



Eliana's Light



Third Annual Report

Fiscal Year Three

April 1, 2019 – March 31, 2020

@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 & Executive Summary 3

 Message From Our Board 5

 Eliana’s Story 6

WHO WE ARE 7

 Our Mission 8

 Our Purpose: Why Whole Health & Wellbeing 8

 Our Vision 9

 Our Values 10

 Our Value Proposition 10

 Our Approach 10

WHAT WE’VE ACCOMPLISHED 12

 Our Programming: How We C.A.R.E. 13

 Monitoring & Evaluation 24

HOW WE’VE GROWN 26

 Fundraising & Donations 27

 Year Three Expenditures 30

WHERE WE’RE HEADED 31

 Year Three Goals 32

 How You Can Help 33

ANNEXES 39

 A. Key Definitions 37

 B. Our Constellation of Care: Eliana’s Light’s Board & Advisory Committee 39

INTRODUCTION





LETTER FROM OUR FOUNDER & EXECUTIVE SUMMARY

Dear Collaborators,

Writing you during this time of COVID-19 is heavy. Heavy in thinking of all of the suffering, and heavy in gratitude for all the helpers. Eliana's Light is with you all as a collaborator in the global effort to give support, comfort, and care. We are so grateful for all the healthcare workers and others who give of themselves selflessly with love each day to help others.

We remain, as always, open to your questions, suggestions, and ideas as we move forward into our 4th operational year of supporting DC, MD, and VA families with children who have complex medical conditions.

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

- **Grew from working with six pediatric medical centers in our first Fiscal Year to collaborating with nine facilities** that support these children and families who live in Washington, DC, Maryland, and Virginia.
- **Donated another \$1,760 to Children's National Hospital** in addition to the more than \$22,000 Eliana's Light previously raised to support the development of an Integrative Medicine and integrative care services division;
- **Posted an additional 25 resources** to our website to total more than 500 resources applicable to caregivers, medical professionals, and integrative care providers;
- **Participated in more than 25 knowledge exchange and advocacy meetings** to support whole health approaches to pediatric medical care;
- **Initiated collaborations with 10 additional organizations and businesses** to extend our reach and enhance our impact, bringing to more than 60 the number of our active collaborators;
- **Engaged more than 2,500 volunteers** in contributing to our work and growth;
- **Gave 3,569 hand-made cards and 1,604 cookies that 2,260 volunteers from 18 states made for pediatric patients and their caregivers** at nine local medical centers (one more than last year) on Valentine's Day 2020;
- **Delivered 477 gift bags to moms and 234 gift bags to dads** at nine participating medical centers on Mother's Day 2019 and Father's Day 2019, respectively;
- **Supported 28 families** that applied for direct support (11 more than last year), providing each family with a personalized gift bag, guidance on additional services and resources, and support in reducing their financial, emotional, mental, and physical stress; and
- **Contributed to four advisory committees and roundtables** to share learning and best practices.

In total, since Eliana's Light launched on February 14, 2017, we have:

- delivered more than **10,000 Valentine's Day cards** to hospitalized children and **4,000 cookies to their caregivers**;
- involved **more than 5,000 volunteers** (including **more than 2,200 at a time**) in our annual community service programs;
- donated **more than 3,000 gift bags to parents** who were with their hospitalized child **for Mother's Day or Father's Day**;
- posted more than **500 resources** on our website for caregivers, kids, and care providers;
- donated **200 "comfort kits", 200 "art therapy kits" and 120 yoga mats + various yoga material** to the Cardiac Intensive Care Unit (CICU) at Children's National Hospital;
- convened **more than 50 people** to be on our team for Children's National's **Race for Every Child** to raise money for integrative care services at the hospital;
- given **personalized direct support to more than 50 families**;
- led or co-led **20 learning events**;
- collaborated with **9 pediatric medical centers**;
- contributed to and learned from **5 advisory committees**;
- worked regularly with **21 professional advisors, 7 board members, 4 parent advisors, and 3 youth advisors**; and
- co-created **1 giant, ever-evolving "Constellation of C.A.R.E."** for local families in which many smaller constellations regularly form and evolve.

We truly believe Eliana's Light is unique in how we **C.A.R.E.:** by **connecting with families** to support them where they are; **advocating for whole health** approaches to patient- and family-centered pediatric medical care and attention; **raising awareness** on whole health and related programming, approaches and strategies that help reduce stress, anxiety, pain, and fear, especially in regards to medical care and treatments; and **exchanging ideas and resources** with collaborators. We are so glad you're interested in reading about our experiences through this report.

It is important to us that we build and maintain authentic connections and relationships in all the work that we do. As we all navigate through a tough time in human existence, we send you our unwavering love. May peace and hope fill your hearts.

Thank you for being with us to help local families with children who have complex medical conditions.

With warm regards,

Whitney Ortiz
Founder and President of Eliana's Light

MESSAGE FROM OUR BOARD

Dear Collaborators,

We join with you in giving help and hope to those in our community who are struggling. As an organization, we remain committed to supporting the whole health of families that include children who have complex medical conditions. We really appreciate your ongoing collaboration with us through your donations and virtual volunteering so we can “be there” for families when they need us.

During this time of COVID-19, we will be focusing first and foremost on directly helping families that are experiencing severe financial and emotional stress. To protect the health of patients, caregivers, care providers, and volunteers, we will be pausing our annual Mother’s Day and Father’s Day volunteer service activities for this year. As these programs involve community members coming together to contribute items for gift bags that we then distribute to participating hospitals, it is not safe to proceed this year.

We will continue to provide financial support, gift certificates and other stress-relief items to families that apply to us directly. We can send these items through the mail and talk with caregivers by phone, giving them emotional support and connecting them to additional services in our community. We will also continue to build on the list of resources that we regularly update on our website for caregivers and care providers to access anytime. Additionally, we’ll stay in touch with families and collaborators by phone, email, and social media.

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

We close with a reflection of gratitude for all the health care workers and other helpers who go to extraordinary lengths each day to care for others. Thank you for all you do. And to all who are reading our note, you are so appreciated. We so appreciate that you have chosen to give of your time and open your heart to being with us on this journey.

Sincerely,

Natalia Isaza Brando, Megan Dennis, Golrokh Fassihian, SangHee Lynn, Melissa Nussbaum, and Gillian Rai

ELIANA'S STORY

Knowing where and how to share our story is difficult. We never shared much publicly about Eli's condition. Everything started on a regular day when I put our 3 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 only vibrating. The doctors didn't know if she'd make it across town from Georgetown Hospital to Children's National Hospital, which has more life-saving machines and medicines.

After the doctors at Children's National conducted many tests over the weeks that followed, 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 one to receive a heart transplant. Eli was the first child in the Washington, DC area to be on a Berlin Heart, which is a ventricular assist device (VAD) 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 of up to 8 months at a time.

While Eli spent the majority of her almost four years in the hospital, as both an inpatient and outpatient, 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, our family members' houses, and more. We got to see them play in the sand, kick soccer balls, twirl in tutus, dance to "Frozen" songs, and start pre-school. Every 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.

In her honor, we began Eliana's Light. We understand what it means to be a caregiver of a child who has a complex medical condition. We know how painful and scary uncertain moments can be. We have experienced the anxiety that comes from being stretched between multiple responsibilities during intense times. We know what it's like to operate on little sleep and exhaustion. We know how it feels when you desperately want to take away the pain, fear, or anguish your child is experiencing; and how their state of being impacts each family member in her/his own way.

And so, we created Eliana's Light to help parents, like us, find additional resources to help their children in every way possible. Grounded in our belief in the importance of a whole health, holistic approach to care, we strive to help you and your family feel better.

With love,

Whitney Ortiz

Founder and President of Eliana's Light

2

WHO WE ARE





OUR MISSION

Eliana's Light supports families with children who have complex medical conditions by providing a community-based collaborative approach to care that's focused on whole health and well-being – a focus that makes the whole family feel better. We help to address and reduce the stress, pain, fear, trauma, anxiety, and depression that many children diagnosed with complex medical conditions, as well as their caregivers and siblings, often experience.

We engage and collaborate with community members (e.g., medical and integrative care specialists, therapists, volunteers, donors, government agencies, support groups, and others) to support families by providing them with the personalized care they need. We call these community members “stars”. These “stars” come together to comprise what we call “Constellations of Care” for a family. Each family’s Constellation of Care is unique and evolving -- as a family’s needs change so do their stars. These stars address the physical, mental, emotional, and financial needs of each family member.

OUR PURPOSE: WHY WHOLE HEALTH & WELL-BEING

Focusing on the body, mind, and spirit improves wellness, well-being, and quality of life. We focus on whole health for the whole family because families with children who have complex medical conditions often experience significant stress, pain, fear, trauma, anxiety, and depression. Many of these children often endure long and frequent hospitalizations, painful and traumatic procedures, and scary discussions. Additionally, their caregivers and siblings are often stressed, scared, and exhausted.

Each member of this family can experience medical trauma, Post-Traumatic Stress Disorder (PTSD), toxic and chronic stress; and feelings of helplessness, loneliness, and desperation. Some of these families also live in high stress environments in which the children have Adverse Childhood Experiences (ACEs) beyond their medical trauma.

Families are searching for help beyond medical treatments to support their minds, bodies, and spirits -- we know because we've been there. There are integrative care

service providers available and interested in helping children and their caregivers in local communities. However, they are often not connected to a local hospital or the families that can benefit from their help. They also tend to be too expensive for many families, as most insurance companies do not yet cover them. Additionally, many medical facilities do not yet offer significant integrative care services or have an Integrative Medicine (IM) program.

We know what children with complex medical conditions and their caregivers go through. The medical and integrative care staff members, and other caregivers who collaborate with us want to relieve these children and their family members' suffering, improve their quality of life, and make their life experience easier. We want to make integrative care services more accessible as part of our effort to improve the whole health of a family.

We believe in the importance of necessary medical procedures, and in the importance of integrative care services working alongside the standard medical practice. Visit our [website \(www.elianaslight.org\)](http://www.elianaslight.org) to learn more about research on medical trauma and stress.

We also recognize that a key component of whole health is connection to community. Eiana's Light thus organizes three large community service activities, in which many smaller ones take place, each year. More than **5,000 volunteers** have engaged in community service programs we have organized since we started in 2017. Our volunteers have generously and graciously made Valentine's Day cards and cookies, and contributed to gift bags for Mother's Day and Father's Day. **More than 4,000 children and their caregivers have received the outpouring of support from these community members.** Many recipients have shared with us how they've felt a greater sense of connection to their community and were uplifted by this support. Our volunteers also have benefited from the experience, with adults and children alike expressing gratitude for the chance to help others in their community feel better.

OUR VISION

We are a go-to health and wellness support system and resource for families that have children with complex medical conditions. We improve each family member's quality of life, wellness and well-being. By extension, we help the whole family unit. We recognize each member of a care team and their roles in transforming today's health

“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)

care system into one that focuses on the whole health of the entire family through collaborative community-based support.

OUR VALUES

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

OUR VALUE PROPOSITION

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

OUR APPROACH

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

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

The following explains how we **C.A.R.E. for families**:

We C.A.R.E. alongside our Constellations of Care. We accompany families for as long as they'd like to stay connected to Eliana's Light. When the family's needs change, we help guide them to other support services that are relevant to their new needs. We do not provide technical expertise directly. We instead help connect caregivers to experts who are part of our Constellations of Care within our communities.

Connect

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

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. For example, we collaborate with hospital staff and with physical, occupational, feeding, and speech/language therapists on ways to incorporate mindfulness and integrative care services into their programming.

Raise Awareness

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

Exchange

We serve on various advisory committees and manage one directly in order to exchange information and resources with local specialists 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 third year!

Our Board

We are excited to share that three wonderful women have joined our board to kick off our Fourth Fiscal Year! We hope you'll join us in welcoming Ms. Golrokh ("Goli") Fassihian, Ms. SangHee Lynn, and Dr. Gillian Rai. Their bios are included in the Annex and posted on the following webpage: <https://www.elianaslight.org/whoweare>.

3

WHAT WE'VE ACCOMPLISHED





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

C = CONNECT

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

Highlights from Year Three:

- ✓ **We provided direct support to the twenty-eight new families that applied**, providing each with a signature *Eliana's Light Constellation Kit*, guidance on additional services and resources, and support in reducing their financial, emotional, mental, and physical stress.
- ✓ **We posted 25 new resources** on our website, bringing the total resources to more than 500. These include lists of relevant providers and organizations, current research on integrative medicine and integrative care services, and tips on financial and legal planning for parents of children with complex medical conditions.

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

Our board reviews each family's application, and we contact families within **24 hours**. Once the board approves an application, which is **within three days**, Whitney then arranges a time and place to meet or talk by phone with the child/ren's parent/guardian(s) to discuss the family's needs and concerns. Our experience and

research have taught us that caregivers applying for support tend to face one or more of the following challenges:

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

We understand how stressful it can be to care for a child who has a complex medical condition, and want to support caregivers in mitigating the stress of the challenges they face. Importantly, we do not provide technical expertise or serve as a coordinator of care; instead, we help *connect* caregivers to relevant experts that form *Constellations of Care* within our communities. **In our third year, we worked with 28 families of children with complex medical conditions who applied to our organization for support.**

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

Eliana's Light Constellation Kits

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



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

complementing one's medical care with other appropriate and safe healing approaches and services.

Each of the 28 "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*:

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

Online Resources

In addition to the in-person connections we make with families, we also connect caregivers - parents, guardians, and professionals - to resources on our website.

During the past three years, we added more than 500 entries to the *Resources*

section of our website (www.elianaslight.org/resources). These free resources provide critical information for anyone interested in tending to the whole health of families with children who have complex medical conditions. Examples of the resources we have compiled online include:

"Eliana's Light is all about integrative care, community, and providing realistic and practical solutions for families. In sum, they get it right. They know what families need and they deliver." A mom to whom we gave direct support during this past year.

- **Lists of other organizations and companies** that can provide financial and in-kind support for families and children in Washington, DC, Maryland, and Virginia. This includes local non-profits with grant-making functions and expertise, government agencies that address mental health, and early childhood intervention programs that evaluate and provide appropriate therapies for children.
- **Names and contact information of local medical personnel and therapists** who take an integrative approach to the care of children and/or adults. These providers can share information on the safety, relevancy and benefits of this kind of care.

- **Names and contact information of local integrative and complementary care providers** who can provide additional support alongside a medical care plan, such as yoga, mindfulness, massage, and acupuncture therapists.
- **Links to up-to-date information** on research related to pediatric Integrative Medicine (IM); IM program models in operation throughout the U.S.; and books, apps and tip sheets for supporting mental and emotional health and wellbeing. **Information on associations** where practitioners can seek additional training and credentials.



Michael's Story

Michael is absolutely adorable, purely sweet, and lovingly playful. Michael has a rare genetic disorder, which has caused various organs to not function correctly. At 2/12 years old, he has already had 11 surgeries.

Michael is understandably tentative when a new person enters the room where he is. Whitney engaged him with puppets in a trust-building activity during her first visit, and the puppets were quickly followed by toy trucks and “stuffies” once Michael started joyfully participating. When Whitney and Michael laughed together, Michael’s younger brother wanted to play too.

Their mom sat on the couch with tears rolling down her face, and gave Whitney many hugs when there was a natural break in the play. Whitney and the mom then talked while the boys played with the items Whitney brought for them. Whitney gave Michael and his brother’s mom various items, such as gift cards for groceries and household items, toys and games the parents said would be appropriate and give joy to the boys, and relaxation tools for the parents. She also provided tip sheets that Eliana’s Light co-developed with partners in Spanish (as the parents are Spanish-speakers) on what to do in the case of various types of emergencies when they are at home with Michael, and also various calming techniques they can use at home.

With all the uncertainties about Michael’s current and future health, as well as how to ensure the family’s basic needs are covered over the long-term, stress can be high. Beyond the gift package Eliana’s Light gave them, we also connected the family to other local resources. We remain in touch regularly, more than a year since we received their application with the help of a social worker.

A = ADVOCATE

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

Highlights from Year Three:

- ✓ **We raised more than \$1,760 specifically for Children's National Hospital** in support of the development of an Integrative Medicine and integrative care services division this past year. Some of the more than \$22,000 we have raised in total for this effort went this year towards developing a "comfort room for caregivers" and purchasing 200 "comfort kits" and 200 "art therapy" kits for the Cardiac Intensive Care Unit's psychosocial team to use with and give to parents of in-patients. The kits are tools for building and strengthening emotional bonds that improve health and well-being.
- ✓ **We participated in more than 25 knowledge exchanges and advocacy meetings** to support whole health approaches to pediatric medical care.
- ✓ **Whitney Ortiz, Eliana's Light's Founder and President, gave a presentation on the importance of taking a whole health perspective when caring for children and their families** as part of an Integrative Care seminar at HSC Pediatric Center.
- ✓ **We managed the finances for the Healing Touch program at Children's National**, which a private donor is funding so nurses at the hospital can learn this approach for bringing greater relaxation to their pediatric patients.

In addition to serving families living in Washington, DC, Maryland, and Virginia, we seek to advocate for and support whole health approaches, Integrative Medicine expertise, and integrative care services at major hospitals and medical centers. In our third year, we continued to collaborate closely with the Child Life and social work team in the Cardiac Intensive Care Unit at Children's National Hospital who are now distributing 400 "art therapy kits" and "comfort kits" to in-patient families to help build the emotional bond between parent and child and reduce stress that the parent and child both experience in their own ways.

We also were thrilled that the comfort room Eliana's Light conceptualized and co-funded with the help of the CICU Family Fund is now operational! Parents can go to

this special room next to the Cardiac Intensive Care Unit to meditate, reflect, or just take a moment away from the intensity of the unit to gain a greater sense of calm. Most parents who have a child in the CICU experience overwhelming stress, anxiety, and trauma. This space gives them respite with soothing music, aromatherapy, yoga mats, meditation cushions, adult mandala coloring books, foot massagers, and other related items. The walls were painted a soothing color of blue, new comfortable furniture was added, along with some shelving for storage. One of our main collaborators, who is a member of our professional advisory committee, Emily Stein, gives a tour of the room through this video: <https://www.youtube.com/watch?v=4aMNSq0JyWo>.

We continue to collaborate with members of this hospital's leadership team as they move forward on plans to increase the coordination and mainstreaming of a greater number of integrative care services to more patients and caregivers (staff included). The hospital's Executive Leadership is committed to integrative care, and to developing evidence-based programming that coordinates, prioritizes, tracks, and funds integrative care services. We're thrilled by other developments there, such as an integrative medicine sickle cell clinic, a Mindfulness-Based Stress Reduction program, regular yoga sessions, and a physician wellness initiative, among other programs.

R = RAISE AWARENESS

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

Highlights from Year Three:

- ✓ **We engaged more than 2,100 volunteers in our community service programs and operations** that contribute to our mission.
- ✓ **We used four social media accounts and our email newsletter** to reach more than 1,100 followers and supporters (858 through social media and 328 via email).
- ✓ **We initiated new and maintained existing collaborations with more than 50 organizations, networks, and businesses** to enhance our reach and impact.

Collaborative Community Service

Bringing people together to help local families is central to our work. We offer numerous community service opportunities for all ages throughout the year. All are designed to give a boost to children and their caregivers while showing their

community cares about them. Volunteers gain from the enhanced connections they experience and when they know they've made a real positive difference in someone else's life.

Examples of community service programs from our third operational year include:

- 2020 Valentine's Day Cards for Kids & Cookies for Caregivers:** In 2017, we organized more than **80 volunteers** to make and deliver over **300 cards to children and 250 cookies to their caregivers** at Children's National Hospital on Valentine's Day. By the next year, our reach and impact had expanded tremendously. With the help of **1,101 volunteers, we delivered 2,395 cards and 504 cookies to six hospitals** serving children with complex medical conditions in Washington, DC, Maryland, and Virginia on Valentine's Day 2018. **In 2019, 2,003 volunteers from 6 states plus the District of Columbia**, made and delivered **3,883 cards and 1,655 cookies to 7 medical centers** in DC, MD, and VA. **In 2020, 2,262 volunteers from 16 states plus DC** made and delivered **3,569 cards and 1,604 cookies to 9 medical centers** in our region. *We've had huge increases in the number of volunteers, states, and medical centers participating each year. The number of cards and cookies we collaboratively make depends on the patient populations at each medical center around Valentine's Day. We only make and deliver enough so each in-patient gets a few cards and mostly all of the direct care providers get a cookie.*
- "Give A Boost to Moms for Mother's Day" and "Give A Boost to Dads for Father's Day":** 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 Hospital on Mother's Day 2017, as well as **250 stress balls to dads** staying at Children's National Hospital and the Children's Inn at NIH on Father's Day in 2017. **In 2018, we delivered 600 gift bags to moms and 600 gift bags to dads for these holidays at 6 medical centers. In 2019, we delivered 477 gift bags to moms and 234 gift bags to dads at 8 medical centers for these holidays.** The number of bags we make and deliver is based on the number of estimated moms and dads who will be with their hospitalized child over those holidays. Collaborating hospital staff members at the participating hospitals provide us with the number in advance of us putting the bags together with community members. These bags were filled with donated self-care items (e.g. toiletries, lavender sachets, stress balls, etc.) and gift certificates from local businesses, organizations, and individuals. Not only have we significantly increased our reach, but we were also able to give these caregivers more items to "give them a boost".
- Race for Every Child.** Eliana's Light organized a team again for Children's National's annual Race for Every Child. The 2019 Race took place October 19th in downtown Washington, DC. Eliana's Light specifically raises funds through this

race to support the development of an integrative care services and Integrative Medicine division/department at Children's National that will mainstream a larger number of a greater range of integrative care services to patients and their caregivers, while providing expertise from those with training in Integrative Medicine and related care modalities. We were pleased to raise an additional \$1,760 for this effort in 2019, and with those funds, help launch a new yoga program in collaboration with a social worker who has training in this area and works at the hospital. Eliana's Light has raised more than \$22,000 to date for integrative care at Children's National.

Additional events are listed in the *Fundraising* section of this report, as well as on the "Events" page of our website, which contains a complete list of all events held during our third 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 third year, we reached more than 2,000 followers and supporters via our website, newsletter and social media channels. The following is a breakdown of our reach via various communications channels:

- **Website** (www.elianaslight.org): Our website has attracted more than 3,000 unique visitors, visits and page views this fiscal year.
- **Facebook** (www.Facebook.com/elianaslight). We have 364 followers on Facebook.
- **Twitter** (www.Twitter.com/elianaslight). We have 141 followers on Twitter.
- **Instagram** (www.Instagram.com/elianaslight) We have 370 followers on Instagram.
- **Highlights**. We disseminate email updates to network members once every quarter.
- **YouTube**. (<https://www.youtube.com/channel/UCyze46yo2s9fIPrECQb0ceQ/featured>) We now have 10 videos on our YouTube channel, which mostly are of our recorded "Conversations With A Caregiver".

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

Shining Stars: Our Volunteers

As a volunteer- and community-based organization, we could not do this work without the help of wonderful members of our community. When kids and their caregivers come together to help other kids and their caregivers, the special moments are indescribable. Not only do volunteers make a positive impact on others' lives, they also gain from building stronger bonds with existing friends and creating bonds with new friends. We welcome and engage volunteers of all ages and from various organizations (e.g., schools, religious institutions, scout troops, sports teams, etc.).



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 Hospital, described above, we would like to recognize a few of our constellation's other bright stars:

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

families to each other's organizations for the unique forms of support we each offer.

- ***Parent Educational Training Center (PEATC)***
 The Parent Educational Training Center (PEATC) builds positive futures for Virginia's children by working collaboratively with families, schools and communities in order to improve opportunities for success in education and community life. Their special focus is children with disabilities. **Eliana's Light and PEATC collaborate on family referrals and learning events.**
- ***Pediatric Medical Centers in Our Region***
 As of early 2020, Eliana's Light collaborates with **Children's National Hospital, Inova Children's Hospital, the Kennedy Krieger Institute, John's Hopkins Children's Center, HSC's Pediatric Center, Medstar Georgetown University Hospital, University of Maryland Medical Center, and Medstar Washington Hospital Center** on our annual community service activities (i.e., "Valentine's Day Cards for Kids & Cookies for Caregivers", "Give A Boost to Moms for Mother's Day", and "Give A Boost to Dads for Father's Day"). **Staff members of these medical centers also tell parents/guardians of children who have complex medical conditions and receive care there that they can apply for additional support through Eliana's Light. Eliana's Light also collaborates with some of these medical centers in other ways that are explained in various sections of this report.**
- ***The Children's Inn at NIH***
 The Children's Inn at NIH is a "place like home" for children and families participating in groundbreaking research at the National Institutes of Health. Eliana's Light supports The Children's Inn at NIH in its efforts to reduce the burden of illness through therapeutic, educational, and recreational programming. **Eliana's Light regularly provides in-kind donations to children and their caregivers staying at the Inn, such as toys and books that promote relaxation. We also provide gifts for Valentine's Day, Mother's Day and Father's Day to residents.** In the future, we're planning to support programming within The Children's Inn that relates to the integrative care services.
- ***The HSC Health Care System***
 Eliana's Light is grateful for the opportunity to collaborate with The HSC Health Care System, which combines the resources of a health plan, pediatric hospital, home health agency and nonprofit foundation to serve and empower families with complex health care needs. **Eliana's Light and the HSC Health Care System, which includes HSC Home Care, collaborate by co-referring families to each other.**
- ***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.

- ***The Nanny Network***

Eliana's Light was thrilled to partner with The Nanny Network in 2019 in order to provide greater support to siblings of children who have complex medical conditions. Through our partnership, The Nanny Network kindly contributed 20 hours of free child care to families with multiple children who apply for support from Eliana's Light. Eliana's Light also supplemented additional child care costs as part of the personalized gift bags (i.e., "Constellation Kits") we give to families, thanks to the generosity of donors who contribute to this effort.



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.

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

Highlights from Year Three:

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

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

- Clinical & Translational Science Institute of Children's National Hospital and The George Washington University (CTSI-CN) (member)
- Palliative Care Parent Advisory Committee of Children's National Hospital (member)
- 2019 Race for Every Child Team (Captain)
- Children with Special Healthcare Needs Advisory Board (member)
- Professional Advisory Committee for Eliana's Light (founder/chair)
- Parent Advisory Committee for Eliana's Light (founder/chair)
- Youth Advisory Committee for Eliana's Light (founder/chair)

MONITORING & EVALUATION

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

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

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

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

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

REFLECTIONS ON OUR THIRD YEAR

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

A Parent Whose Family Received Support From Eliana's Light: *"Having two special needs children can be strenuous and financially daunting especially with no family support. Eliana's Light provided many resources and tools to help my family's situation. Our situation*

has been less stressful since we received assistance from them. We hope one day to pass the favor along and be a blessing in someone else's life the way Eliana's Light was a blessing in ours."

A Cardiac Intensive Care Unit Nurse Practitioner at Children's National Hospital.

"Eliana's Light is filling many gaps throughout our health care system. It's also giving a net to families when they go home after discharge. The accompaniment helps them feel they're not going to fall off a cliff."

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

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

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

LOOKING AHEAD

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

HOW WE'VE GROWN

4





FUNDRAISING & DONATIONS

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

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

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

We typically (i.e., pre-COVID-19) share with potential partners the following suggestions of donation levels:

- 10,000 enables us to support hospital-based programming that partners can help co-create with Eliana's Light, while they also enable us to give personalized care to 15 families.
- \$5,000 enables partners to co-create a new initiative with us, and also enables us to give personalized care to at least 5 local families.
- \$1,000 enables us to give personalized care to at least 2 local families.
- \$500 enables us to give a customized Constellation Kit to at least 1 local family.
- \$250 enables us to fill half of a Constellation Kit, which will be supplemented with in-kind donations we receive from our [Amazon Wish List](#) or through purchases we make from other financial donations.
- up to \$250 enables us to purchase items to include in Constellation Kits for families.

Below is the list of our programs that currently receive designated funding :

HEALING TOUCH

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

RACE FOR EVERY CHILD

Eliana's Light organized a team for Children's National Hospital's Race for Every Child in October 2019. As aforementioned, this collaborative effort with members of the community raised more than \$1,760 for integrative care services and related supports for a whole health approach to care at Children's National.

DONATIONS FROM INDIVIDUALS AND BUSINESSES

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

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

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

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

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

In addition, we encourage businesses to:

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

IN-KIND DONATIONS

Parents with children who have complex medical conditions, Child Life Specialists, and therapists carefully helped us select the items that are on our Amazon Wish Lists. These items are given as in-kind donations to create *Eliana's Light Constellation Kits* and gift bags for Mother's Day and Father's Day.

Our Amazon Wish List for the *Constellation Kits* contains options for children of various ages and capabilities, and also items for their caregivers. It can be accessed at: https://www.amazon.com/gp/registry/wishlist/34MIV25ZGRIOV/?ref=nav_wishlist_lists_1.

Our Amazon Wish List for making Mother's Day and Father's Day gift bags contains stress-relief items for adults that our parent advisors and also specialists at our partner medical centers suggested. The direct link is: https://smile.amazon.com/hz/wishlist/ls/3F2XBZ572OD12/?ref=nav_wishlist_lists_2?_encoding=UTF8&type=wishlist.

We received in-kind product, clothes, and book donations with a total value of at least **\$3,000 this past year.**

Beyond the gifts we received from our Amazon Wish List, we also received a great deal of in-kind professional support. We are tremendously grateful to the following companies and organizations that provided support to Eliana's Light during our Third Fiscal Year:

- **All the participating medical centers:** Collaborated on disseminating Valentine's Day cards, as well as cookies and gifts on Mother's and Fathers Day. Also informed caregivers of the services we provide to local families. The following medical centers collaborated : Children's National Hospital, HSC's Pediatric Center, Inova's Children's Hospital, Kennedy Krieger Institute, Johns Hopkins Children's Center, Medstar Georgetown University Hospital, Medstar Washington Hospital Center, University of Maryland Medical Center, and the Children's Inn at NIH.
- **Beltway Bambinos:** Promoted our community service activities.
- **Bloom OB/GYN and Stork:** Organized Valentine's Day card-making event and contributed gift cards for Mother's Day and Father's Day.
- **Building Blocks Therapy:** Made in-kind and financial donations to support families.
- **Cole Tax Services:** Donated accounting services.
- **Fit4Mom of Montgomery County:** Donated time to organize their members for participation in our community service activities.
- **Gabrielle Marchand with Georgetown University's Social Impact Communications Program:** Donated communications support.
- **Jill Shalett Bookkeeping:** Donated bookkeeping support.
- **Kuvio Creative:** Grant of 60 hours of professional services to design a fundraising campaign and branding colors, and also develop a fundraising video.
- **The Nanny Network:** Organized members to participate in Valentine's Day card-making event, organized gift card drive for Mother's and Father's Days, and donated 20 hours of sibling care time.
- **Wellness by Shari:** Donated expertise in Healing Touch other modalities.

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

The volunteer members of our community who collaborate with us to share their professional expertise and/or give family members a boost during Valentine's Day, Mother's Day, and Father's Day are true stars in families' *Constellations of Care*. Taking

into account the volunteer hours of our professional volunteers (generalized at eight hours per volunteer), and the more than 2,000 volunteers who worked with us on our community service projects (generalized at four hours per volunteer), volunteers donated more than **9,500 hours of work** in our third Fiscal Year, valued at **\$241,585** (with \$25.43 as the recognized hourly value of volunteer time, as according to the Independent Sector: <https://independentsector.org/news-post/new-value-volunteer-time-2019/>). This calculation does not take into account the dozens of staff members at participating medical centers who distributed cards, cookies, and gift bags to patients and their caregivers.

YEAR THREE EXPENDITURES

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

Item	Cost
Business/Non-profit fees	\$1,098.29
Gifts for caregivers, kids and/or families (including supplies for Valentine's Day, Mother's Day and Father's Day events)	\$9,245.13
Board Insurance	\$2,236.00
Legal, consultant and professional fees	\$6,225.00
Healing Touch Program	\$5,355.00
Supplies for events	\$325.00
Administrative supplies (ink toner, paper, water and snacks for events, business cards, other event supplies, etc.)	Donated (-\$207.36)
Gas to get to meetings with families and partners	\$1,266.50
Printing & copying	\$11.04
Website	\$197.32
Advertising to potential applicants and for events (e.g. flyers with information on how to apply, which we give to staff at participating medical centers to give to caregivers)	\$1,012.71
Mailing remaining Dr. Breyer books from previous FY progr	\$350.41
Other business expenses	505.79
TOTAL EXPENSES	\$27,620.83
NET INCOME	\$4,119.45

5

WHERE WE'RE HEADED





YEAR FOUR GOALS

We invite your engagement and collaboration in 2020 as we focus on supporting families experiencing significant hardship as a result of COVID-19. We continue giving personalized **C.A.R.E.** for families in our community, and now focus on helping them cover basic needs. The families we support are under tremendous financial, mental, physical, and emotional stress every day, and COVID-19 has exacerbated their difficult circumstances. 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 provide intensive ongoing support to at least 50 more families that apply**, providing them with financial support to help them buy needed food and pay for rent, utilities and other bills. We will also connecting them to additional services, specialists, and organizations. We are increasingly playing a “care coordination” role with diverse and non-traditional care providers (e.g., therapists, food banks, housing authorities, etc.).
- **We will participate in at least 2 learning events organized by partner organizations** in order to reach more families and demonstrate how our organizations collaborate to create *Constellations of Care*.

ADVOCATE

- **We will continue to develop and use 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 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.
- We will post resources regularly on our website and through our social media channels to help local families access needed resources.

HOW YOU CAN HELP

DONATE!

Financial and in-kind donations help us provide needed financial relief during COVID-19, 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. Every amount can make a positive difference.

While the following is our regular breakdown of how funds are used from donations, we are currently putting all donations towards helping families cover basic needs:

- For \$10,000, you can co-create new programming with us related to a specific aspect of whole health for families with children who have complex medical conditions.
- For \$5,000, you can sponsor an aspect of our C.A.R.E. framework.
- For \$3,000, you can support three families over at least three months each.
- For \$1,000, you can meet the immediate needs of two local families.
- For \$500, you can meet the immediate needs of one local family.

- **For financial contributions of less than \$500**, you can contribute to our support for a local family by enabling us to purchase relevant items for tailored *Eliana's Light Constellation Kits* and also develop relevant tip sheets and learning events.

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

- **Contribute to our *Eliana's Light Constellation Kits*** by making an in-kind donation from our [Amazon Wish List](#).
- **Host a fundraising event** for financial or in-kind donations. Many partners and volunteers are hosting virtual fundraisers on social media.
- **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 sharing positive messages with us to health care providers and caregivers.
- **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 supermarkets, 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

ANNEXES

6



A. KEY DEFINITIONS

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



Children With Complex Medical Conditions: Children who have one or more chronic conditions associated with morbidity and/or mortality; have high health care needs and/or utilization patterns, including requiring multiple specialists, therapists, and/or surgeries; have many unexpected and long hospital stays; endure multiple medical procedures and/or surgeries; are dependent on technology and/or devices and/or multiple medications to overcome functional limitations; and often need home nursing care and/or care coordination.

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

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

NIH's National Center for Complementary & Integrative Health provided this definition in 2020 that we also use: "Integrative health emphasizes a patient-focused approach to health care and wellness – often including mental, emotional, functional, spiritual, social and community aspects – treating the whole person rather than, for instance, one organ system."

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

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

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

and vitality.”³ Note that when a child is in-patient within a medical facility and receives IM or has access to an IM program, this is usually part of a medical care program and approach.

Integrative Care: This is used to denote “personalized, participatory, and relationship-based care, promoting optimal health. It emphasizes healing of the whole person to achieve each individual's unique physical, emotional, mental, spiritual, and social health goals. The primary therapies used to achieve these goals are healthy habits (nutrition, activity, sleep, mindful self-care, and fellowship) in a healthy habitat (social, natural, and built environment). Integrative health care skillfully uses the best of both conventional and complementary strategies to attain patients' health goals.”⁴

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

Mind-body Medicine: "Mind-body medicine is based on the scientific understanding of the inextricable connection among our thoughts, sensations and feelings, and our mind, body, and spirit – between ourselves and the social and natural world in which we live." [Center for Mind-Body Medicine](#)

Whole Person Health: “Whole person health considers the whole person and the relationships among numerous factors, including biologic, environmental, behavioral, mental, and social factors, in determining health.” NIH’s National Center for Complementary & Integrative Health.

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.

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

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

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

BOARD OF DIRECTORS

Natalia Isaza Brando, MD

Neonatology Attending Physician, Children's National Hospital (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 Hospital. 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.

Golrokh Fassihian

Strategic Marketing & Communications, Advocacy, Public Relations Specialist; Mother of Child with Complex Medical Condition

Golrokh ("Goli") has 20+ years of combined experience in strategic marketing and communications, advocacy, and public relations having worked on large global outreach programs within the U.S. Government as well as the commercial and non-profit sectors. Over the years, she has worked on maternal and child health, HIV and AIDS, reproductive health and family planning both within the U.S. and internationally. She has held leadership positions within the U.S. Agency for International Development and the healthcare practices of several top public relations agencies. Goli holds a Master's in Public Health from Columbia University's Mailman School of Public Health and a BA in International Relations from George Mason University. In 2016, Goli paused her career to become her son's caretaker when he was born premature at 24 weeks gestation. Goli joined the March of Dimes as their Senior Director for Audience & Multichannel in 2019.

SangHee Lynn

Social Worker; Mother of Child with Complex Medical Condition

SangHee is a mom of two beautiful boys, one of whom has a complex medical condition. She's also a social worker who provides comprehensive social work services to young people and their families in the District of Columbia. Having supported her own child and worked within organizations such as Catholic Charities and The Kennedy School, SangHee knows intimately what's involved in managing, implementing, and overseeing healthcare plans; communicating with specialists; and advocating for, setting up, and using assistive devices and medical supplies. Originally from South Korea, she's actively engaged in Korean cultural events through the Korean Heritage Foundation, Korean Government, and the Smithsonian. She has a certificate in Basic Programming for all AAC Devices (Communication Devices for non-verbal people); is trained in Tracheostomy Care, Gastrostomy (Feeding) Tube Care, and CPR. SangHee is fluent in Korean and English, and has significant mastery of American Sign Language.

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 Hospital 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.

Gillian Rai

Founder, SubLime Kidz and Sublime Living; Occupational Therapist; Professor

Gillian is a South African native, mother of 5, entrepreneur, community service social advocate and champion of whole health approaches to care. She's a passionate and innovative educator, coach, international speaker and Occupational Therapist (OT) committed and dedicated to working with children, adults and families in diverse, inclusive and multicultural settings. Dr Rai is the founder and principal owner of SubLime Kidz and Sublime Living LLC, a holistic

Occupational Therapy practice serving families in DC, MD and VA, as well as around the globe. Dr Rai is also an adjunct professor in the OT department at New York University (NYU) where she teaches Pediatrics and Teaching in the Health Professions. Additionally, she also serves as Commissioner on the DC Board of OT and is the former director of the GWU Occupational Therapy Doctorate program.

ADVISORY COMMITTEE

Dr. Elva Anderson

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

Ms. Caryn Anthony

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

Ms. Donna Anthony

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

Dr. Elizabeth Bettini

PhD, Advanced Practice Registered Nurse (APRN), Psychiatric Clinical Nurse Specialist (PCNS-BC), Certified Hospice and Palliative Care Nurse (CHPCN), PANDA Palliative Care, Children's National Hospital; 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 Hospital; 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

Cal 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), formerly Shift Coordinator, Heart & Kidney Unit, Children's National Hospital

Dr. Karen Fratantoni

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

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); formerly Clinical Instructor, Co-Chair of Nursing Advocacy Council, Cardiac Intensive Care Unit, Level II Healing Touch Practitioner, Children's National Hospital

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 Hospital

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 Hospital; 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. Judy Ross

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

Ms. Pleasance Silicki

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

Ms. Terry Spearman

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

Dr. David Steinhorn

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

Dr. Lillian Su

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

Parent Advisors

Rashida Humphrey-Wall

LaJoy Johnson-Law

Maura Perez

Brittany Vance

Youth Advisors

Maya H.

Molly Y.

Jose G.



Eliana's Light

Fiscal Year 3 Second Annual Report April 1, 2019 – March 31, 2020

Copyright © 2020 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](https://www.facebook.com/elianaslight) * [www.Twitter.com/elianaslight](https://www.twitter.com/elianaslight) * [www.Instagram.com/elianaslight](https://www.instagram.com/elianaslight) *