



A Survivorship Story: Supporting the Transition After Treatment

Friends of Karen began a pilot program in late 2022 to continue to provide a limited number of supports to children who have gone off formal treatment, but continue to have serious healthcare, social and educational needs. Olivia's mother Johanna shares more below about how Friends of Karen has helped her family during this crucial stage, after Olivia was treated for Medulloblastoma, a brain cancer that occurs most often in young children.

"Olivia was three years old when she started to vomit all the time and was having balance issues. After several doctor visits with no resolution, we went to the Emergency Room and Olivia had a CAT scan that showed a brain tumor. I felt like my heart just stopped.

It took seven days to find out Olivia had Medulloblastoma, and then she needed two surgeries. The doctors tell you ahead of time about the side effects of the surgery, but we were barely surviving. It was hard to see that Olivia's whole right side was paralyzed and she could not speak or walk.

I am the kind of person that needs to feel in control and illness isn't something you can control. It made me look at the future differently, and at that moment my hopes and dreams changed for Olivia. I just wanted her to live. Nothing else really mattered.

While I spent many sleepless nights at the hospital, I got a look behind the curtain at what our life would become. I needed others who understood what we were going through, so I researched resources every night and near the end

of Olivia's treatment I found Friends of Karen. During Olivia's treatment we received emergency food assistance and help paying COBRA for our health insurance, which lessened our worries.

At this point, Olivia had endured eight months of inpatient care, and being discharged carried big emotions and new challenges for us all. We were trying to heal, cope and adjust to our new life while trying our best to parent and help our daughter process the trauma she experienced. I found a play therapist for Olivia, but it wasn't helping. I had spoken to different counselors myself, but I found I spent so much of each session describing the medical terms or updating the therapist on my daughter's care that I never got the help I needed.

I was in contact with Friends of Karen social worker Alyssa who suggested the organization's Sibling Support Program and Olivia was paired with child life specialist Melissa. My hope was that Melissa would be able to provide resources in navigating Olivia's behavioral changes, and how I could support her transition to living isolated at home. This transition has also been eased by Friends



Olivia enjoying a moment of fun dressing up for a photo.

of Karen's Survivorship Program paying for Olivia to have music therapy to help address separation anxiety and for developmental stimulation.

Melissa is different because she understands the medical procedures and the experiences we had. She helped me to anticipate and best prepare for new experiences and eliminate anxiety. She is a sounding board for decisions I am preparing to make and navigating conversations with Olivia's care team and advocating for her. She is there to help me understand the issues for Olivia in school, and what our life will look like when the support finishes. We are so grateful for Friends of Karen helping us through this stage of Olivia's life."



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.



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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FROM OUR EXECUTIVE DIRECTOR

Support Changes Lives.



We dedicate this issue of *Connections* to children present and past who have had their life upended by cancer. Every September we mark Childhood Cancer Awareness Month by spotlighting the children helped in their cancer journey by Friends of Karen, and by raising awareness of the prevalence of childhood cancer and the devastating impact it has on the whole family. Consistently, more than 80% of the children we support each year are diagnosed with some form of cancer.

That's why our hashtag, **#alwaysgold** — gold being the color that symbolizes childhood cancer — represents our year-round focus on being a lifeline for these children and families.

But did you know that Friends of Karen also supports children with life-threatening illnesses besides cancer? Often we are the only help available to them. Presently, we are assisting 10 children undergoing bone marrow transplants, the only known cure for sickle cell disease. In September, we also acknowledge Sickle Cell Awareness Month by recognizing the strength of children living with this painful disease, in the hope of improving their quality of life and health outcomes. Burgundy is the color symbolizing sickle cell disease.

Besides wearing a gold or burgundy ribbon to show your support for the children suffering from these debilitating illnesses, what can you do?

One effective way is to **make a contribution to Friends of Karen**, to provide the resources to help these children and their families. Your contribution will assure that children receive the medical care they need, have the means to get to treatment, have a place to live that has heat and electricity, have healthy food to eat and clothes to wear, and have the steadfast support of our outstanding social workers, child life specialists and creative arts therapists. We depend on your generosity so that children will have the best chance to beat their illness and families will have the wherewithal to survive the trauma a child's life-threatening illness brings.

There's an envelope enclosed and a QR code below to make giving easy. It's you, our dedicated partners, who bring help and hope to children and families all year long. Thank you.

With much gratitude,

Judy

Judith Factor
Executive Director



Scan the QR code to be taken to our secure website to make your contribution and become a vital link in the lifeline for a critically ill child and their family.

"We depend on your generosity so that children will have the best chance to beat their illness..."

Helping Children Understand Leukemia

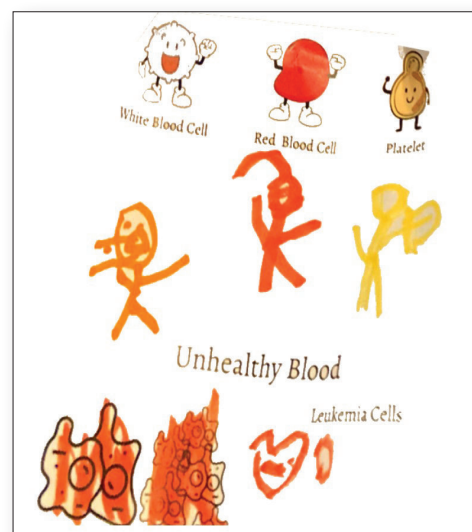
Sibling Support Program

Our Sibling Support Program team of four child life specialists and creative arts therapists knows that learning about an illness is different than understanding it. Often when illnesses are not explained to children in an age-appropriate manner they may fill in the gaps with their imaginations, creating stories that may be even scarier than the reality. To help ill children, siblings and their parents understand how Leukemia affects a child's body, our Sibling Support Specialists provide an interactive illness education session.

The Sibling Support Specialist begins by explaining that Leukemia is cancer of the blood, and guides in exploring the parts of the blood (red blood cells, white blood cells, and platelets inside plasma) using a worksheet Friends of Karen staff created. After learning how each of these parts function, the child writes about or draws pictures of the cells in action. The Sibling Support Specialists will often use the book *Chemo to the Rescue: A Children's Book about Leukemia* by Mary Brent and Caitlin Knutsson, in tandem with the session.

The next step is to create some "healthy blood." In a small container we use water to represent plasma, the liquid portion of our blood. Then, we add two different colored beads; red (red blood cells that transport oxygen) and white (white blood cells that fight off germs), and a jeweled sticker to hold things together like platelets that help our blood clot.

Then we make a sample of "unhealthy blood" that is the same as the healthy blood but has one major difference - there are Leukemia cells represented with small balls of tissues. Once the tissue balls are in the water they enlarge and take up space. This represents how Leukemia cells multiply rapidly and minimize the space for the other healthy blood cells to do their job, resulting in side effects like, being tired, bruising easily, and getting sick more often. Friends of Karen Sibling Support Specialists complete the session by explaining how chemotherapy and radiation can help get rid of the Leukemia cells. We will often give children the opportunity to "act like chemo" by removing the tissues/Leukemia from the blood.



Regina's Leukemia worksheet helped her understand how cancer affects the blood.



Johnny and his twin sister Julie read the book *Chemo to the Rescue* to learn more about how treatments help children with Leukemia.

FRIENDS OF KAREN

45th Anniversary Gala

SAVE THE DATE

11.3.23 | GUASTAVINO'S NYC | 6:00PM

HONORING



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RESERVE YOUR TICKET TODAY!

SPONSORSHIP & GIVING OPPORTUNITIES AVAILABLE



UPCOMING EVENTS

Show your support by joining us at one of our events, a great opportunity to meet our staff, board members, and the families we serve.

Journey of the Heart Bike Tour

Sept. 30-Oct. 1, Bicycle Tour Company, Kent, CT

Adina's Angels 5K Walk

October 8, Rockland Lake State Park, Valley Cottage, NY

Mamma Rosa's Italian Dinner

October 17, Mamma Rosa Ristorante, Somers, NY

45th Anniversary Gala

November 3, Guastavino's, New York, NY

For more information, visit our website at friendsofkaren.org

Because of You...



Alexis Menendez, owner of Street Beatz Dance Studio, organized and hosted "Dancers Against Cancer" with showcase performances by Street Beatz Dance Studio, Star Struck Dance Studio, Epic Dance Center, Next Level Dance, East Pointe Dance and Farmington Valley Dance & Music to benefit Friends of Karen. The dancers raised \$12,000.

Friends of Karen Team at the Jovia Long Island Marathon on May 5, 2023, at Eisenhower Park. We thank our generous sponsors: Atman, H2M Architects, Carter, DeLuca & Farrell LLP, Stony Brook Children's Hospital, Worldnet, West Corporation Foundation, Cohen's Children's Hospital, Farrell Fritz, LDI ColorTool Box.



Jaclyn Sandoval hosted a successful and heart-filled Galentine's fundraiser. What better way to celebrate Valentine's Day with all your girlfriends; complete with a DJ, photobooth, candy bar, raffle and live auction. Thanks to Jaclyn and all her friends, over \$17,000 was raised for Friends of Karen.



We love the Girl Scouts, and especially love the "Summer Sacks" that high school junior Meghan donated for her Girl Scout Gold Award project. Meghan filled 52 backpacks as part of her Gold Award, the highest award in Girl Scouting. Each sack contains a beach towel, insulated water bottle, spray sunscreen, summer hat, insect repellent band, card game and hand-made friendship bracelet. The summer sacks were distributed to Friends of Karen children attending camp and other summer activity programs. Thanks, Meghan!



Thank you, Henry, for organizing a Kids Calming Kit project for Friends of Karen. Henry, a high school junior, raised money and created 192 kits which include spinners, mini cube puzzles, Silly Putty, pop-it bracelets, other sensory toys and a clever poem which Henry wrote. Our Family Support team will give the kits to Friends of Karen ill children and their well siblings.



Thank you, Somers High School National Honor Society, for collecting party plates, napkins and birthday candles and assembling more than 60 birthday bags for Friends of Karen children. SHS senior Kaeleigh, vice-president of the NHS board, shows off the wonderful donation.

LI AlwaysGold Gala honored Donald Gelestino (L), President, Champion Elevator and Rob Koppersmith (R), Executive Director, Cushman & Wakefield. Friends of Karen child Matteo and his family were our Spotlight Family.



Friends of Karen was highlighted at the grand opening of Valley National Bank's prestigious 5th Avenue Flagship Branch. In this photo, staff members Leslie Bellissimo, Lexi Latino and Gwen Salmo are joined by Ira Robbins, CEO of Valley National Bank, and members of the Bank's leadership, including Michael Dondero, Angie Angiros, and Daniel Ramirez. Also pictured are Steve Tenedios, NYC Advisory Board, and Jonathan Malawer, Board of Directors.

A Father's Story: A Special Reason to Walk

Shania was 12 when she was diagnosed with Ewing Sarcoma and Friends of Karen supported the family through her treatment with emotional support, medical, travel, and household expenses along with sibling support for her sister Sadie. As a charity partner of the Jovia LI Marathon, Friends of Karen fields a team that raises funds to support our work with Long Island and NYC families. Corporate sponsors also sponsor Friends of Karen families to participate in the 1K Family Fun Run held during the Marathon weekend. Shania's father Jeffrey shares why participating in the event was so important to his family.

"When my family was contacted by Friends of Karen to see if my daughter Shania, and we, would like to participate at the Long Island Marathon 1K event, we jumped at the chance!

You see there was a time after our daughter's 2017 cancer diagnosis when Shania was unable to walk 10 feet. At that time our prayers were constantly asking for strength and miracles, and Friends of Karen and our FoK social worker Marla were that crutch to lean on.

They provided the aid needed to help our family through this ordeal, from financial help to sibling art therapy, to school supplies and so much more. They were always checking in with us, and speaking with them always felt sincere and organic, the way friends should be.

So, when Friends of Karen invited Shania to walk the 1K, they were doing so on her anniversary month, for little did they know she just achieved her five-year mark from the date of her last



Shania crosses the finish line at the Long Island Marathon 1K event.

treatment, officially proclaiming her to be in remission and transitioning her to survivorship.

So, it was with great pride and honor that we walked this event united as a family, as friends, together, as we crossed that finish line, and what made it even sweeter was seeing Leslie (Long Island-Metro NY Regional Director) and Marla's smile to cheer us on! What a beautiful event on a blessed day. You can count on us to be there every year forward."

– Jeffrey

CHILDHOOD CANCER AWARENESS MONTH

As of June 30, 2023

81%

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

Of those 81%, the types of cancer are:

13%

BRAIN
TUMORS

23%

OTHER
CANCERS

64%

LEUKEMIAS/
LYMPHOMAS



Malik, 14 and sister, Layla, 11 create tissue paper collages. Malik is on the list to receive a kidney. We provide sibling support to manage difficult feelings, and build resilience and coping skills.

In Loving Memory

Honoring the lives of our children who have died from March 1, 2023 to July 15, 2023

Gilbert.....8 years
Basir.....4 years
Sheyla.....21 years
Legend.....4 years
Sidney17 years
Jurnee14 years
Kaiden.....6 years
Jeremiah.....13 years
Amora.....14 years
Jeremiah.....11 years

"Human relationships are primary in all of living. When the gusty winds blow and shake our lives, if we know that people care about us, we may bend with the wind, but we won't break."

– Fred Rogers

Living Alongside Grief

Retreats for Grieving Families

Friends of Karen's continuum of care extends through end-of-life and bereavement, as sadly, some children do not survive their illness. We always remember these precious children at our annual memorial service, through personal notes our social workers send to families on the anniversary of the child's death, support groups, and individualized help for parents and siblings.

This spring, thanks to a grant from the New York Life Foundation, Friends of Karen piloted two unique, one-day grief education retreats entitled "Living Alongside Grief." Our goal was to create a comfortable and safe environment for bereaved children and parents to connect with each other and form new family memories while healing from their loss, providing a pathway for joy and the expression of grief. The value of family members sharing this experience helps them reconnect with each other in the context of their devastating loss, and creates a feeling of community among a group of bereaved families.

The retreats, held at Iona University in New Rochelle, engaged 43 families, including 32 children and 80 adults. Our Family Support team thoughtfully created a program that incorporated family activities and age-appropriate activity groups for children, tweens, and teens. All the day's activities were designed to explore the grieving process, styles of grieving, and ways to integrate their loved

ones and a renewed sense of joy into their lives in a meaningful and connected way.

Family activities of memorializing and commemoration help the bereaved reminisce and eventually mourn. For example, each family received a shadow box with a photo of their deceased child. The boxes had a slot on the top in which families added hearts with handwritten messages on them. They were encouraged to continue adding hearts to make it an ongoing activity. Families had the shadow box to bring home along with a family photo taken at the workshop. The day featured a lively scavenger hunt, emotional discussion groups for parents to share advice and lessons learned, inspirational songs sung by a bereaved parent, groups for children to explore and express their feelings and learn coping skills, and a make-your-own-sundae social respite enjoyed by all.

Bereaved families often share that people in their lives become reluctant to say the name of their deceased child. To conclude the program, families stood together and shouted their child's name. This ritual punctuated the end of an emotional day and symbolized the power and energy of this newly forming community.

In assessing the experience, one mother said, "Today I learned that I am not alone, and it is not wrong to heal in my own time without pressure." A ten-year-old spoke similarly about the day, saying "It was the first time I didn't feel like the only person that lost a sibling."

Rhonda Ryan, Director of our Family Support Program, reflects, "Friends of Karen's capacity for caring and building community is one of our many strengths. These grief retreats demonstrate just that. Bringing together a community of grieving families allowed them to experience the day with one another while building relationships with other families sharing similar circumstances, challenges, and memories."



Attendees at a recent retreat.

A Family Story: Changes Made Easier With Support

Last summer 14-year-old Jaynalee was excited to enjoy a trip to the Florida theme parks with her extended family from Puerto Rico. But just as the fun was beginning, she came down with a sore throat. The antibiotics Jaynalee received from the emergency room still weren't helping several days later, and she suddenly turned grey, weak and could not swallow. After another ER visit, blood tests and a bone marrow biopsy, Jaynalee was diagnosed with high-risk b-cell Acute Lymphocytic Leukemia, a blood and bone marrow cancer.

Jaynalee started chemotherapy near home in New Jersey shortly after the diagnosis and made the choice to shave her hair off then so she would not have to go through her hair falling out. Her mother Angela shaved off her own hair in solidarity.

Other changes came all at once. Angela, a single parent of Jaynalee and her 6-year-old sister Mikaela, had to quit her job as an insurance specialist at a fertility clinic to care for her children. Jaynalee was looking forward to her freshman year of high school with her friends, but Leukemia meant that milestone would also be missed. Angela moved the family across the street from the hospital knowing the daily commute for Jaynalee's treatment would be too much, and now

they all would have to start their lives over in a new place.

Then there was the reality of how Angela was going to survive financially. "I worried how we were going to live," she said. "Am I going to be able to continue to pay the rent and make my car payment?"

Angela knew she could not go it alone and found Friends of Karen through a Google search and was relieved to be paired with social worker Alyssa. "When I spoke to Alyssa, she understood what I was going through without me having to explain it," Angela noted. "A lot of well-meaning people would say 'if you need anything let me know,' but Friends of Karen knows what kinds of support you need, sometimes before you do. I was relieved that Friends of Karen helped with our rent and car payment for several months – it was a huge burden off me. Without their help I would have broken down and would not be able to give Jaynalee the care and attention to help her feel better."

Alyssa encouraged Angela to have Jaynalee and her sister participate in Friends of Karen's Sibling Support



(L-R) Mikaela, Angela and Jaynalee

Program, knowing the children were isolated. Jaynalee was not able to have the typical social life of a teenager which can be stressful. So, the girls worked with Jane, a creative arts therapist from our Sibling Support Program.

Jaynalee found it helpful because "it helped me keep my mind off of my cancer." For Mikaela it was an opportunity for distraction, to decrease her isolation, and to interact with someone else while her sister was at the clinic with their mother.

Jaynalee has now entered the maintenance phase of her treatment that includes some chemotherapy and monthly spinal taps. While it is still physically challenging for her, the family is beginning to ease back into old routines as they are not at the hospital every day. Angela went back to work this summer and Jaynalee is planning to go back to school in September.

GIFT A BRICK IN OUR WALKWAY OF COMPASSION AND HOPE



A great way to celebrate the holidays, a milestone occasion, or to honor or remember someone special.

HOLIDAY ADOPT-A-FAMILY PROGRAM

What better way to celebrate the holiday spirit than by giving to a child? Help Friends of Karen deliver gifts and smiles for the holidays! Nearly 950 "Holiday Wish Lists" need to be filled this year. Program begins in early October.

For more information about our holiday gift program or purchasing an engraved brick, call (914) 277-4547, email info@friendsofkaren.org, or visit friendsofkaren.org.



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"We are so grateful for Friends of Karen helping us through this stage of Olivia's life."

– Johanna, mother of Olivia
(see story on cover)

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

Sibling Art

Sibling Support Program Nurtures Powerful Expression of Feelings

Art is a natural way for children to express themselves, especially when the words get stuck or language isn't enough. With the guidance from our Sibling Support Specialists (Licensed Creative Arts Therapists and Certified Child Life Specialists) Friends of Karen children use art to tell their stories, to act as a bridge to communicate with their families.



Art by
Brandon.
What I would do
if I could see my
sister, Mel, again.



Art by
Cooper.
In loving
memory
of his
brother,
Astor.

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