

Eliana's Light



First Annual Report

Fiscal Year One

January 17, 2017 – March 31, 2018

@elianaslight

* 5347 28th Street, NW * Washington, DC 20015 * 703-899-6129 * www.elianaslight.org *

*www.Facebook.com/elianaslight * www.Twitter.com/elianaslight * www.Instagram.com/elianaslight *

TABLE OF CONTENTS

TABLE OF CONTENTS 1

INTRODUCTION 2

 Letter from Our Founder 2

 Message From Our Board..... 4

 Eliana’s Story 5

WHO WE ARE 6

 Our Mission 7

 Our Purpose: Why Whole Health & Wellbeing 7

 Our Vision 8

 Our Values 8

 Our Value Proposition 8

 Our Approach 9

WHAT WE’VE ACCOMPLISHED 10

 Our Programming: How We C.A.R.E..... 11

 Monitoring & Evaluation 23

HOW WE’VE GROWN 25

 Fundraising & Donations 26

 Year One Expenditures 30

WHERE WE’RE HEADED 31

 Year Two Goals 32

 How You Can Help 33

ANNEXES..... 37

 A. Key Definitions 38

 B. Events From Our First Year..... 40

 C. Our Constellation of Care: Eliana’s Light’s Board & Advisory Committee..... 47

1

INTRODUCTION





LETTER FROM OUR FOUNDER

Dear Collaborators,

We are pleased to share with you our first annual report! The contents of this report span from when Eliana's Light was officially recognized as a 501 (c) (3) tax-exempt non-profit organization on January 17, 2017 through the end of our first Fiscal Year (FY), March 31, 2017. Our inaugural year focused on activities meant to form a strong foundation for the future: building partnerships, learning about existing resources and expertise in our community, creating strong internal systems, planning for sustainability and impact, launching learning events, and starting to serve families directly.

Eliana's Light is named in loving memory of Eliana Ortiz, one of my twin daughters who passed away at three years old from a heart condition after having spent the majority of her life in the hospital. With another child at home, a marriage and health insurance to maintain, and basic needs to meet, our family knows intimately the emotional, physical, mental, and financial stress that many families with children who have complex medical conditions often endure. We have since conducted significant research and spoken with dozens of families, medical staff, and complementary and integrative care specialists, seeking to better understand the needs and interests we had seen expressed by a range of these caregivers over the years.

We wanted to help these families through indescribably difficult times with a unique approach, one that builds upon and contributes to existing services. We listened and learned about how a new non-profit could help fill existing gaps in person- and family-centered care while promoting improved quality of life through a focus on whole health and wellbeing. We discussed and contemplated how we could work with stakeholders across the spectrum to build a replicable and scalable service model, one that creates *Constellations of Care* to support families and caregivers.

In our first Fiscal Year, **we grew from working with one local children's hospital and families living in Washington, DC to collaborating with six medical centers** that support these children and families that live in Washington, DC, Maryland, and Virginia.

Through the support of our funders, collaborators and volunteers, we:

- **Donated more than \$10,000 to Children's National Medical Center** to support the development of an Integrative Medicine and integrative care services division;
- **Posted 300 resources** on our website;
- **Participated in more than 50 knowledge exchange and advocacy meetings** to support whole health approaches to pediatric medical care;
- **Initiated collaborations with 43 organizations and businesses** to enhance our reach and impact;

- **Organized 17 in-person and online learning events** to disseminate information and build awareness;
- **Engaged 1,300 volunteers** in contributing to our work and growth;
- **Gave more than 2,600 hand-made cards and 600 cookies to all pediatric patients and their caregivers** at six local medical centers on Valentine's Day 2017 and 2018;
- **Delivered 250 lavender sachets to moms and 250 stress balls to dads** at the Children's National Medical Center on Mother's Day 2017 and Father's Day 2017, respectively;
- **Visited seven families** that applied for support, providing each with a tailored gift bag, guidance on additional services and resources, and support in reducing their financial, emotional, mental, and physical stress; and
- **Founded/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**, 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 first 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; **reaching children and caregivers** through our tailored gift packages and learning events that address the impact of stress on and need to improve the quality of life of these families; 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 relish opportunities to learn from others, and invite input and feedback on our work and ideas. We want to ensure we are affecting positive change and have the flexibility to adapt as needed. Our support to families and our collaborations with organizations are always tailored to their unique needs and interests.

We invite you to read through each section of the report, and welcome your feedback and ideas for our future. We hope you will join us during our next Fiscal Year to support local families with children who have complex medical conditions. We're so grateful 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 aim to relieve caregivers' feelings of helplessness, which often accompany significant stress and exhaustion. We want caregivers to feel more empowered, balanced, and peaceful so they can most effectively accomplish all they need to while caring for their children. While we can't take away all of the challenges, we want to make the whole family's life experience easier.

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

2

WHO WE ARE





OUR MISSION

Eliana's Light improves the quality of life of families with children who have complex medical conditions by focusing on their whole health and wellbeing. We are supporters of integrative and integrated care who empower families while reducing the stress, pain, fear, trauma, anxiety, and depression that many of these family members often experience. We connect families to resources, information, specialists and tools while we advocate for Integrative Medicine and integrative care services. Throughout our programming, we raise awareness on holistic ways to address physical, mental, and emotional health.

OUR PURPOSE: WHY WHOLE HEALTH & WELLBEING

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.**

OUR VISION

We envision a local health and wellness system that supports and empowers families and caregivers of children with complex medical conditions, improving the health, wellbeing, and quality of life for each family member. We seek to build *Constellations of Care*—communities of committed specialists, organizations, companies, and individuals—to address families' physical, mental, emotional, and financial needs through referrals, advocacy, information exchange, and access to integrative and complementary care services. We aim to create a scalable and sustainable model of integrative care that can be replicated in major cities with high-quality children's hospitals, in which hospitals form learning networks to share evaluation-based insights, lessons learned, and promising practices in Integrative Medicine.

OUR VALUES

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

OUR VALUE PROPOSITION

Eliana's Light recognizes the need to focus on the body, mind, and spirit in order to improve health, wellness, and wellbeing. We accomplish this by building *Constellations of Care*: networks of committed specialists, organizations, companies, and individuals working together to support the unique needs of families of children with complex medical conditions. Families will be better positioned to access appropriate support to reduce the significant stress, pain, fear, trauma, anxiety, and depression that many family members often experience. **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 takes a Policy, Systems and Environment (PSE) approach to our work. This approach to health programming recognizes the many social and cultural systems that work together to shape our experience – from the communities we live in to the health systems we utilize.¹ In using this framework, we take into account the full reality in which families of children with complex medical conditions live, work, attend school, and receive medical attention. We appreciate that there are policies (within government and institutions), systems (within institutions, families, and communities), and environmental factors (within institutions and communities) that work together to affect a family's whole health and wellbeing.

PSE promotes long-term, collaborative interventions that address these varied influences. It emphasizes the need to build on the cultural and social assets of a community to create sustainable solutions, prioritizing community engagement and empowerment as well as strategic public-private partnerships. By fostering collaborations and building on existing resources, interventions addressing policy, systems and environmental barriers will be better positioned to have a lasting impact.

Recognizing the many influences on families and children dealing with complex medical conditions, Eliana's Light works to affect change at multiple levels. Our activities follow a structure we have come to call **C.A.R.E.**:

- **C= Connect:** We connect families to resources and information that can help reduce their physical, mental, emotional, spiritual, and/or financial stress. We also connect *with* them, building trusting, compassionate relationships through our shared humanity.
- **A= Advocate:** We advocate for Integrative Medicine (IM) and integrative care services within pediatric medical facilities and as part of standard medical care, therapy programming and research initiatives.
- **R=Reach:** We expand our reach through strategic collaborations, a growing network of volunteers, and ambitious communication and community outreach.
- **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 first year!

¹ The Comprehensive Cancer Control National Partnership & The American Cancer Society. (2016). The Policy, Systems and Environmental Change (PSE) Resource Guide. Available at: <https://www.cccnationalpartners.org/new-resource-policy-systems-and-environmental-change-resource-guide>

3

WHAT WE'VE ACCOMPLISHED





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

As Eliana's Light evolved during its first Fiscal Year, we packaged our work into the C.A.R.E. framework: *Connect, Advocate, Reach, Engage*.

C = CONNECT

We connect families to resources, specialists, other organizations, and information that can help reduce their physical, mental, emotional, spiritual, and/or financial stress. We also connect with them, building trusting, compassionate relationships through our shared humanity while we develop a new community.

Highlights from Year One:

- ✓ **We visited seven families that applied for support**, 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 300 resources** on our website, including 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, 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. 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 meal services, and distraction toys to help children during difficult medical procedures. We accept applications in English, Spanish, and Portuguese at any time. We will begin accepting applications in Arabic, Amharic, and French in the coming months.

Our board reviews each family's application, and we contact families within a week. 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; we instead help *connect* caregivers to relevant experts that form *Constellations of Care* within our communities. **In our first year, we worked with seven families of children with complex medical conditions that applied to our organization for support.**

Once a family contacts Eliana's Light for support, we stay with a family in friendship 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 continue to check in with them by phone, providing counseling, coaching and resource referrals as appropriate. We offer connection and comfort that lets 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 wellbeing that comes from complementing one's medical care with other appropriate and safe healing approaches and services.

Each of the seven 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 complex medical condition, received a tailored Eliana's Light Constellation Kit in our first Fiscal Year

- Yoga mat and tip sheet on mindfulness meditation
- Distraction toys for children
- Age-appropriate children's books
- 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
- Gift certificates to supermarkets, complementary care providers, and/or meal delivery services
- Discounts to attend local wellness and fitness classes
- 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 families to resources on our website. **During the past year, we added more than 300 entries to the *Resources* section of our website.** These free resources provide critical information for anyone interested in tending to the whole health of families and children with complex medical conditions, from parents, to members of the medical community, to providers of integrative care services. 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, 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.

Connecting with a local family: Sandra's Story

Sandra is a beautiful young girl with whom many feel an immediate connection. She has Epilepsy and cannot sit or roll on her own. A gastronomy tube (G-tube) helps to provide her nutrition. Sandra faces 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.

Whitney emailed the father to arrange a time to meet in person. Sandra had recently been admitted to the hospital, so Whitney visited her hospital room. Whitney brought the family an *Eliana's Light Constellation Kit* containing a gift certificate for a stroller that would fit their growing child and her medical equipment; a gift certificate for a cleaning service so Sandra's parents wouldn't have to use their limited time to get their apartment to the high level of

cleanliness Sandra needed to protect her health when she went home; a stuffed animal and donated books for Sandra to enjoy; and assorted stress-relief gifts for Sandra's parents. Whitney spoke with the parents about their concerns, and offered guidance in finding additional support to help with the family's basic needs. She also helped them complete an application for rent assistance through a local organization.

Since then, Whitney visited the family twice in the hospital and once at their home. She continues to check in regularly via text message, and has shared some calming breathing exercises for the caregivers to complement their regular prayers. The family also uses calming music and dims the lights to help Sandra relax during traumatic moments. The family has expressed gratitude for the personalized and practical care and attention from Eliana's Light. Sandra's mother 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.*



A = ADVOCATE

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

Highlights from Year One:

- ✓ **We raised more than \$10,000 in individual donations for Children's National Medical Center** to support the development of an Integrative medicine and integrative care services division.
- ✓ **We participated in more than 50 knowledge exchanges and advocacy meetings** to support whole health approaches to pediatric medical care.
- ✓ **We discussed three new research initiatives** related to Healing Touch and mindfulness therapy with local practitioners.

In addition to serving families living in Washington, DC, Maryland, and Virginia, we seek to advocate for and support Integrative Medicine programming at major hospitals and medical centers. In our first year, we worked closely with staff from Children's National Medical Center in Washington, DC to realize this vision. As the region's leading hospital in pediatric care, Children's National Medical Center has been a key partner in our work and growth. 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. The staff has been a critical source of referrals to our organization.

Advocating for Whole Health at Children's National Medical Center

Children's National Medical Center, located in Washington, DC, is nationally ranked in the top five pediatric medical facilities in the U.S. After speaking with dozens of parents and reflecting on her own family's personal experience, Eliana's Light's Founder and President Whitney Ortiz held a series of meetings with hospital staff to better understand the number, reach, and coordination of existing integrative care services. She spoke both one-on-one and in groups with hospital administrators, doctors, nurses, therapists, Child Life specialists, case managers, social workers, and members of the chaplain and concierge teams.

She worked with three committed integrative health specialists and champions – all trained experts in various integrative care modalities – to start a collaborative, grassroots effort to exchange information and ideas on how to increase the number, range, and coordination of integrative care services at the hospital. The group aimed to develop an Integrative Medicine program that would mainstream these services to all hospital patients.

The effort gained steam, and up to 40 staff members met regularly, creating an informal “Integrative Medicine Planning Team”. Whitney presented to members of the hospital's administration on the lessons she had learned from her research and conversations, including existing interest in having these services more readily available for parents; research on the benefits of using complementary and integrative care modalities for children; models of IM programs at other U.S. hospitals; and the investments needed to develop these types of programs. The administration responded favorably, paving the way for the creation of a Special Purpose Fund and a new program.

The funds Eliana's Light has raised have been allocated thus far to a Special Purpose Fund (SPF) for Integrative Medicine and Integrative Care Services within the Heart Institute, enabling us to track how these funds are used and the resulting impact they have on managed programs with a specific patient population over time. Funds from the SPF have been used to date for professional development for staff to receive training in evidence-based approaches (e.g., Mindfulness-Based Stress Reduction) that reduce pain, stress, and anxiety. They also provided the means for the Cardiac Intensive Care Unit (CICU) to purchase yoga mats for parents and staff members. Yoga classes are now going to be offered for those in the CICU, and parents can also use the mats in their child's hospital room to stretch their tired muscles and relax. Whitney Ortiz has also created an informal Parent Advisory Committee for Integrative Medicine and Care to provide input throughout the planning process to ensure these efforts meet the unique needs of parents and families.

R = REACH

We reach families directly through strategic collaborations, a growing network of volunteers, and an investment in community outreach and communications.

Highlights from Year One:

- ✓ **We organized 17 in-person and online learning 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.
- ✓ **We initiated collaborations with 43 organizations and businesses** to enhance our reach and impact.
- ✓ **We engaged 1,300 volunteers** to contribute to our work.

Community Engagement and Learning Events

Throughout our first year, we organized a variety of in-person and [online](#) events designed to reach caregivers, families and children and raise 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 relax and connect to each other. Examples of events from our first year include:

- **2017 & 2018 Valentine's Day Cards and Cookies:** In 2017, we organized more than **80 volunteers** to deliver over **300 cards to children and 250 cookies to their caregivers** at Children's National Medical Center on Valentine's Day 2017. 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.
- **#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.

- **Four-Part Infant Massage + Fine Motor Movement Workshop:** In September 2017, we organized four learning events on infant massage and fine motor movement in collaboration with PlayWellDC, a local therapy company. Approximately **10 families of children with complex medical conditions attended**, gaining better understanding of their baby's sensory system as well as her/his processing of touch, sight, sound, and smell. The instructor discussed strategies for tummy time, offered guidance on general developmental milestones, and demonstrated key massage strokes for parents to use on infants.
- **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 with access to information and professionals they might otherwise go without. In our first conversation, Dr. Anne Berkeley, a licensed and board certified naturopathic physician, discussed the impact that stress has on our bodies – particularly caregivers spending significant amounts of time in hospitals and at doctor appointments – and shared practical tips for alleviating stress. For our second conversation, mother Christina Spencer kindly shared her reflections on being a caregiver to her beautiful children, one of whom suffered from a complex medical condition.

Additional events are listed in the *Fundraising* section of this report, as well as in *Annex B*, which contains a complete list of all events held during our first 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 first year, we reached more than 2,000 followers and supporters via our website, newsletter and social media channels. In addition to our website, which has attracted 1,800 unique visitors, we shared 286 posts on Facebook, 428 messages on Twitter, and 89 posts on Instagram. We also circulated nine installations of *Highlights*, our email newsletter, to 500 subscribers. These outlets provide important updates on news and events to the families and caregivers we serve as well as our supporters.

We continue to search for new ways to reach our audiences. As an example, we established an Eliana's Light YouTube Channel to host video content, including our online learning series *Conversations With a Caregiver*. We are excited to continue this journey of learning in Year Two, exploring how various complementary and integrative care modalities can support the wellness and wellbeing of pediatric patients and their caregivers.

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 1,300 volunteers in meaningful community 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.

The following are some examples of our volunteer stars:

- **Girl Scout Troop 54**

We are very thankful to the Girl Scouts of Troop 54 in Virginia for the tremendous support they have given Eliana's Light. In 2017, this Troop selected Eliana's Light as their non-profit to engage in community service work. In addition to organizing a bake sale and raising funds for the organization, they made 200 distraction and relaxation tools (e.g., "calm down jars" and "feather sticks"), 22 New Year's encouragement cards for children, 49 Valentine's Day cards for children, 33 name tags for children's hospital rooms, and a video on how yoga can help children. They also organized three Paint Night fundraisers and a social media campaign to ask for in-kind donations through [Eliana's Light's Amazon Wish List](#). With the in-kind donations we've received from these efforts to date, we've been able to give many gifts to children staying at Children's National Medical Center and The Children's Inn at NIH. Thank you so much!

- **Om Shanti Rhi**

Endless thanks to board member, Rhiannon Landesberg (Om Shanti Rhi), for her time spent on various initiatives for Eliana's Light. "Ms. Rhiannon" has organized and led two yoga fundraisers as well as a Valentine's Day card-making event with young students from her yoga class at the River School. She also connected us to Until Jewelry Designs, which designed a special Mala necklace and bracelet to raise money for Eliana's Light. Rhiannon also engaged in a research study at Children's National Medical Center on the impact of yoga on health outcomes. Thank you, Rhiannon, for being an amazing yoga and mindfulness instructor to our girls and to hundreds of children throughout the Washington, DC area.

- **LilOmm**

We are tremendously grateful to Pleasance Silicki, founder of [LilOmm](#), for her generous guidance, time, and efforts in support of Eliana's Light. It was at Pleasance's LilOmm studio where Whitney first witnessed the power of yoga to support physical and occupational therapy. Since Eliana's Light started, Pleasance has been an inspirational mentor, creative catalyst, and thoughtful connector. Visit her [website \(www.lilomm.com\)](#) to check out her wonderful stress-relief and empowerment sessions for women in the Washington, DC area.

- **The wonderful individuals, organizations and companies that participated in:**

- **Eliana's Light's team in the 2017 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 \$8,301 in individual donations, making up most of our \$10,000 donation to integrative care services at Children's National Medical Center in 2018. We would like to especially recognize [Washington Fine Properties](#), [Om Shanti Rhi](#), and [PlayWellDC](#).
- **Our 1st, 2nd, and 3rd annual Valentine's Day Cards for Kids & Cookies for Caregivers initiative:** Thanks to the involvement of more than 1,100 volunteers from six states, we delivered home-made cards and cookies 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, and the Children's Inn at NIH in on Valentine's Day 2017 and 2018. *(Note: We count our first Valentine's Day initiative when we delivered home-made cards and cookies to Children's National in 2016 as a family when Eliana was still with us; we made them alongside another family that also has a child with a complex medical condition.)*
- **Our 1st #WeCareForMoms and #WeCareForDads initiative:** Together we delivered more than 250 sachets of organic lavender to moms who stayed 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 on Father's Day in 2017. In particular, we thank the dozens of staff members at Children's National who kindly provided input into the selection of these items and then delivered them to these caregivers.



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:

- *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.** We are deeply appreciative of their collaboration, and are always excited to work alongside these awesome students who give of their time to help others.
- *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.**
- *Mary's Center*

Mary's Center is a community health center in the Washington, DC area that provides integrated health, education, and social support services to 40,000 individuals whose needs often go unmet by public and private systems. The center uses a holistic, multi-pronged approach to support patients in accessing individualized services, setting them on the path toward good health, stable families, and economic independence. **Eliana's Light is entering a collaboration with Mary's Center to provide additional support for families with children who have complex medical conditions and already access Mary's Center's services.** In our first Fiscal Year, we delivered gift packages to Mary's Center of items such as mindfulness and meditation CDs for teens and arts and crafts kits for younger kids for Mary's Center to use them at the Center and during the therapy they provide. We are thrilled to be working with Mary's Center's staff and families to expand integrative care programming in the clinic and at home.

- 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.** They make important contributions to Constellations of Care for Virginia families.
- 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.** 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 collaborate by co-referring families to each other.** We 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.**



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 One:

- ✓ **We founded and/or contributed to five advisory committees and roundtables** to share learning and best practices.
- ✓ **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. We aim to facilitate information sharing and dialogue with medical professionals, integrative and holistic care providers, and families of children with complex medical conditions.

We serve on various advisory committees and manage two 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, has participated on the following advisory committees during our first 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)
- 2017 Race for Every Child Planning Committee (member)
- Parent Advisory Committee for Integrative Medicine and Integrative Care Services at Children's National Medical Center (founder/chair)
- Advisory Committee for Eliana's Light (founder/chair)

MONITORING & EVALUATION

Eliana's Light's adheres to the following guiding principles as an organization, which we return to when conducting monitoring & evaluation: *altruism, collaboration, community, empowerment, flexible, grateful, inquisitive, immersed, integrity, participant-centered, 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 that 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 questions.

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

REFLECTIONS ON OUR FIRST 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 Mom Whose Family Received Support From Eliana's Light: *"Overnight, my life changed – my dreams, my expectations, my hopes – all shattered when my baby boy was born extremely premature at 24 weeks. No one could've prepared me for the roller-coaster ride of his first year of life: over 230 days of hospitalization, numerous surgeries, countless ER visits and all the other medical challenges, including almost losing him on numerous occasions, that resulted from his early birth. The support I have received from Eliana's Light has been a godsend. Compassionate, reliable, and an enormous source of strength and hope. The organization has provided me with helpful and practical tools to manage my stress, fears and anxiety, and the daily emotional pressures that come with caring for my son. Sometimes it takes a person who's been there to truly help you get through the dark days."*

Winn Sams, Doctor of Chiropractic: *"Eliana's Light brings much-needed support to those who are critically ill, and those who are stressed or tired from being a caregiver, through services and therapies that align with true health. The World Health Organization states: 'health is the state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity.' Complementary approaches have this definition as their core expression. I am grateful that the mission of Eliana's Light is to offer gifts of healing to so many in such a difficult and draining time."*

Celinha Martins, Physical Therapist, Founder of Vida Therapy and member of Eliana's Light's Board of Directors: *"I joined this Constellation of Care because I believe in the power of love, hope, caring, and positive thinking. Through the work I do each day with children as a physical therapist, I see the tremendous highs and the deep lows that families experience; the celebrations when a new milestone is reached, and the devastation and desperation that come when the unexpected happens. This non-profit is filling a real need. We're working collaboratively with others in our community to bring families comfort, improve their access to services, and raise awareness on the importance of taking a holistic approach to their health care. I am so thrilled to be a part of this effort, and to help make a positive difference in these families' lives."*

Dr. Maria Luz Lara-Marquez, MD, PhD, Allergist & Immunologist and Integrative Medicine Specialist in San Diego, CA; member of Eliana's Light's Advisory Committee: *"I support this extraordinary initiative from patients to patients, raising awareness in the physician and other medical providers on the importance of the Integrative Medicine approaches to heal our patients. Eliana's story is an inspiration to all caregivers and health care providers."*

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.

4

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.

With the generous contributions of our supporters, we raised \$33,500 from individual donations, \$934 in in-kind product donations, and \$1,000 from fundraising events in our first Fiscal Year. Thirty-two businesses also contributed their professional expertise, space, and/or time to us. We are so grateful to all who contributed!

Below, we list our fundraising approaches and examples of success.

FUNDRAISING EVENTS

Throughout the Fiscal Year, we partnered with volunteers and community organizations to hold a number of fundraising events. The following are examples of events held in collaboration with local businesses and organizations to date:

- **A Family Yoga Fundraiser and Awareness Raiser Event**, in partnership with Washington Yoga Center. The event was held in March 2017 and raised \$220.
- **A Bake Sale and Self-Care Event** led by Virginia-based Girl Scout Troop 54 in April 2017. The event brought in \$266.66.
- **A Self-Care and Wellness Day for Caregivers** at Core72, a clothing store in Washington, DC. The event, held in September 2017, raised \$440 in partnership with five other local women-owned businesses.
- **A Play Therapy and Magic Show** with The Great Zucchini, a local magician and children's entertainer, raised \$200 in May 2017.

We have also worked with individuals eager to organize fundraisers in their community. We enjoy collaborating with community members looking to organize a fundraiser at their house 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.

Finally, **Eliana's Light** organized a team for **Children's National Medical Center's Race for Every Child in October 2017** while **Whitney served on the Race's Planning Committee**. The Eliana's Light team raised money to support the development of an IM and Integrative Care Services division/program/department at Children's National Medical Center. Based on hospital staff's input, our fundraising efforts were specifically focused on IM initiatives within the Heart Institute, where there is significant staff motivation, buy-in, and interest in further developing this whole health approach to their existing programming. **This collaborative effort with members of the community raised more than \$10,000 for this Special Purpose Fund during our first Fiscal Year.**

Please see *Annex B* for more detail on these fundraising events, along with learning events held in our first Fiscal Year.

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. As this is a volunteer-based organization, zero percent of donations go towards salaries and benefits. 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:** Checks can be made payable to "Eliana's Light" and sent to: Eliana's Light, 5347 28th Street, NW, Washington, DC 20015.
- **Donate through PayPal:** Individuals can pay through their PayPal account or their credit or debit card: <https://www.paypal.me/ElianasLight>.
- **Give through PayPal's Giving Fund:** Eliana's Light is now 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>.
- **Purchase an Eliana's Light Mala Necklace or Bracelet:** Until Jewelry Designs, our treasured partner and an amazing jewelry company, kindly designed a signature Eliana's Light Mala Necklace and Bracelet to support our organization. Thirty percent of all sales go directly to support families Eliana's Light serves. These beautiful pieces of jewelry make great gifts for caregivers, as well as for children who have complex medical conditions. They are a symbol of love, healing, and self-care. Individuals can [email](#) us for details.

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 now 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.

Beyond the gifts we received from our Amazon Wish List, we have 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 first Fiscal Year:

- **Amanda Sandlin:** Designed Eliana's Light's logo.
- **Barbara Tamberlich-Arnaud:** Translated resources from English to French.
- **Beltway Bambinos:** Promoted our 2017 and 2018 Mother's Day and 2018 Valentine's Day initiatives.
- **Bloom OB/GYN:** Organized Valentine's Day card-making event in their office space.
- **Building Blocks Therapy:** Contributed a tailored gift bag for families receiving feeding therapy.
- **Carr Maloney:** Provided discounted legal services for registering our 501 (c) (3).
- **Children's National Medical Center:** 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.
- **Cole Tax Services:** Donated accounting services.
- **Core72:** Donated space to hold a fundraiser, and contributed 30 percent of sales proceeds on that day to Eliana's Light.
- **Helping2Heal:** Donated resource guides on how to reduce toxic intake, which we now include in many of our gift bags.
- **Inova Children's Hospital:** Collaborated on disseminating Valentine's Day cards and cookies. Also informed caregivers of the services we provide to local families.
- **Jill Shalett Bookkeeping:** Donated bookkeeping support.
- **Johns Hopkins Children's Center:** 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.
- **Kennedy Krieger Institute:** Collaborated on disseminating Valentine's Day cards and cookies. Also informed caregivers of the services we provide to local families.
- **Kuli Kuli Foods:** Donated 50 Moringa health food bars for use in gift bags and at learning events.
- **Lil Omm:** Provided advice, initiated a fundraising event at Core72, and organized a Valentine's Day card-making event.
- **Little Flower Yoga:** Donated children's yoga cards and DVDs for use in gift bags for families.
- **LWC App Studio:** Donated time and expertise to develop our website.
- **Medicine To Thrive:** Donated time and expertise to develop our first *Conversation With a Caregiver* on stress.
- **OmShantiRhi:** Donated time and organized yoga fundraisers.
- **PlayWellDC:** Donated time to organize learning events on developmental milestones and infant massage.
- **Rula Qawas:** Translated resources from English to Arabic.
- **Shopkeepers:** Donated store space to host learning events with PlayWellDC.
- **Still Quiet Place:** Donated meditation CDs for children and youth for use in gift bags for families.
- **StudioRed:** Provided discount on graphic design for communications pieces.
- **The Great Zucchini:** Donated time to perform a magic show for a fundraiser.

- **The Nanny Network:** Organized members to participate in Valentine's Day card-making event.
- **The Nussbaum Group:** Contributed fundraising and communications advice.
- **The WholeChild Center:** Shared resources for posting on our website.
- **Until Jewelry:** Designed Mala necklace and bracelet and provided 30 percent of sales proceeds to Eliana's Light.
- **Washington Yoga Center:** Donated space for yoga fundraisers.
- **Wellness by Shari:** Donated expertise in aromatherapy, Healing Touch, and herbs.

YEAR ONE EXPENDITURES

As a volunteer-based organization, zero percent of donations go towards salaries and benefits. Our operational costs for the first Fiscal Year fell into the following categories:

Item	Cost
Business/Non-profit registration fees	\$705.10
Gifts for caregivers, kids and/or families (including supplies for Valentine's Day, Mother's Day and Father's Day events)	\$2,988.49
Sub-grants to Children's National (as Eliana's Light's contribution via our Race team in support of IM and Integrative Care Services for in-patients and their caregivers)	\$2,950.00
Consultant and professional fees (i.e., lawyer to help with registering and obtaining recognition of non-profit status)	\$4,820.00
Venue rental for The Great Zucchini event	\$102.00
Graphic design (i.e., three types of info cards, banner stand, table tent for events, logo)	\$251.99
Supplies (ink toner, paper, water and snacks for events, business cards, other event supplies, etc.)	\$793.58
Staff reimbursement for gas/parking	\$325.39
Printing & copying	\$422.24
Website	\$291.76
Advertising for events (posting on list-serves, stickers and cards included with Valentine's Day, Mother's Day and Father's Day gifts)	\$234.41
Fundraising fees	\$3.00
TOTAL	\$13,887.96

5

**WHERE WE'RE
HEADED**





YEAR TWO GOALS

We invite your engagement and collaboration in 2018 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 connect with at least 30 more families** in Washington, DC, Maryland, and Virginia, providing them with tailored gift packages and sharing resources and information to support them.
- **We will participate in at least three 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 three months.
- **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 Memphis Spencer, who we had the honor and privilege of getting to know this year. Memphis passed away on April 9, 2018 after spending his entire first year in the Cardiac Intensive Care Unit at Children's National Medical Center. We are grateful to Memphis' parents and sister who invited us into their lives. Memphis will always be in our hearts, and his brilliant light will always shine.

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 wellbeing 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."²

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."³

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."⁴ 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

² 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/>

³ 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/>

⁴ 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.”⁵

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.*

⁵ Mind-Body Skills Training for Resilience, Effectiveness, and Mindfulness. Hosted by the Ohio State University College of Medicine: <https://mind-bodyhealth.osu.edu/>

B. EVENTS FROM OUR FIRST YEAR

Eliana's Light has partnered with numerous organizations, businesses and community members to hold a wide variety of events designed to reach children, caregivers and advocates. The following is a list of learning events and activities organized during our first Fiscal Year.

FEBRUARY 2017 & 2018

Valentine's Day Cards & Cookies



We officially launched Eliana's Light on Valentine's Day in 2017 as a symbol of the support, comfort, and friendship we hope to offer families of children with complex medical conditions. To mark this occasion, we organized more than **50 young volunteers** to make Valentine's Day cards for children spending the holiday at Children's National Medical Center. We also worked in collaboration with more than **30 adult volunteers** to prepare homemade cookies for their caregivers. Volunteers included members of Girl Scout Troup 54 in Fairfax, Virginia, who in 2017

chose Eliana's Light as the non-profit to which they would dedicate their community service hours. Together, **we delivered more than 300 cards and more than 250 cookies** to Children's National Medical Center for Valentine's Day.

By Valentine's Day 2018, our reach and impact had expanded tremendously. With the help of **1,101 volunteers** from 17 schools in six states, eight local companies, 15 groups of friends, and five organizations, **we delivered 2,395 cards and 504 cookies to six hospitals** serving children with complex medical conditions in Washington, DC, Maryland, and Virginia. Participants came from a variety of sources including two Girl Scout troops; a university sorority; local medical offices (pediatric medicine, obstetric/gynecology, and physical therapy practices), children's playgroups, a nanny network, and local schools that support children with special needs. The messages the children shared in the cards were cleared by hospital staff members who serve on our Advisory Committee, and aimed to give a positive boost to the children who received them (e.g., "You are loved").

In both 2017 and 2018, Eliana's Light received positive feedback from the many parties involved in this work: from the volunteers who made the cards and cookies, to those who delivered and distributed the treats, to

"We hope that all who receive the cards and cookies may know that many people who don't know them personally are thinking of them and sending them best wishes."

- Message included with our delivery to Children's National Medical Center

the children and caregivers who received them. A young volunteer named Paige, who helped to make cards, told us "I had fun making these cards, and knowing the difference that they could make for just one child over the holiday makes it more special." Michele Grady, the Patient Experience Liaison at Children's National Medical Center shared, "A million thanks to you and the donors who have brought comfort to our families."

MARCH 2017

Yoga Family Fundraiser and Awareness-Raiser



On March 19, 2017, Eliana's Light board member Rhiannon Landesberg led a family yoga class and fundraiser at Washington Yoga Center (WYC) in Washington, DC. WYC kindly donated its space and Rhiannon generously donated her time and expertise. **The event convened eleven families and raised a total of \$220 for Eliana's Light.** It also raised awareness on the positive impact yoga can

have on one's wellness and well-being, engaging and informing local families with our work.

APRIL 2017

Bake Sale With Girl Scout Troop 54



We were so excited that Girl Scout Troop 54 in Fairfax, Virginia selected Eliana's Light as their non-profit for community service work. In addition to helping with our Valentines Day activities, this amazing group of 10 and 11 year-old female leaders organized a bake sale at their school to support Eliana's Light. In the weeks preceding the

April 6, 2017 event, the founder and president of Eliana's Light met regularly with troop members to help construct relaxation tools such as "calm down jars" and "feather sticks", which the girls demonstrated and sold alongside the baked goods. Troop members also created signs highlighting the importance and benefits of young people learning to calm and center themselves. It was a fun community-building and awareness-raising event for Eliana's Light. Moreover, it was an important opportunity for these girls to learn new life skills, and to share their knowledge as spokes(young)women for self-care. **Troop 54 raised \$266.66 through this event, which they used to purchase items from our Amazon Wish List.** We continue to include these items in *Eliana's Light Constellation Kits* for families that apply for support, and are so grateful for their contributions.

MAY 2017

Play Therapy with The Great Zucchini



We were lucky to have The Great Zucchini, a magician and children’s entertainer in Washington, DC, lead **30 parents and their kids** through a laugh-a-minute gathering on May 6, 2017. Known as Washington, DC's #1 children's entertainer, The Great Zucchini kindly donated his time for the event, which was held in a rented space at a local community center. **This fun event raised approximately \$200 for Eliana’s Light**, and highlighted the importance of giving all kids the time and space to play and have fun. Laughter can be the best medicine!

Mother's Day at Children's National Medical Center

Recognizing the tremendous love and support mothers give to their children, as well as the stress that can come from caring for a child with a complex medical condition, Eliana's Light distributed relaxation-based gifts to mothers of in-patient children on Mother’s Day 2017. Under the guidance of aromatherapists and herbalists, **we distributed 250 sachets of organic lavender buds with essential oils** throughout Children's National Medical Center, to help mothers experience moments of relaxation during a stressful time. The tags on the sachets read: *These are symbolic and also useful gifts to let mothers know we're thinking of them, and wanting to care for them.*

JUNE 2017

Father's Day at Children's National Medical Center and The Children's Inn at NIH



Eliana’s Light also honors the many fathers who extend themselves beyond what they think is possible in order to support their child who has a complex medical condition. Building on our successful Mother’s Day event, **we distributed 250 Eliana’s Light branded stress balls** to all fathers staying at Children's National Medical Center and The Children's Inn at NIH on Father's Day in June 2017. We had recently established a new collaboration with The Children’s Inn at NIH and were thrilled to be able to reach fathers staying there. Our organization thought a lot about the kind of practical stress-relief gift fathers across cultures might appreciate. Many people we spoke with suggested stress balls, and the response we received from both institutions post-event was very positive. We plan to continue to gift stress balls to fathers for this and other events.

SEPTEMBER 2017

Four-Part Infant Massage + Fine Motor Movement Workshop

In September 2017, we organized four separate learning events on infant massage and fine motor movement in collaboration with [PlayWellDC \(http://www.playwelldc.com\)](http://www.playwelldc.com), a local therapy company. A certified instructor of infant massage donated her time for instruction and Shopkeepers Gallery, a local clothing store and art gallery, donated its space. **Approximately 10 families of children with complex medical conditions attended**, gaining better understanding of their baby's sensory system as well as her/his processing of touch, sight, sound, and smell. The instructor discussed strategies for tummy time, offered guidance on general developmental milestones, and demonstrated key massage strokes for parents to use on infants. Families also learned how to:

- Help their baby sleep more deeply and for longer.
- Bond with their baby through comforting touch and play.
- Reduce or avoid fussy time.
- Relieve their baby's colic, gas, and constipation.
- Read their baby's cues and promote regulation in their baby.
- Stimulate their baby's growth and development.
- Prevent their baby's head from flattening.
- Increase their baby's head and neck control.
- Build their toddler's fine motor skills through work on coordination, grasp, and pinch.
- Include sensory play in playtime to increase their toddler's motor skills, promote attention to tasks, and improve cognitive skills.

Day of Care and Comfort at Core72

On September 16, 2017, we organized a day of care and comfort at [Core72 \(www.core72dc.com\)](http://www.core72dc.com), a local clothing store that sells active wear and lifestyle brands. The day-long fundraising and awareness-raising event was developed in collaboration with the following group of fantastic local women-owned businesses and organizations:

- **LilOmm:** A community of women inspired by healthy habits and well-being practices rooted in wisdom and wellness. Through retreats, workshops, classes and events, they support and uplift one another at all stages of life: www.lilomm.com.
- **OmShantiRhi:** A mobile yoga company that offers classes and workshops for adults and children at studios, schools, companies, and homes: <https://rhiannon-landesberg.squarespace.com>.
- **Gouter:** A local company that produces raw and organic tonics for cleanses and everyday: www.heygouter.com.

- **Until Jewelry Designs:** A jewelry designer who hand-crafted a signature Eliana's Light Mala necklace and bracelet for our organization to use for fundraising purposes: <https://until-jewelry-designs.myshopify.com/products/elianas-light-mala>.
- **StudioRed:** A local design studio that partners with a variety of change agents to make a positive and meaningful difference in our world: www.studiorred.us.

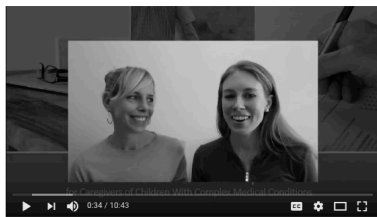
Participants bought Eliana's Light Mala jewelry, registered to run with the Eliana's Light team in the 2017 Children's National Medical Center's Race for Every Child, created Vision and Gratitude Boards to promote well-being, tasted Gouter's organic tonics and cleanses, and bought items from Core72. Core72 kindly donated 20 percent of sales proceeds that day to Eliana's Light. **In total, the event raised \$440 for Eliana's Light.**

OCTOBER 2017

National Kids Yoga Conference

On October 13, 2017, Whitney Ortiz participated in the 2017 National Kids Yoga Conference in Alexandria, Virginia. This annual conference, organized by YoKid, convenes the kids' yoga and mindfulness community – including educators, mental health professionals, yoga teachers, researchers, therapists, and parents – in a professional forum. Participants learned about the research, techniques, and best practices needed to thoughtfully lead the movement to bring yoga and mindfulness to children and youth across the country. Whitney shared the positive effect yoga had on Eliana and the potential it holds for many children with complex medical conditions.

Conversation With a Caregiver: Online Learning Event on Stress Relief for Caregivers



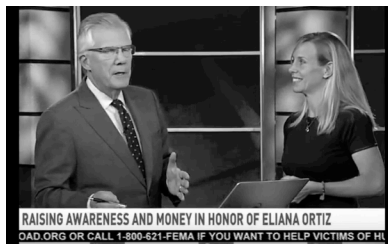
"Conversation with a Caregiver": Focusing on Stress with Dr. Anne Berkeley, Naturopathic Physician

On Oct 14, 2017, we kicked off our online learning series called *Conversations with a Caregiver*, which is now available on our new [YouTube](#) channel. The series seeks to increase caregivers' access to information on how to cope with the many aspects of having a child with complex medical conditions. The inaugural episode was produced in collaboration with Dr. Anne Berkeley, a licensed and board certified naturopathic physician who specializes in a holistic and integrative approach to health, combining modern medicine with traditional healing. It focused on identifying and coping with stress, a common challenge across all families with children who have complex medical conditions. Dr. Berkeley highlighted the effects that stress can have on the body over the short- and long-term. She also shared practical tips specifically for caregivers who spend significant amounts of time in hospitals and at doctor appointments with their children. If you're interested in learning more or accessing similar *Conversations with a Caregiver*, please sign up to receive *Highlights*, our email newsletter (<https://www.elianaslight.org/newsletter/>). We welcome your ideas and questions, as we are collaboratively developing these *Conversations* so that they can be as helpful and relevant to you as possible.

Children's National Medical Center's Race for Every Child



We organized a team (named “Eliana’s Light”) for Children’s National Medical Center’s 2017 Race for Every Child. More than 20 people participated. The Race took place October 21, 2017 in Washington, DC. Team Eliana’s Light raised money to support the development of an Integrative Medicine (IM) and Integrative Care Services division/program/department at Children’s National Medical Center. Based on hospital staff’s input, we focused our fundraising to support IM initiatives in the Heart Institute where there was already significant staff motivation, buy-in, and interest in further developing this whole health approach to their existing programming. **This collaborative effort with members of the community raised more than \$10,000 for this Special Purpose Fund in our first Fiscal Year.**



As a member of the 2017 Race’s Planning Committee, Whitney was interviewed on local news Channel 7 on August 29, 2017. Her appearance increased the Race’s visibility and raised awareness around its fundraising efforts. The interview is available on our [YouTube channel](#).

DECEMBER 2017

Conversation With a Caregiver: Mother of a child with a complex medical condition



For our second installment of our online learning series, *Conversations with a Caregiver*, Christina Spencer kindly offered to share her reflections on being a caregiver to her beautiful children, one of whom had a complex medical condition. Her son, Memphis, spent the entire year of his life in the Cardiac Intensive Care Unit (CICU). This report is dedicated in his loving memory. When this *Conversation* was recorded, Memphis was eight months old. Christina spoke movingly about the struggles of daily life: how she and her husband travel regularly between the hospital and home; how Christina is on an extended leave of absence from work; how her husband tries to maintain his job; and how they care for both children under difficult circumstances. Her candid, generous insights will no doubt offer many families a sense of comfort and belonging in knowing that they are not alone. Our thoughts are forever with their family; we know Memphis’ beautiful light will forever shine.

MARCH 2018

Integrative Care Services Panel at Children's National Medical Center



On Thursday, March 22, 2018, Whitney Ortiz presented on a panel on Integrative Care Services at Children's National Medical Center, as part of Patient Experience Week. Whitney joined the following panelists from Children's National Medical Center to highlight the importance of integrative care services as part of the medical care and attention a patient and his/her family receives:

- Ms. Martha Para, VP, Clinical Support Services
- Mr. Gregory Scott, Gallery & Exhibit Coordinator
- Dr. Laila Mahmood, Palliative Care, Hematology & Oncology
- Ms. Marian McEvelly, RN, CPN, Certified Coding Associate (CCA) with Anesthesia, Level V Healing Touch Practitioner, Certified Aromatherapist, Certified Horse Therapist, and Reiki Master
- Ms. Victoria Paytonwebber, Sound Therapist

C. 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.

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.

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. 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

Ms. Lilly Kavar

RN, Heart and Kidney Unit, Level III Healing Touch Practitioner, 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

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 1

First Annual Report

January 17, 2017 – March 31, 2018

Copyright © 2018 by Eliana's Light

All rights reserved. Eliana's Light does not discriminate on any grounds prohibited by applicable law, including race, color, religion, age, sex, national origin or ancestry, sexual orientation, marital status, status as a disabled or Vietnam veteran or as a qualified disabled individual.

@elianaslight

* 5347 28th Street, NW * Washington, DC 20015 * 703-899-6129 * www.elianaslight.org *

*www.Facebook.com/elianaslight * www.Twitter.com/elianaslight * www.Instagram.com/elianaslight *