



Helping a Family Cope After a Cancer Diagnosis

On his 16th birthday in December 2019, Luis got in the shower to get ready for his day to celebrate. When he stepped out of the shower his whole world fell apart. He was immediately short of breath and thought he was having one of his asthma attacks, but when he started vomiting he knew something much worse was happening.

His mother, Melissa, took him to the hospital where tests showed a mass on his heart the size of a cantaloupe. When they learned the diagnosis was a rare heart and lung cancer called Thymic Neoplasm, Melissa said she froze in a panic.

"I am a single mother with no mother and father to help, so it's just me and Luis, and I had no idea how I would get through this," Melissa recalled. "My whole world just crashed. I was already working double shifts at my customer service job at a butcher, but I still struggled to pay my bills. No matter what, I knew I had to quit my job to be with Luis through it all."

By the time she met with the hospital social worker weeks later, she was afraid Luis would not have a home to come to as her landlord was about to evict them from their apartment in the Bronx. The hospital social worker referred Melissa to Friends of Karen, and after completing the intake

process, she was paired with Friends of Karen social worker Rhonda.

"It was a blessing to meet Rhonda and she jumped right in," Melissa said. "She got me financial help to pay my back rent and Friends of Karen assisted to help me keep up with the payments. That was the only way I could be with Luis throughout his treatment, and to make sure he was getting enough sleep and eating enough to stay strong."

Melissa shared that it was not easy to accept help as she had been on her own and taking care of herself since she was 16. She is glad Rhonda was there to help her cope with the stress and help her understand Luis' medical conditions and treatment options. She is grateful that Friends of Karen provided food assistance, including ensuring they could buy food for a nice Thanksgiving meal, and that they made sure Luis had a comfortable new daybed to recuperate in after treatments.

To date, Luis has endured treatment that has included surgery to remove the tumor, chemotherapy, and radiation. He lost several critical months when COVID-19 interrupted his access to the hospital after treatment ended in early 2020. By the time he could safely go



Luis

back to the hospital for checkups the cancer had spread to his lungs. The doctors found seven new tumors, so he continues to receive chemotherapy in the hope of keeping him stable.

While Luis' illness has left him with multiple challenges due to treatment, he and Melissa are living by her motto to never stop fighting and keep pushing forward and harder. Luis is looking forward to his senior year of high school. Despite a pandemic and Luis' cancer, Melissa is celebrating graduating with an associate's degree that is her first step towards helping others through a career in the healthcare field.



A gold ribbon is the universally recognized symbol for childhood cancer awareness. Gold is precious, like the most precious thing in our lives — our children. At Friends of Karen, we are #alwaysgold in support of our children and their families who face the consequences of childhood cancer year round. Join us in giving them the help and hope they so deserve in September and all year long. This issue provides a glimpse into the path families take with Friends of Karen's Family Support Program during the child's journey from cancer diagnosis through treatment, and sometimes the family's grief.



friendsofkaren.org

Our Mission

To provide emotional, financial, and advocacy support for children with life-threatening illnesses and their families, in order to help keep them stable, functioning, and able to cope.

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Sheila Petersen (1938-1990)

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Welcoming Families to a Circle of Support



Estel

When parents learn their child has cancer they are immediately thrown into an overwhelming crisis. The child's medical care team gives them a thick binder mapping out what the child's treatment will look like for the next months or even years. But, no one gives parents a binder on how to cope with the many ways their child's cancer diagnosis will upend their lives

When a hospital social worker refers parents to Friends of Karen, no matter how much they are struggling financially or emotionally, they don't often always call right away. Many times parents are trying their best to juggle everything on their plate, or they think someone else needs help more than they do.

The day they do decide to call, they will reach the reassuring voice of Friends of Karen Intake Coordinator/Case Manager Estel on the other end. Estel interviews parents to determine whether or not they meet the criteria to receive services. Spanish speaking families go through the interview process with Estel's colleague Elvira. Those initial phone conversations are more than a simple screening interview, according to Estel.

"It's an opportunity for a parent or guardian to share the details of what led up to the diagnosis and the very personal experiences they've had while taking care of their sick child," Estel observed. "It's a place to establish trust between the Friends of Karen staff and the families that we serve. It's allowing a mom or dad to be heard during an extremely difficult time."

Even if the child's diagnosis is the same as in hundreds of other children we have worked with, every family and situation is different and each intake is done respecting that this family is unique.

During an intake, the information collected is used to help get an understanding of the stage the child is in of his or her cancer treatment, what the family structure looks like, and to discuss the family's finances. This discussion is conducted in a way that is not too intrusive, but gives a clear idea of the state of the family's finances prior to diagnosis and what they look like now.

Often parents don't even have a quiet moment to participate in an intake. Estel has done intakes with parents who are in their car on the highway leaving the hospital, or on a city bus or train. Sometimes, they are in their child's hospital room bathroom because that is the only place they can take a moment to themselves. After the intake interview, to complete the process she sends an application to the family either at home or to the hospital social worker if the child is in the hospital.

"To say that these parents are overwhelmed is an understatement, yet they are able to somehow find the words to articulate their situation and begin to access the support they need," Estel said. "The entire intake process is more than just an introduction to the organization. It lays the foundation for what Friends of Karen will do to assist families."

Faces of Childhood Cancer

Briany,
14 years old



Who We Serve

A child, newborn through age 21, diagnosed with a life-threatening illness is eligible to receive Friends of Karen services. The child must be a US citizen or lawful, permanent resident of the US, and must reside in the guideline area for 12 months prior to diagnosis.

Staying with Families Every Step of the Way

By Beth Ferrari, BSW, Social Worker, Family Support Program



Beth

When a crisis happens in your life it feels like time stops. It leaves you reeling and you struggle to find your way back to a stable place.

Imagine what it would be like if someone stepped in, stood with you and guided you from the moment that event began to upend your life. When I work with the families assigned to me, I am that consistent person supporting them every step of the way. I am a social worker on the Friends of Karen Family Support Program team that consists of social workers, child life specialists and creative arts therapists. Together, our ultimate goal is to help families remain stable, functioning, and able to cope throughout the child's illness.

"...when a family is rocked by a child's cancer diagnosis, every aspect of their life changes."

That isn't easy because when a family is rocked by a child's cancer diagnosis, every aspect of their life changes. I am there to help every member of the family navigate through this new and complicated world.

After the family completes the intake process, they get paired with the social worker that will stay with them through every phase of their journey. I start by

speaking with the parents and completing an in-depth assessment to determine the services they will receive, including a referral to our Sibling Support program. Since I am in touch with the family often, I am able to respond to their needs as they change. I advocate for them and provide the financial support to pay their bills and provide the psychosocial supports they need to cope. (see Sidebar).

Prior to the COVID-19 pandemic, I would meet with families at the hospital or in their home. For more than a year, these conversations have happened on the phone or via video chats.

Friends of Karen's goal is to eliminate barriers to getting help, so we respond quickly when a family is in crisis. For example, when I hear a family can't pay their rent or there is no food in the refrigerator, we provide financial assistance quickly.

All Friends of Karen social workers are trained and experienced working with children who have a life-threatening illness like cancer. Because nearly 90% of the children we serve have some form of cancer, we help families address a wide range of issues that arise from cancer's impact on their lives. Because of our depth of experience, we can anticipate many of the problems families will face and can help them plan for or avoid these pitfalls and challenges.

When the child finishes treatment, the family will receive periodic check-ins from our case managers. During these conversations, we learn if any new issues have arisen or if the child has relapsed. If they have new needs, their social worker will be alerted to work with them again. If a child passes away, we will be there for the family and offer bereavement support to the family. Every family member we serve gets this personalized approach, and can be reassured that they never have to go through their child's cancer alone.

Psychosocial Supports

According to the National Institutes of Health's National Cancer Institute, psychosocial support is defined as "support given to help meet the mental, emotional, social, and spiritual needs of patients and their families. Diseases, such as cancer, can affect a patient's thoughts, feelings, moods, beliefs, ways of coping, and relationships with family, friends, and co-workers. There are different kinds of psychosocial support that can help cancer patients."

Here are just a few examples of the many different psychosocial supports Friends of Karen provides: disease education, assistance with insurance issues, assistance with special educational needs, connecting families to relevant organizations and government programs, referrals for legal assistance, sibling support, end-of-life and bereavement support, and a gifts program to mark holidays and milestones.

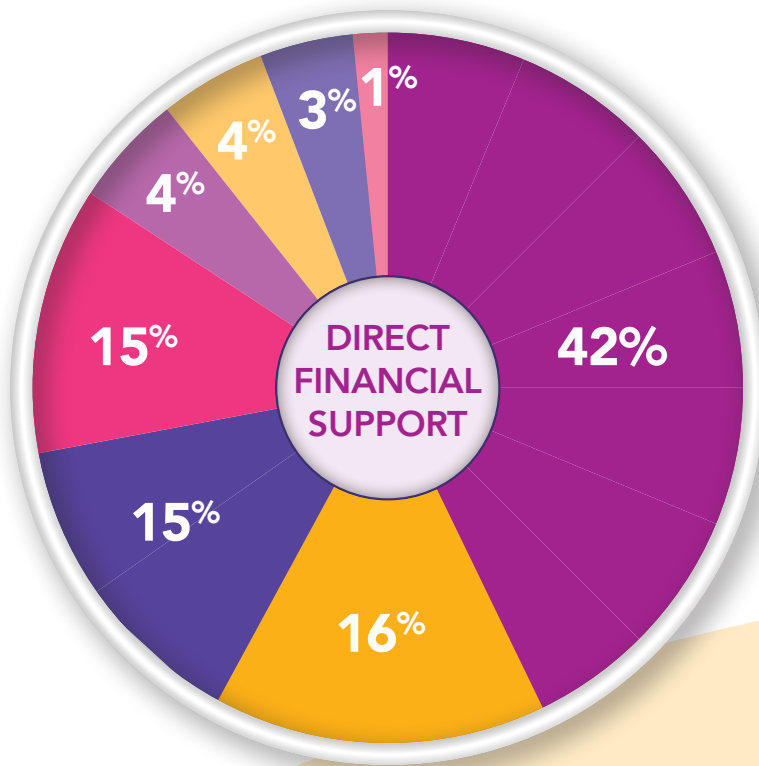
Faces of Childhood Cancer



Eliana, 6 years old

How We Support Families

During Fiscal Year '21 (4/1/20 through 3/31/21) Friends of Karen provided families of seriously ill children with direct financial, emotional, and advocacy support to help them remain stable, functioning and able to cope. This direct financial support includes the following assistance:



Housing & Utilities \$557,600



Food \$215,200



Gift Programs \$205,400
(Birthdays, Holidays, Back to School)



Hospital Travel / Auto \$198,350



Funerals & Bereavement \$52,100



Clothing \$48,300



Hospital/Medical \$40,200



Childcare \$12,600

Note: Friends of Karen's Family Support Program staff also provide critical emotional and advocacy support to the families we serve. Along with our educational services, these vital services brought our total support to families to more than \$3 million in FY '21.

"While you have been working with us for many years to ease the burdens felt by our families, we are especially conscious of the efforts you have made this past year, under the stress of a pandemic, when the need has been even greater, and the fund-raising less available. You have made it possible for us to continue to provide relief to families all-the-more needy, thanks to your being ever-present in the most challenging of circumstances."

— Pediatric Oncology Social Work Team at
Cohen Children's Medical Center

Faces of Childhood Cancer



Kathleen,
10 months old



Matteo,
5 years old

Looking Forward: Christopher's Story

Christopher, 25 years old, was diagnosed with Leukemia at age 20, just 10 days before starting college. He reflects on his journey then and now.

How did cancer change your daily life?

This journey has made me appreciate every day. I realized that life doesn't always go as you plan it and to just take what life throws at you. I became a more positive person. I realized how strong I really am. I was able to see who my true friends and family are.

What did Friends of Karen do for your family that meant the most to you?

Many times when a family member is sick, the attention is focused on that person, and not the family and friends around them. Friends of Karen has helped my family feel included and listened to during a difficult time. My brother and sister were sent gift cards also on holidays and birthdays. It made them feel special. Seeing how much Friends of Karen has helped us, made my family so happy and very grateful.

As you neared the end of your treatment, what did you look forward to the most?

The sense of accomplishment knowing

that I finally beat cancer after almost four years. Knowing that my family's worries and stress about my health will be lessened.

What kind of work do you do?

I buy and sell antiques and collectibles, and I love what I do. I have been doing this since I was 13 years old. I got into it when my great Grandma passed away. Her house was full of antiques and amazing stuff she collected over the years, and it sparked an interest in me that kept growing. I now have my own collection of amazing antiques.

What do you like to do in your spare time?

I like to spend my time with family and friends. I go upstate every few weeks to hang out with friends and get away for a little bit.

Why is it important to you to "pay it forward" and how have you gone about helping others?

I find it important to help others because that one small act of kindness could mean the world to that person. You never really know what someone is going through. While I was an inpatient at the hospital many times the first year of my treatment, I always tried to find ways to help others.



Christopher

During Christmas time, I made paper snowflakes to hang up around the hospital floor. It was a very boring place and I thought it needed a little shine to lift people's spirits. During Easter time, I bought dozens of plastic eggs, filled them with candy and put inspirational quotes inside. I passed them out to all of the doctors, nurses and patients.

When I went back to college after my first year of treatment, I joined the American Cancer Society's Relay for Life on campus. I have also spoken at two Friends of Karen galas and serve on the Friends of Karen Long Island Advisory Board. If my story can help others get through their difficult times, it would mean the world to me.

"I can truly say that I would not be able to be as effective as I am without Friends of Karen. I am always confident that any issue will be handled with professionalism and compassion. I witness the relief in a family's face and voice when they hear that they will be helped with bills or emotional support. I have also witnessed how Friends of Karen has evolved and changed with the times and the needs of the community with their own additions of unique and valuable programs such as sibling support and grief and bereavement."

**— Barbara McLain, LCSW, Social Worker,
Pediatric Palliative Care Team, Maria Fareri Children's Hospital**

Sibling Support Program Nurtures Powerful Expression of Feelings



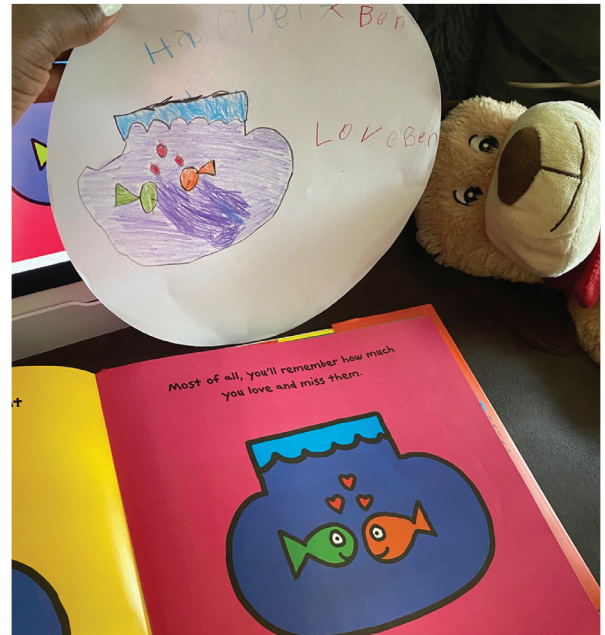
Crosby's drawing shows the hospital where his sister is being treated.



Angelina made a wand and her sister Sandra and brother Xavier made shields to illustrate how they would all fight Angelina's cancer together.



Nicolette drew all of the different feelings she has in her head and heart. Nico's mask displays two different feelings that he shows to others.



This drawing by Harper helps process his grief for his deceased brother after reading the goodbye book.

Bereavement: Helping Families as They Grieve

By Rhonda Ryan, LMSW, Director, Family Support Program

Sadly, not all of the children we help at Friends of Karen survive their illness, but Friends of Karen's help does not stop after the death of a child. Since the organization was established, we have been providing grief support to families.

Friends of Karen's bereavement help includes supporting parents through phone calls and visits, support for siblings from our child life specialists and art therapists, grief books for parents and siblings, cards and small gifts to acknowledge the birthday of the deceased child or the anniversary of their death, and an annual memorial ceremony. We continue to send birthday gifts and holiday gifts to siblings for one year after the death of their brother or sister, so siblings know they are not forgotten.

This year, due to COVID, we found new ways of helping our bereaved families. One of those ways was to begin a virtual parent support group held on the third Thursday of every month. We have an English speaking and a Spanish speaking group running simultaneously. The groups are led by members of our Social Work team.

While we have run support groups in the past, we are finding virtual sessions are attended more regularly due to the convenience. Also, we can reach families in all three states we serve that otherwise would likely never meet, which has created a diverse group of parents who all share the same pain of losing a child due to illness.

Unlike other bereavement groups, our group is only for parents who have had a child die as a result of illness. The impact of that is clear, as one parent recently noted that "I went to another group, but I could not relate to other parents whose child did not die because of an illness, I need to talk about what my child went through, and everyone here understands." Another parent added, "People compare the death

of their mother or aunt or grandmother to the death of my child, but it's not the same. Only this group can understand the pain and heartache of experiencing the death of our children."

"Only this group can understand the pain and heartache of experiencing the death of our children."

Another parent shared, "This is the only time I allow myself to really cry. It is my time to fall apart where my kids don't see me."

What I find most powerful about a group like this, is that parents actually think the thoughts they are having are crazy, until they hear what other bereaved parents are thinking, and then they realize they are not crazy after all. Going to a grief group often normalizes the grief process and this is critical because it helps people realize what they are experiencing is expected.

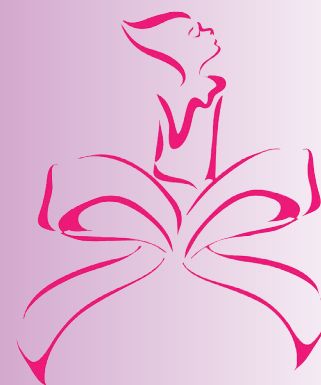
From my experience as a social worker, I know an effective group is one that works together and helps each other by making themselves vulnerable enough to share their pain and experiences. That communicates to the group that this is a safe space where they can help one another. From the feedback we have gotten from parents, we have achieved this safe space, as they often tell us how grateful they are for this group.

This safe space extends beyond the first year after families lose a child. We have families that attend the annual memorial ceremony each year and many parents remain feeling connected to Friends of Karen and stay in touch years after the death of their child because we were such a big part of their journey.

In Loving Memory

Honoring the lives of our children who have died from March 1, 2021 to July 15, 2021

Angel.....15 years
Owais18 years
Zyasia17 years
Josniel11 years
James8 years
Adxel15 years
Patrick.....5 years
Hugo6 years
Randy15 years
Gabriel19 years
Finley1 year
Anna19 years
Ethan10 years
Christine17 years
Leanna6 years
Nosima17 years
Roxana1 year
Josnell3 years





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"It is heartwarming
to be the
beneficiary of an
organization that
has people like you
reaching out to
offer support."

– Sara

When you have finished reading this
newsletter, please share it with a friend.

CHILDHOOD CANCER AWARENESS MONTH ISSUE

As of
June 30,
2021

86%

of children served by
Friends of Karen have
some type of cancer.

Of those 86%,
the types of
cancer are:

14%

BRAIN
TUMORS

26%

OTHER
CANCERS

60%

LEUKEMIAS/
LYMPHOMAS



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list and stay current on all our programs and activities.