation with Eileen Walters, nurse and program manager with the Beyond the Spectrum program at Children’s National Health System”:** February 25, 2019. Hear from Eileen Walters on practical ways she and her colleagues support children with Autism before, during and after medical procedures to make these experiences easier for them. For additional resources, please visit:
<http://childrensnational.org/autismvisualresources>. 7 minutes, 21 seconds.
<https://www.youtube.com/watch?v=TVLtWPfEY2E&feature=youtu.be>
 - **"Conversation with Lauren Cate, Licensed Massage Therapist and founder of Healwell":** June 27, 2018. Hear from Lauren Cates on how massage therapy can contribute to health and wellness for children and caregivers, and how you can comfort your child through gentle touch. 6 minutes.
<https://www.youtube.com/watch?v=TVLtWPfEY2E&feature=youtu.be>
 - **"Conversation with Greg Scott, Art Curator and Artist, Children's National Health System":** April 26, 2018. Hear from Greg on how he chooses certain art pieces to create a healing environment at a pediatric hospital. 4 minutes, 32 seconds.
https://www.youtube.com/watch?v=P__eHsjvvDM&t=70s
 - **"Conversation With Erin Gris, Certified Child Life Specialist, Cardiac Intensive Care Unit (CICU), Children’s National Health System":** April 14, 2018. Hear from Erin on how she uses guided imagery, therapeutic touch, pediatric clinical hypnosis, and other mind-body techniques with pediatric patients and their caregivers in the CICU. 3 minutes, 30 seconds.
<https://www.youtube.com/watch?v=AFoGwMe1hHQ&feature=youtu.be>

Additional events are listed in the *Fundraising* section of this report, as well as on the “Events” page of our website, which contains a complete list of all events held during our second Fiscal Year. For information on upcoming events, please visit: <https://www.elianaslight.org/new-events/>.

Communication Channels and Initiatives

We use a variety of communications channels to share research, tip sheets, toolkits, information on learning events, and other practical resources that may be of interest to caregivers, children with a complex medical condition, pediatric medical providers, and complementary and/or integrative care providers. Our primary communications channels are our website, social media channels, and email newsletter (<https://www.elianaslight.org/newsletter/>).

In our second year, we reached more than 2,000 followers and supporters via our website, newsletter and social media channels. The following is a breakdown of our reach via various communications channels:

- **Website** (www.elianaslight.org): Our website attracted 2,525 unique visitors in 2018 (from 1,800 in FY1) and 1,238 from January 1-March 31, 2019; 2,800 visits in 2018 and 1,200 visits from January 1-March 31, 2019; and 6,002 page views in 2018, and 2,720 page views from January 1-March 31, 2019.
- **Facebook** (www.Facebook.com/elianaslight). We have 304 followers and shared 279 posts (from 286 posts in FY1) on Facebook.
- **Twitter** (www.Twitter.com/elianaslight). We Tweeted 487 times (from 428 times in FY1).
- **Instagram** (www.Instagram.com/elianaslight) We made 178 posts (from 89 posts in FY1) on Instagram.
- **Highlights**. We disseminated 27 of these emailed communications (from the nine we sent in FY1).
- **YouTube**. (<https://www.youtube.com/channel/UCyze46yo2s9fIPrECQb0ceQ/featured>) We now have 10 videos on our YouTube channel, which mostly are of our recorded “Conversations With A Caregiver”.

These outlets provide important updates on news and events to the families and caregivers we serve as well as our supporters.

Shining Stars: Our Volunteers

As a volunteer- and community-based organization, we could not do this work without the help of wonderful members of our community. When kids and their caregivers come together to help other kids and their caregivers, the special moments are indescribable. **In our first year, we actively and intentionally engaged more than 2,300 volunteers (up from 1,300 volunteers in FY1) in meaningful community service initiatives.** We watched young volunteers initiate, learn, and practice compassion, empathy, and kindness. We saw caregivers and children

dealing with complex medical conditions form unique bonds with families from the community.

Wonderful individuals, organizations and companies participated in:

- **Eliana's Light's team in the 2018 Race for Every Child:** We remain so thankful to the dozens of individuals and companies that contribute to Team Eliana's Light for this race. Their donations and organizing efforts raised \$1,000 for integrative care services at Children's National Medical Center in 2018. Please see page 18 for additional information.
- **Our 4th annual Valentine's Day Cards for Kids & Cookies for Caregivers initiative:** Thanks to the involvement of **more than 2,000 volunteers** from six states, we delivered **3,800 hand-made cards (1,000 more than last year) and more than 1,600 cookies (1,000 more than last year)** to each in-patient at Children's National Medical Center, Inova Children's Hospital, John's Hopkins Children's Center, HSC's Pediatric Center, the Kennedy Krieger Institute, the Children's Inn at NIH, and Medstar Georgetown University Hospital (one more medical center than last year) on Valentine's Day 2019.
- **Our 2nd annual "Give A Boost to Moms for Mother's Day" and "Give A Boost to Dads for Father's Day":** Together we delivered more than 1,200 gift bags of self-care items and gift certificates that members of our community donated for parents who needed to stay at one of our seven collaborating medical centers on these holidays in order to care for their hospitalized children.



Constellations of Care: Our Collaborators

Collaboration is a core value for our organization, and is a critical step in building diverse and meaningful *Constellations of Care*. Eliana's Light is grateful to the dozens of local medical facilities, integrative and complementary care service providers, and funders, that are collaborating with us to form our *Constellations of Care* within Washington, DC, Maryland and Virginia. In addition to Children's National Medical Center, described above, we would like to recognize a few of our constellation's other bright stars:

- *Advocates for Justice and Education (AJE)*.
AJE empowers families, youth, and the community to be effective advocates to ensure that children and youth, particularly those who have special needs, receive access to appropriate education and health services. **We co-refer families to each other and promote each other's special initiatives.**
- *Beltway Bambinos*
Beltway Bambinos is a local blog that a local mother started to share information and build community within the Washington, DC area. **Beltway Bambinos has collaborated with Eliana's Light by sharing information on community service opportunities we organize, inviting their thousands of readers to participate.**
- *DC Association for Special Education (DCASE)*
DCASE is an alliance of nonpublic and charter schools that provide special education services to students from the District of Columbia. Members are dedicated to improving educational opportunities for all DC students with disabilities. **Eliana's Light and DCASE collaborate to provide meaningful volunteer opportunities for children with special needs who are students in DCASE's partner schools.**
- *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. **Eliana's Light collaborates with Little Lobbyists by sharing information Little Lobbyists highlights about policy and legislative matters related to health care for children with complex medical conditions.**
- *Lollipop Kids Foundation*
The Lollipop Kids Foundation is a tremendous community-based organization that has been transforming lives for years. They work to combat social stigmas, ease the financial burden placed on families with children who have special needs, support the emotional health of families, and provide assistance so that every child with a disability has access to a hope and a future. **Eliana's Light and Lollipop Kids co-create practical learning events for families, and refer families to each other's organizations for the unique forms of support we each offer.**

- ***Parent Educational Training Center (PEATC)***
 The Parent Educational Training Center (PEATC) builds positive futures for Virginia's children by working collaboratively with families, schools and communities in order to improve opportunities for success in education and community life. Their special focus is children with disabilities. **Eliana's Light and PEATC collaborate on family referrals and learning events.**
- ***Pediatric Medical Centers in Our Region***
 As of early 2019, Eliana's Light is currently collaborating with **Children's National Medical Center, Inova Children's Hospital, the Kennedy Krieger Institute, John's Hopkins Children's Center, HSC's Pediatric Center, Medstar Georgetown University Hospital, and Medstar Washington Hospital Center** on our annual community service activities (i.e., "Valentine's Day Cards for Kids & Cookies for Caregivers", "Give A Boost to Moms for Mother's Day", and "Give A Boost to Dads for Father's Day"). **Staff members of these medical centers also tell parents/guardians of children who have complex medical conditions and receive care there that they can apply for additional support through Eliana's Light. Eliana's Light also collaborates with some of these medical centers in other ways that are explained in various sections of this report.**
- ***The Children's Inn at NIH***
 The Children's Inn at NIH is a "place like home" for children and families participating in groundbreaking research at the National Institutes of Health. Eliana's Light supports The Children's Inn at NIH in its efforts to reduce the burden of illness through therapeutic, educational, and recreational programming. **Eliana's Light regularly provides in-kind donations to children and their caregivers staying at the Inn, such as toys and books that promote relaxation. We also provide gifts for Valentine's Day, Mother's Day and Father's Day to residents.** In the future, we're planning to support programming within The Children's Inn that relates to the integrative care services.
- ***The HSC Health Care System***
 Eliana's Light is grateful for the opportunity to collaborate with The HSC Health Care System, which combines the resources of a health plan, pediatric hospital, home health agency and nonprofit foundation to serve and empower families with complex health care needs. **Eliana's Light and the HSC Health Care System, which includes HSC Home Care, collaborate by co-referring families to each other. Eliana's Light also supported caregivers during a respite session for the first time in March of 2019.** We are planning to co-develop learning events in late 2019; and look forward to building on proven practices, implementing innovative initiatives, and raising awareness of ways to support families with children who have complex medical conditions.

- *The Parents' Place of Maryland (PPMD)*

PPMD helps families of children with disabilities and special health care needs throughout Maryland. They offer learning events, direct support to families, and resources that help families learn about the special education process and parent rights. They collaborate with a number of local educators and professionals who provide special education, early intervention, transition, and related services. **Eliana's Light and PPMD partner by co-referring Maryland families.** We are also exploring opportunities to co-create learning events in support of Maryland families.

MEDIA COVERAGE

Eliana's Light was featured on "The Mother Side", a program of ABC Channel 7, on various time blocks within March of 2019. To view the show, please visit:

<https://wjla.com/features/the-mother-side/magnificent-mom-spotlight-whitney-ortiz-of-elianas-light>.



E = EXCHANGE

We manage and serve on various advisory committees to exchange information and resources with local specialists and caregivers in areas relevant to our mission.

Highlights from Year Two:

- ✓ **We founded and/or contributed to five advisory committees and roundtables** to share learning and best practices.
- ✓ **We distributed 500 copies of Dr. Joanna Breyer's new book, *When Your Child Is Sick: A Guide to Navigating the Practical and Emotional Challenges of Caring for a Child Who Is Very Ill*, as part of a grant we received from the James M. and Cathleen P. Stone Foundation.**
- ✓ **We participated in dozens of meetings** with local parents, researchers, advocates, and practitioners as part of these exchanges in order to learn more about and contribute to various health care approaches for local children and families.

We are committed to inquisitiveness and inclusivity, and believe that sustainable, systemic solutions will only be realized through a healthy exchange of learning and ideas. Continued communication is critical, both within and between groups of caregivers and care providers. We aim to facilitate information sharing and dialogue with all those who care for members of families with children who have complex medical conditions.

We serve on various advisory committees and manage one directly in order to exchange information and resources with local specialists and caregivers in areas relevant to our mission. We also raise awareness within these groups and via others' support groups on whole health and IM-related programming and integrative care services as they pertain to individuals and families.

Whitney Ortiz, the Founder and President of Eliana's Light, participated in the following advisory committees during our second Fiscal Year:

- Clinical & Translational Science Institute of Children's National Medical Center and The George Washington University (CTSI-CN) (member)
- Palliative Care Parent Advisory Committee of Children's National Medical Center (member)

- 2018 Race for Every Child Team (Captain)
- Children with Special Healthcare Needs Advisory Board (member)
- Advisory Committee for Eliana's Light (founder/chair)

MONITORING & EVALUATION

Eliana's Light's adheres to the following guiding principles and values as an organization, which we return to when conducting monitoring & evaluation: *altruism, collaboration, community, empowerment, flexible, grateful, inquisitive, immersed, integrity, participant-centered, personalization, and respect*. We take a high-performance, demand-driven, results-oriented, and business-minded approach to our work. We strive to achieve meaningful and measurable results throughout our collaborative programming. We are consistently learning, and make adjustments to programming and plans as necessary.

To track our progress, we collect the contact information of families who apply for support through our website or attend in-person learning events. Whenever possible, we ask for in-person feedback on the initiative in which they were engaged. We follow up on our learning events with evaluation surveys and in-person conversations.

We highly value and appreciate our relationships with all who are involved in Eliana's Light, regularly asking them for their feedback and input during our in-person conversations, social media exchanges, and emails. We continuously ask relevant stakeholders – including members of our board and advisory committee, staff members of partner organizations, volunteers, donors, and participating parents – for input when we are planning a new initiative. This effort ensures that our programming continues to address specific needs, and is designed in a way that is most helpful to the families we're supporting.

We maintain an open and trusting learning environment with our board and advisory committee. Outcomes from a March 2018 evaluation questionnaire sent to our Advisory Committee showed that members collectively value the connections Eliana's Light makes between care providers and families in support of a family's, and each individual family member's, whole health. In-person evaluation meetings with our Advisory Committee held in February and March of 2019 shared that these same actions are deemed highly important. Family members share during face-to-face meetings and phone conversations that they especially appreciate the personalized approach to care we provide, the quick turn-around, the multiple languages in which we can communicate, and the connections we make to other forms of support when necessary.

During our meetings with various stakeholders, we discuss what is working, what needs to change, our lessons learned, and the return on the investments we made. We transparently share the goals, outputs, outcomes, and impacts of our programming; and are pleased to have obtained a Gold Seal of Transparency from GuideStar within our first Fiscal Year.

REFLECTIONS ON OUR SECOND YEAR

With their permission, we are sharing below some reflections from individuals who have engaged with Eliana's Light in various ways, gathered during our monitoring and evaluation activities. They are mothers of children with complex medical conditions, members of our board and advisory committee, and participants in our community. All of them are connected by the shared desire to relieve suffering, and to make the everyday life experience one of love and comfort. We are so grateful to all who donate, volunteer, and otherwise contribute to our shared vision and mission.

A Parent Whose Family Received Support From Eliana's Light: *"Having two special needs children can be strenuous and financially daunting especially with no family support. Eliana's Light provided many resources and tools to help my family's situation. Our situation has been less stressful since we received assistance from them. We hope one day to pass the favor along and be a blessing in someone else's life the way Eliana's Light was a blessing in ours."*

A Cardiac Intensive Care Unit Nurse Practitioner at Children's National Medical Center. *"Eliana's Light is filling many gaps throughout our health care system. It's also giving a net to families when they go home after discharge. The accompaniment helps them feel they're not going to fall off a cliff."*

A Child Life Specialist at John's Hopkins Children's Center. *"You are doing such wonderful work and we all really appreciate it."*

A Volunteer after She and Her Family Participated in the 2019 Valentine's Day Service Activity and Received Information on the Outcomes from It: *"This is so wonderful to see! The girls are still so full of pride. It really made the holiday special for us. Thank you so much - we so love being a part of your mission!"*

A Donor: *"Thanks for letting us be a part of Eliana's Light. We look forward to doing more with you in the future!"*

LOOKING AHEAD

Within the next three years, we aim to have a turn-key monitoring & evaluation system in place, one that is appropriate for our organization's size and capacity. We also hope to have additional data management capacity within the organization, allowing for better access to qualitative and quantitative data for key stakeholders, grant proposals, and program development. We will maintain our event questionnaires and personalized approach to understanding how Eliana's Light is creating positive impact through our work.

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HOW WE'VE GROWN





FUNDRAISING & DONATIONS

Eliana's Light, Inc. is a tax-exempt 501(c)(3) non-profit organization based in Washington, DC. Our EIN number is: 32-0517020. Gifts are deductible to the full extent allowable under IRS regulations. We are pleased to share Eliana's Light achieved a Gold Seal of Transparency from GuideStar.

We aim to achieve financial sustainability by following a variety of income-generation paths. In our first Fiscal Year, we focused on collecting financial and in-kind donations from individuals and local businesses, selling a product a partner organization made for us, and registering with services online that make donation options easy for people who use a variety of platforms. In our Second Fiscal Year, we placed more emphasis on building lasting relationships with individuals who are interested in partnering with us over the long term in support of our mission. We thus held less fundraising events, and instead invited people to contribute their resources and/or time and/or make in-kind donations to support our community service activities and personalized approach to care.

With the generous contributions of our supporters like you, we raised **\$34,164.86** from individual donations, which included \$5,000 for the specific purpose of distributing Dr. Breyer's book and \$5,000 for the specific purpose of the Healing Touch program.

Below, we list our programs that have designated funding :

HEALING TOUCH

In partnership with a local donor, Eliana's Light served as the financial manager of the Healing Touch program at Children's National Medical Center. Healing Touch is a form of energy medicine. Eliana's Light managed the \$5,000 in funds to pay for the trainer and related expenses. The donor has requested Eliana's Light to continue this role into our third Fiscal Year.

RACE FOR EVERY CHILD

Eliana's Light organized a team for Children's National Medical Center's Race for Every Child in October 2018. As aforementioned, this collaborative effort with members of the community raised more than \$1,000 for integrative care services and related supports for a whole health approach to care at Children's National.

BOOK DISTRIBUTION OF WHEN YOUR CHILD IS SICK

As mentioned previously, Eliana's Light managed the distribution of 500 copies of Dr. Joanna Breyer's book, *When Your Child Is Sick*. Eliana's Light remains grateful to the James M. and Cathleen P. Stone Foundation for their \$5,000 grant, which enabled us to distribute these books by mail and in-person to caregivers (both parents and professionals) across the country. One book was also sent to Uganda by request. We also attended and promoted two events in Washington, DC at which Dr. Breyer spoke about her book ; and shared information about it through our communications channels.

We also worked with individuals eager to organize fundraisers in their community. We enjoy collaborating with community members looking to organize a fundraiser at their homes or in their community. Examples of fundraisers that individual supporters have organized for Eliana's Light include: paint nights, lemonade stands, clothing and book drives, and birthday parties that donate in the name of the birthday girl/boy.

DONATIONS FROM INDIVIDUALS AND BUSINESSES

Financial donations support tailored *Eliana's Light Constellation Kits* for families and programming related to integrative care services for children with complex medical conditions and their caregivers. All gifts are tax-deductible. We work with our donors as partners, and welcome their collaboration.

There are a number of ways that individuals and businesses can support our organization:

- **Donate by check:** Make checks payable to "Eliana's Light" and mail them to: Eliana's Light, 5347 28th Street, NW, Washington, DC 20015.
- **Donate online** Individuals can make donations through our new Neon online system: <https://elianaslight.z2systems.com/np/clients/elianaslight/donation.jsp?campaign=2&>
- **Give through PayPal's Giving Fund:** Eliana's Light is a verified charity within PayPal's Giving Fund (Merchant ID NLHPS9F9S7M5S.) When using this platform for giving, PayPal covers all fees. Contributors will receive a PayPal Giving tax receipt by email: <https://www.paypal.com/us/fundraiser/charity/2718705>.
- **Select Eliana's Light on Amazon Smile:** Amazon has approved our request to be listed as a registered charity with Amazon Smile. Shoppers can select Eliana's Light as their preferred charity by going to <https://smile.amazon.com/> and shopping directly from this address. A portion of their purchase will benefit our non-profit.
- **Support Eliana's Light when using Evite:** When designing an email invitation at www.evite.com, users can click on the "Add Donations" button and write "Eliana's

Light" in the corresponding box. They can then ask their invited guests to give a donation to Eliana's Light in addition to or in lieu of a gift.

- **Select "Eliana's Light" when on Humble:** Individuals can select Eliana's Light to receive a portion of the cost of their purchase from the list of charities on Humble. Humble gives a share to charity from everything they sell, from bundles to Store games to their Humble Monthly subscription: <https://www.humblebundle.com/>.
- **Ask employers to match individual donations:** A donation can have double its impact if an employer matches gifts to non-profit organizations. We ask individuals to please email us if they'd like to discuss a matching donation.
- **Allocate giving to Eliana's Light in Donor-Advised Fund(s):** We are grateful when individuals decide to support Eliana's Light through their donor-advised fund(s). We ask individuals to please email us if they'd like to discuss this option. DAF Direct can make this designation easy: <http://bit.ly/2FOZLFR>.

In addition, we encourage businesses to:

- **Give through Pledgeling:** Pledgeling connects brands and consumers to their favorite causes around the world. Companies can contribute through Pledgeling's Impact Giving Toolkit. At least 90 percent of the donation amount tends to go directly to participating non-profits, including Eliana's Light: <https://www.pledgeling.com/organizations/32-0517020/elianas-light>
- **Support Eliana's Light on Ebay:** Eliana's Light is a recognized charity on @eBay4CharityUs. When sellers make a sale on eBay, they can choose to contribute a portion of their sales to Eliana's Light: <https://givingworks.ebay.com/charity/Eliana's-Light/2718705>

IN-KIND DONATIONS

Parents with children who have complex medical conditions, Child Life Specialists, and therapists carefully helped us select the items that are on our Amazon Wish List. These items are given as in-kind donations to create *Eliana's Light Constellation Kits*. There are options for children of various ages and capabilities, and also for their caregivers. Our Amazon Wish List can be accessed at: https://www.amazon.com/gp/registry/wishlist/34MIV25ZGRIOV/ref=nav_wishlist_lists_1. We received in-kind product, clothes, and book donations with a total value of at least **\$3,000**.

Beyond the gifts we received from our Amazon Wish List, we also received a great deal of in-kind professional support, including dedicated time and the use of space at local businesses for learning events. We are tremendously grateful to the following companies and organizations that provided support to Eliana's Light during our second Fiscal Year:

- **All the participating medical centers:** Collaborated on disseminating Valentine's Day cards, as well as cookies and gifts on Mother's and Fathers Day. Also informed caregivers of the services we provide to local families.
- **Barnes & Noble in Arlington:** Donated space for Eliana's Light to wrap gifts over the holidays and receive donations.
- **Beltway Bambinos:** Promoted our 2018-2019 community service activities.
- **Bloom OB/GYN and Stork:** Organized Valentine's Day card-making event and contributed gift cards for Mother's Day and Father's Day.
- **Building Blocks Therapy:** Made in-kind and financial donations to support families.
- **Cole Tax Services:** Donated accounting services.
- **Fit4Mom of Montgomery County:** Donated time to organize their members for participation in our community service activities.
- **Gabrielle Marchand with Georgetown University's Social Impact Communications Program:** Donated communications support.
- **Jill Shalett Bookkeeping:** Donated bookkeeping support.
- **Joanne Killeen, Independent Consultant:** Donated time and expertise to help with end-of-year campaign.
- **The Nanny Network:** Organized members to participate in Valentine's Day card-making event and organized gift card drive for Mother's and Father's Days.
- **Wellness by Shari:** Donated expertise in Healing Touch other modalities.

We are also so grateful for the time our Advisory Committee members give us. Their expertise and experience have helped tremendously in the development of Eliana's Light. They are leaders in their field and outstanding individuals. For the complete list, please visit: <https://www.elianaslight.org/whoweare>.

The volunteer members of our community who collaborate with us to share their professional expertise and/or give family members a boost during Valentine's Day, Mother's Day, and Father's Day are true stars in families' *Constellations of Care*. Taking into account the volunteer hours of our professional volunteers (generalized at eight hours per volunteer), and the 2,300 volunteers who worked with us on our community service projects (generalized at four hours per volunteer), volunteers donated more than **9,500 hours of work** in our second Fiscal Year, valued at **\$235,048** (with \$24.69 as the recognized hourly value of volunteer time, as according to the Independent Sector: <https://independentsector.org/news-post/the-new-value-of-volunteer-time/>). This calculation does not take into account the dozens of staff members at participating medical centers who distributed cards, cookies, and gift bags to patients and their caregivers.

YEAR TWO EXPENDITURES

Our operational costs for the second Fiscal Year fell into the following categories:

Item	Cost
Business/Non-profit registration fees	\$290.00
Gifts for caregivers, kids and/or families (including supplies for Valentine's Day, Mother's Day and Father's Day events)	\$10,117.25
Dr. Breyer's Book Distribution	\$4,422.97
Consultant and professional fees	\$1,350.00
Healing Touch Program	\$4,633.15
Supplies for events	\$1,321.43
Administrative supplies (ink toner, paper, water and snacks for events, business cards, other event supplies, etc.)	\$246.44
Travel to meetings	\$178.55
Printing & copying	\$645.10
Website	\$333.46
Advertising to potential applicants and for events (e.g. flyers with information on how to apply, which we give to staff at participating medical centers to give to caregivers)	\$825.25
Fundraising fees (including coffee to partners)	\$8.32
TOTAL EXPENSES	\$24,371.92
NET INCOME	\$9,792.94

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WHERE WE'RE HEADED





YEAR THREE GOALS

We invite your engagement and collaboration in 2019 and 2020 as we continue to **C.A.R.E.** for families in our community. Your partnership helps ensure our programming is demand-driven and meeting specific needs in a holistic way that involves our community through *Constellations of Care*. The families we support are under tremendous financial, mental, physical, and emotional stress every day. We hope you'll join us to shine bright lights into otherwise dark moments by showing that, together, we **C.A.R.E.**:

CONNECT

- **We will directly connect with at least 15 more families that apply**, providing them with tailored gift packages and sharing resources and information to support them.
- **We will participate in at least 5 learning events organized by partner organizations** in order to reach more families and demonstrate how our organizations collaborate to create *Constellations of Care*.

ADVOCATE

- **We will create a robust, systematized data collection and evaluation process** that will enable us to share outcomes and impacts for more effective advocacy.
- **We will continue to participate on and lead advisory committees** where we can contribute to our shared mission and objectives.
- **We will explore ways to incorporate mindfulness and wellness programming** into existing therapy sessions, in collaboration with local therapists.
- **We will continue to collaborate with staff members at local pediatric medical facilities** who are interested in creating whole health approaches for families with children who have complex medical conditions.

REACH

- **We will engage at least 30 additional collaborators** interested in joining our *Constellations of Care*, working synergistically to build an evidence base of effective integrative care approaches.
- **We will lead at least five learning events** to promote acceptance and understanding of integrative care services for children with complex medical conditions and their caregivers.
- **We will amplify the messages of existing knowledge shares and create new knowledge shares** with parents of children who have complex medical conditions.

- **We will build our communications capacity** to effectively share the stories of the families we're supporting and the urgent need to care for them in a collaborative, community-based way.

EXCHANGE

- **We will continue our participation in at least three advisory committees** in order to enhance our understanding of integrative care services and holistic health care approaches that facilitate, support and promote whole health.
- **We will remain in regular communication with a diverse range of stakeholders in our region** who are interested in supporting the whole health of families with children who have complex medical conditions.
- **We will collaborate with like-minded organizations around health care policy and programming** that has local, regional, and national impact.

HOW YOU CAN HELP

DONATE!

Financial and in-kind donations help us create *Eliana's Light Constellation Kits* tailored for families in need and support programming related to integrative care services for children with complex medical conditions and their caregivers. All gifts are tax-deductible. As a volunteer-based organization, zero percent of donations go towards salaries and benefits. Every amount can make a positive difference.

- **For \$10,000**, you can co-create new programming with us related to a specific aspect of whole health for families with children who have complex medical conditions.
- **For \$5,000**, you can sponsor an aspect of our **C.A.R.E.** framework.
- **For \$3,000**, you can support three families over at least three months each.
- **For \$1,000**, you can meet the immediate needs of two local families.
- **For \$500**, you can meet the immediate needs of one local family.
- **For financial contributions of less than \$500**, you can contribute to our support for a local family by enabling us to purchase relevant items for tailored *Eliana's Light Constellation Kits* and also develop relevant tip sheets and learning events.

Interested in donating? We are grateful for your generosity and invite you to contact us anytime at info@elianaslight.org. We have also assembled some suggestions for ways you can help. Please see the *Fundraising & Donations* section of this report for a comprehensive list of the ways you can donate. Every dollar counts!

- **Contribute to our *Eliana's Light Constellation Kits*** by making an in-kind donation from our [Amazon Wish List](#).
- **Host a fundraising event** for financial or in-kind donations.
- **Choose "Eliana's Light Inc." as your preferred charity** on Amazon Smile (<https://smile.amazon.com/>) and when you sell on Ebay through Ebay's @eBay4CharityUs program (<https://givingworks.ebay.com/charity/Eliana's-Light/2718705>).
- **Invite guests to donate** to Eliana's Light when you create an invitation on www.evite.com. Just select "Eliana's Light" as the charity you're supporting.
- **Talk to your employer** about providing company matched gifts.
- **Include Eliana's Light** in your planned giving and estate planning.
- **Join our monthly giving program.** Please email us your interest (info@elianaslight.org).

VOLUNTEER!

Eliana's Light is a community-based, volunteer-run organization – we couldn't do this without the support of our wonderful collaborators and volunteers! There are many ways you can help us in achieving our goals throughout our next Fiscal Year:

- **Contribute your professional expertise** to help with the development and execution of our operations and systems.
- **Organize friends, family members, and colleagues** to participate in our gift-making events for Valentine's Day, Mother's Day and Father's Day.
- **Help with planning and/or staffing** our fundraisers and learning events.
- **Research and share resources** that may be helpful to local families with children who have complex medical conditions.
- **Introduce us to medical, complementary, and/or integrative care specialists** who may be interested in joining our Constellations of Care.

SHARE YOUR RESOURCES!

At our heart, we are an organization dedicated to building and fostering connections. We love learning from others and welcome opportunities for collaboration. From recommendations for holistic health providers to ideas for a partnership or initiative, we welcome your feedback and input! Email us at info@elianaslight.org anytime. Stumped on what to share? We have found the following gestures to be enormously helpful:

- **Introduce us to potential donors and grant-making foundations** in line with our mission.
- **Send us your publications, articles, and other resources** you believe might be helpful for families and/or caregivers of children with complex medical conditions.

- **Share your unused gift cards** for restaurants, stores, or services. We can include them in *Eliana's Light Constellation Kits* or use them to purchase relevant items for families.
- **Contribute your gently used children's books and clothes.** Please email us at info@elianaslight.org for details.
- **Offer the free use of your company's space** for learning events and meetings.
- **Invite us to present at your workplace and/or support group** to raise awareness on the work we're doing.

CONNECT WITH US!

We hope you will join us as we continue to grow. Stay up-to-date on our latest goings-on through our website, newsletter and social media accounts:

- **Stop by our website** for information on upcoming events:
<https://www.elianaslight.org/new-events/>
- **Sign up to receive *Highlights***, our email newsletter:
<https://www.elianaslight.org/newsletter/>
- **Subscribe to our YouTube Channel** and check out our online learning series *Conversations with a Caregiver*:
<https://www.youtube.com/channel/UCyze46yo2s9fIPrECQb0ceQ>
- **Follow and like us** on social media:
 - Facebook: www.Facebook.com/elianaslight
 - Twitter: www.Twitter.com/elianaslight
 - Instagram: www.Instagram.com/elianaslight

IN LOVING MEMORY

Eliana's Light holds in loving memory sweet Diego, Javier, Rocio, and Sandra, all children we were directly supporting and who passed away this year. We are grateful to have known them. They will always be in our hearts, and their brilliant lights will always shine.

We also hold dear in our hearts Margarita Roque who passed away in January 2019. Margarita most recently was a chaplain at Children's National. She was a dear friend throughout the time Eliana was in the hospital, and she spoke at Eliana's funeral. Since we started Eliana's Light, Margarita connected many Spanish-speaking families with us. We are forever grateful to her for all she did for us and other families. We miss her greatly, and reflect on her often while supporting some of the most vulnerable families in our region. She showed us how important it is to accompany others in their life journey with compassionate care.

6

ANNEXES



A. KEY DEFINITIONS

Whole Health: When we say we focus on an individual's and family's "whole health", we mean that we recognize each person's physical, mental, emotional, spiritual, and financial health; the well-being of the family unit; and the community in which a family lives.



Total Health: We ascribe to the World Health Organization's definition of total health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity."¹

Integrative Health: Similar to total health, this means "a state of wellbeing that reflects aspects of the individual, community, and population. It is affected by 1) individual biological factors and behaviors, social values, and public policy, 2) the physical, social, and economic environment, and 3) an integrative healthcare system that involves the active participation of the individual in the healthcare team in applying a broad spectrum of preventative and therapeutic approaches. Integrative health encourages individuals, social groups, and communities to develop ways of living that promote meaning, resilience and well-being across the life course."²

Integrative Medicine: This term refers to "an approach to care that focuses on the whole person. Health practitioners employ a personalized strategy that considers the patient's unique conditions, needs and circumstances to treat illness and help regain and maintain optimal health and vitality."³ Note that when a child is in-patient within a medical facility and receives IM or has access to an IM program, this is usually part of a medical care program and approach.

Integrative Care: This is used to denote "personalized, participatory, and relationship-based care, promoting optimal health. It emphasizes healing of the whole person to achieve each individual's unique physical, emotional, mental, spiritual, and social health goals. The primary therapies used to achieve these goals are healthy habits (nutrition, activity, sleep, mindful self-care, and fellowship) in a healthy habitat (social, natural, and built environment). Integrative

¹ Preamble to the Constitution of WHO as adopted by the International Health Conference, New York, 19 June-22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of WHO, no. 2, p. 100) and entered into force on 7 April 1948: <http://www.who.int/about/mission/en/>

² Witt, Claudia M. et al. (2017). Defining Health in a Comprehensive Context: A New Definition of Integrative Health. *American Journal of Preventive Medicine*, Volume 53, Issue 1, 134-137: <https://tiih.org/whats-integrative-health/>

³ Duke Integrative Medicine: <https://www.dukeintegrativemedicine.org/about/what-is-integrative-medicine/>

health care skillfully uses the best of both conventional and complementary strategies to attain patients' health goals.”⁴

Integrative Care Services: This term refers to approaches, techniques, tools, and therapies that have been shown to reduce stress, pain, fear, trauma, anxiety, and/or depression in both children and adults. These complementary care approaches, techniques, tools, and therapies can be used alongside necessary medications and medical procedures. Examples include acupuncture; aromatherapy; essential oils; Healing Touch; massage; meditation; Mindfulness-Based Stress Reduction (MBSR); music, art, and play therapy; Reiki, and other related healing modalities. They may also include mental health support, marriage counseling, and other types of support required by an individual or family as part a total health approach to achieving wellness and wellbeing.

We advise that caregivers collaborate closely and communicate often with their child(ren)'s medical doctor(s) in order for an appropriate and continuous total health and integrative care services program to be designed for the child. We recommend that the adult caregiver also discuss the caregiver's health and wellbeing with her/his own doctor; and seek integrative and complementary care specialists as necessary to develop a care plan that boosts the caregiver's strength, immune system, and wellbeing. Integrative and complementary care specialists should be licensed and certified as appropriate within their professions.

*We invite you to browse through the **Resources Page** of our website for more information on these topics at www.elianaslight.org/resources.*

⁴ Mind-Body Skills Training for Resilience, Effectiveness, and Mindfulness. Hosted by the Ohio State University College of Medicine: <https://mind-bodyhealth.osu.edu/>

B. OUR CONSTELLATION OF CARE: ELIANA'S LIGHT'S BOARD & ADVISORY COMMITTEE

BOARD OF DIRECTORS

Natalia Isaza Brando, MD

Neonatology Attending Physician, Children's National Medical Center (CNMC)

Natalia originates from Colombia and is a mother of two. As a neonatologist in the Neonatal Intensive Care Unit (NICU) at CNMC, Natalia works on a daily basis with families from around the world. She has conducted research on how skin-to-skin contact (i.e. "Kangaroo Care") between mothers and their infants can reduce the mothers' stress levels. She completed her residencies at Universidad CES in Colombia and the Albert Einstein Medical Center in the U.S., and her fellowship at CNMC in Washington, DC. Natalia is fluent in Spanish and English, and is certified with the American Board of Pediatrics.

Megan Anne Dennis

Early Childhood Development Expert; Mother of Child with Complex Medical Condition

Megan Dennis has a Bachelor's degree in Early Childhood Education and Master's Degree in Special Education. She taught elementary school to varying populations in the Washington, DC area for nine years before leaving the education field to care for her twin boys, James and Leo. Megan's son Leo had multiple complex health needs and spent much of his short, but beautiful, life at Children's National Medical Center. Megan is honored to work with Eliana's Light to assist families dealing with life threatening illnesses by sharing her personal experiences and offering support.

Rhiannon Landesberg

Founder of BreathEd

Rhiannon is a child, family and adult yoga and meditation instructor with a passion for sharing the benefits of mindfulness practices with people of all ages. Rhiannon has worked as a yoga and mindfulness teacher in public, charter and private schools, implementing programs that emphasize stress reduction and wellbeing. She has also partnered with a number of studios and community organizations in Washington, DC to share the benefits of wellness practices. Rhiannon's life was deeply touched by Eliana's Light and she is thrilled to be a part of this initiative, which she believes will help so many children and families. Please note that Rhiannon moved to California, and will serve as an Advisory Committee member into FY3.

Celinha Martins

Physical Therapist and Founder of Vida Therapy

The twelfth of fourteen children from a rural community in Brazil, Celinha knows well the challenges of living and working in a new community, language, and culture. Despite the

absence of electricity, telephone, or gas, her family had love. Celinha believes in the power of love, caring, and positive thinking. She put herself through physical therapy (PT) school and now runs her own PT business, often working with families through Washington, DC's Early Intervention program. She is enthusiastic about taking a holistic and evidence-based approach towards helping children with complex medical conditions achieve their physical goals. An important part of Celinha's work is motivating and providing hope to both the pediatric patient and his/her caregiver(s). Celinha is fluent in Portuguese, Spanish, and English. Please note that Celinha is starting another business, and thus will serve as an Advisory Committee member in FY3.

Melissa Nussbaum

Principal, The Nussbaum Group

Melissa Nussbaum is the Principal of The Nussbaum Group. With over 15 years of experience building and managing international fundraising teams, Melissa is uniquely qualified to partner with organizations and talented leaders to successfully maximize revenue and build fundraising capacity across your organization. Melissa has held senior-level roles in several organizations in the non-profit and private sectors. Her deep level of expertise in fundraising, philanthropy, economic development, social justice, and Information and Communications Technology (ICT) for development offers insights to help organizations build strategic funding plans, enabling them to achieve mission success.

Whitney Ortiz

Founder of Eliana's Light; Mother of Child with Complex Medical Condition

Whitney Ortiz is the mother of twin daughters, Emilia and Eliana. Eliana passed away from a heart condition in March 2016. In Eliana's loving memory, Whitney created Eliana's Light in collaboration with individuals and organizations dedicated to helping children with complex medical conditions and their caregivers. Through a Policy, Systems and Environment (PSE) approach, Whitney hopes to help families at the hospital and in their homes in a way that is demand-driven and evidence-based. Whitney brings to Eliana's Light twenty years of work experience in U.S. government, non-profit and business sectors, and international organizations. She has an MA in international development from The Fletcher School of Law & Diplomacy, and is fluent in Spanish. Whitney currently serves on various advisory committees within Children's National Medical Center and the Washington, DC community related to children's health. Whitney's mission is to reduce the stress, pain, fear, anxiety, trauma and depression that many children with complex medical conditions and their caregivers often experience by supporting a whole health approach to improving their wellness and wellbeing.

ADVISORY COMMITTEE

Dr. Elva Anderson

PhD, Registered Art Therapist (ATR), Children's National Medical Center; Licensed Professional Counselor (LPC), Certified Nutritional Consultant (CNC), Licensed Reflexologist, Licensed Aromatherapist, Certified Mindfulness Teacher, Laughter Yoga Teacher, and Level III Healing Touch Practitioner

Ms. Caryn Anthony

Principal, CLA Consulting and Coaching: Organizational development consultant and certified executive coach, specializing in nonprofit organizations. Author of "Any Way the Wind Blows", a blog geared for families with a child managing a significant medical condition.

Ms. Donna Anthony

Executive Vice President, Clinical Strategy, The HSC Health Care System; Leads HSC Pediatric Center, Medical Programs & Therapy and HSC Home Care

Dr. Elizabeth Bettini

PhD, Advanced Practice Registered Nurse (APRN), Psychiatric Clinical Nurse Specialist (PCNS-BC), Certified Hospice and Palliative Care Nurse (CHPCN), PANDA Palliative Care, Children's National Medical Center; Certified Level V Healing Touch Practitioner

Ms. Erin Gris

MS in Childhood Development, Certified Child Life Specialist (CCLS), Cardiac Intensive Care Unit, Children's National Medical Center; Certified in Therapeutic Touch and Pediatric Hypnosis

Ms. Josephine Bias Robinson

Executive Vice President, External Affairs, The HSC Health Care System; Leads external affairs and strategies for each of The HSC Health Care System business entities, and serves as the staff lead for the HSC Foundation

Ms. Lauren Muser Cates

Founder, Executive Director and Board Chair, HealWell; Licensed Massage Therapist; Provides and supervises massage for medically complicated, oncology and end of life patients at numerous hospitals; Speaker on a variety of topics related to integrative medicine, emotional self-care for practitioners and the mechanics and politics of introducing massage therapy into clinical settings

Ms. Katie Conway

Masters of Science in Nursing (MSN), Bachelor in Science in Nursing (BSN), Registered Nurse (RN), Certified Pediatric Nurse (CPN), Shift Coordinator, Heart & Kidney Unit, Children's National Medical Center

Dr. Karen Fratantoni

MD, Masters in Public Health (MPH), Medical Director of Complex Care Program, Children's National Medical Center

Dr. Vicki Freedenberg

PhD, Registered Nurse (RN), MSN, Electrophysiology Nurse Scientist, Conway Nursing Research Scholar, Children's National Health System; Assistant Professor of Pediatrics, The George Washington University

Ms. Ashleigh Harlow

BSN, RN, Critical Care Registered Nurse (CCRN), Clinical Instructor, Co-Chair of Nursing Advocacy Council, Cardiac Intensive Care Unit, Level II Healing Touch Practitioner, Children's National Medical Center

Ms. Melissa Jones

MSN, APRN, Certified Pediatric Nurse Practitioner in Acute Care (CPNP-AC), Nurse Practitioner Team Lead for Critical Care, Ventricular Assist Device (VAD) Coordinator, Cardiac Intensive Care Unit, Children's National Medical Center

Dr. Maria Luz Lara-Marquez

MD, PhD, Senior Researcher, Division of Allergy and Immunology, University of California in San Diego (UCSD), Integrative Medicine Specialist

Ms. Marian McEvelly

RN, CPN, Certified Coding Associate (CCA), Anesthesia, Children's National Medical Center; Level V Healing Touch Practitioner, Certified Aromatherapist, Certified Horse Therapist, Reiki Master

Dr. Asha Nair

MD, Cardiologist, Boston Children's Hospital; Instructor of Pediatrics, Harvard Medical School

Ms. Candice Peggs

Licensed Certified Social Worker-Clinical (LCSW-C), Licensed Certified Social Worker (LCSW), Licensed Therapist for Individuals, Groups, and Families; Meditation Practitioner; Registered Yoga Teacher

Ms. Judy Ross

Child Life Specialist, Children's National Medical Center; Certified Infant Massage Therapist

Ms. Pleasance Silicki

Founder, Lil Omm; Yoga, Wellness, and Mindfulness Coach

Ms. Terry Spearman

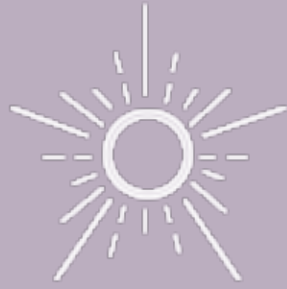
Interim Director, Child Life & Integrative Care Services, Children's National Medical Center

Dr. David Steinhorn

MD, Professor of Pediatrics; Medical Director, PANDA Palliative Care Program, Division of Critical Care, Children's National Medical Center

Dr. Lillian Su

MD, Pediatric Critical Care Intensivist, Lucile Packard Children's Hospital



Eliana's Light

Fiscal Year 2

Second Annual Report

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