



News from Friends of Karen

SPRING 2023

CONNECTIONS

SUPPORTING CRITICALLY ILL CHILDREN AND THEIR FAMILIES

A MOM'S STORY: The Gift of More Time to Care

Logan is a four-year-old boy who was diagnosed in 2022 with Aplastic Anemia, which is characterized by bone marrow failure when the body stops producing enough new blood cells. His mother, Elizabeth, a registered nurse, shares how Friends of Karen helped her, Logan and his twin sister Gianna, his older siblings Jayda and Jeremy, and his father Ismael as they coped with his diagnosis and treatment. Elizabeth was Logan's donor for a bone marrow transplant and his condition is stable now.

"One day last summer my husband Ismael called to tell me that he noticed Logan suddenly had broken blood vessels all over his face and bruises on his body. Then Logan asked us to go to the doctor saying he was not feeling well. Up until this point, we had been doing well in our careers and had just moved into a new apartment the month before.

I have worked in all kinds of roles and settings in my nursing career, including in a pediatric ICU and in medical research. Even with my knowledge and background, getting Logan diagnosed was a very difficult and frustrating journey. As the doctors worked to eliminate all kinds of diagnoses, we watched helplessly as Logan got sicker. At one point he was hospitalized in the ICU with literally zero

platelets and his urine was the color of red wine. A bone marrow test showed Logan's body was in bone marrow failure, but doctors did not know why.

At that point my whole world was falling apart as we were expecting the worst. I couldn't stop crying every day and I was losing weight. During that month, Logan had more tests and after another hospital stay, we found out that he had Aplastic Anemia. This is not a kind of anemia like the kind from a poor diet, but much more serious and the treatment is similar to how children are treated for cancer. Logan even lost his hair during treatment.

We are thankful our hospital social worker told us about Friends of Karen as we were trying to juggle everything going on. Our 20-year-old daughter Jayda had to help Ismael take care of Gianna and keep our home together. I had to stop working at my full-time job to be there for Logan and pick up public health nursing shifts here and there.

Our finances started getting tight and I don't know what we would have done without Friends of Karen's help to pay our phone, cable and light bills. Our Friends of Karen social worker Alyssa was always there for us. She is amazing and I can call or text her anytime. Alyssa



Back: sister Jayda, dad Ismael, mom Elizabeth, brother Jeremy. Front: twin sister Gianna, Logan.

always tries to find a solution for whatever issue comes up, she keeps her word and always calls me back, and there is never any judgement when we speak.

Everything Friends of Karen does for our family is a big deal for us. When Christmas was coming, I had not been working and we worried about gifts for the kids. Friends of Karen sent gifts for the kids with wrapping paper, bows, and tape. Thinking about that it's so moving it gives me chills. Logan and Gianna met with Siobhan, a Friends of Karen art therapist, who was so good at what she was doing to help them. I also joined the support group for parents whose children were recently diagnosed, and it has been really helpful.

We are thankful that Friends of Karen's support has helped us live so we have more time for Logan and his care. Right now, everything is stable and knowing they are here for us gives me peace of mind."

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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

CELEBRATING 45 YEARS



2023 marks Friends of Karen's 45th year. A modest act of kindness was our beginning when Sheila Petersen rallied the community to enable 16-year-old Karen to come home from the hospital to live her last days amid the love of her family. Not only was Sheila a genuinely good person, but she was a savvy one too! Long before social media and "GoFundMe," Sheila shared Karen's story in the local press. She established the "Friends of Karen Fund" for the contributions that subsequently poured in for Karen's care. Imagine, \$35,000 in just six weeks, enough for Karen's 24-hour care at home for the remaining 11 months of her life. After Karen died, leftover funds and memorial contributions enabled Sheila to help more children.

I've told this legendary story many times. It's amazing that the commitment of one compassionate woman motivated hundreds of people to assist a dying child and her family at an unbelievably difficult time. What's more, Friends of Karen developed far beyond Sheila's original intent. Here we are, 45 years later. Friends of Karen has assisted 18,000 children, including the ill child and siblings.

Few people may know that Sheila published a book entitled "A Special Way to Care" after she had been running Friends of Karen for 10 years. The book provides a "how to" for "neighbors, friends and community" moved to undertake a campaign to benefit a seriously ill child, their "Karen."



Sheila received requests for help from across the country. She knew she couldn't respond to them so she decided to share her considerable experience in this insightful guide. She figured if she could roll up her sleeves to help a family in need, so could you. Sheila pictured a network of dedicated volunteers "assisting the terminally and catastrophically ill by giving them the highest quality of life possible when they are least able to obtain it on their own."

Our service model has evolved significantly from Sheila's vision. Today's Friends of Karen is staffed by a team of professional social workers, child life specialists and creative arts therapists who do the hands-on work with children and families. Hundreds of dedicated volunteers help, but not in the way Sheila envisioned. Yet, Sheila's fundamental truths like the necessity of establishing an open, trusting relationship with a family, the focus on the whole family because every member is affected by a child's illness, and my favorite – promise only what you can deliver – guide us to this day.

In this milestone year of celebration and reflection, we honor Sheila Petersen for her wisdom and inspiration, along with so many creative, generous, and dedicated people and organizational partners on whose broad shoulders we stand. This newsletter highlights the impact of Friends of Karen's core services today and describes new ways we are supporting children and families in these changing times.

Thank you for being part of 45 incredible years of bringing help and hope to critically ill children and families in our community.

Judy

Judith Factor
Executive Director

A SIBLING STORY: Finding A Way Through Grief



Above: Cooper with Friends of Karen Creative Arts Therapist, Siobhan



Right: Cooper with mom, Joan and dad, Roger

Cooper, now seven years old, participated in the Friends of Karen Sibling Support program with creative arts therapist Siobhan. Cooper's mother Joan shared that Friends of Karen's ongoing support has been helpful as they grieve the loss of Cooper's older brother Astor. Astor passed away at age eight after being treated for Childhood Cerebral Adrenoleukodystrophy, a progressive neurodegenerative disorder. The family's experience with Friends of Karen began when they were paired with social worker Rhonda and received emotional and financial support, as well as practical guidance. They also had end-of-life and bereavement support, including taking part in the parent's Bereavement Support Group. Below, Siobhan and Cooper discuss the impact of the sibling support he received.

Siobhan: What did you worry about when Astor was sick?

Cooper: I was worried about him dying.

Siobhan: How did you help him when he was sick?

Cooper: I helped my parents bring things to him. I would sometimes hold his hand and that calmed him down. He was scared because he couldn't see or really hear anymore.

Siobhan: When you think about Astor, what is your favorite time with him that you remember?

Cooper: So many things! Being outside and playing with his dog Iris. I loved going to the park with Astor on his scooter. We would play zombie tag or freeze tag or hide and seek. We also liked doing puzzles together. Me, Astor and Daddy built a two story huge Lego building that took days to build!

Siobhan: What did you like to do best during the Sibling Support sessions?

Cooper: I really liked when we made picture frames and albums to hold memories of Astor. I liked the clay too, but mostly I like spending time with you.

Siobhan: How has talking with me helped when you are sad or feeling other big feelings?

Cooper: Because it's been a long time I know you, that makes it easier to talk about and the art makes me feel better. You tell me anything I feel is ok.

Siobhan: What else helps?

Cooper: I listen to music that makes me think of him. When I make art I ask you to play "Willow Tree" ("You and me born from the same branch and leaves..../ But when you leave, the world is never what it seems.") and "See You Again" ("It's been a long day without you, my friend / And I'll tell you all about it when I see you again"). He loved to eat, and he used to finish my bowls. When I miss him, I like to eat his favorite foods, like salmon with yummy soy sauce, and sushi and pizza.

OBSERVING CHILDREN'S GRIEF

"Children will often jump in and out of their grief. One moment they may be sharing how lonely and quiet the house feels after their brother died, and in the next breath will be singing along to "The Gummy Bear Song" and telling a favorite knock-knock joke. Grief can be a beast, but children seem to understand that they must hold two truths simultaneously – the pain of their tremendous loss and the fact that their own world continues to spin. The Family Support Team at Friends of Karen has the unique privilege to stay with families throughout the course of the illness, that sadly in some cases like Astor's require bereavement support."

-Siobhan, Friends of Karen Licensed Creative Arts Therapist

Creating New Programs to Help Families



As the effects of COVID linger and the rising cost of everyday living expenses continues to be a concern, families are turning to Friends of Karen for more intensive support. Because we are committed to supporting families throughout their illness journey, Friends of Karen has added creative new programs that join our core Family Support Program. These programs address a family's financial, emotional, practical and advocacy needs, and focus on additional ways to fulfill our mission to ensure families remain stable, functioning, and able to cope during their child's illness. The following is a summary of Friends of Karen's new offerings.

Peer Support for Adolescents

Separate virtual support groups for ill tweens and teens were launched in 2022 to provide greatly needed social connection and mutual support for children at a vulnerable age.

Support for Parents of Newly Diagnosed Children

Parents are overwhelmed when they receive the shocking news of their child's life-threatening illness. We have introduced a multi-week online group focused on helping parents adjust to living with their child's new diagnosis and finding ways to cope throughout their child's treatment. Additionally, the group provides peer support for families who are experiencing similar circumstances, helping them to feel understood and less isolated.

Survivorship

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 needs. We plan to create support groups for children to help them navigate the unique issues they experience after treatment, like the return to school after a long absence due to their illness.

Grief Education

A New York Life Foundation Grief Reach Grant is helping us develop the first educational workshops of their kind in the Tri-state New York region for grieving families. Two one-day programs this spring will focus on education for parents and children on what is "normal" grief when a child passes away due to cancer or another life-threatening illness.

Support via Social Media

We launched the Instagram handle @familysupportfok to use as an educational tool for parents and professionals. Our Family Support Team develops special content to circulate on Instagram, including tips for communication, identifying feelings, needs and practical interventions. Posts may include words to use when supporting a grieving child, child development guidance, highlight a family or activities, and share educational videos.

WAYS TO HELP

Become a monthly Guardian of Hope

By joining our Guardian of Hope caring community, you will help provide emotional support for the entire family, pay for food, housing, mounting medical expenses and so much more each month. Your 12 reliable monthly gifts will bring critically ill children and their families strength and hope all year long. Fill out your reply envelope or join online.

Enroll in the Sheila Petersen Legacy of Giving Circle!

Leave your imprint to benefit future generations by naming Friends of Karen in your estate plans. You will continue to impact the lives of critically ill children and their families well into the future. Visit our website for more information.

Want to help with our gift programs for the children?

Programs include Summer Sacks, Back to School, Feed a Family, Holiday Adopt-a-Family, and Birthdays. Please call Denise at 914-617-4052 or email denisetredwell@friendsofkaren.org.



Jorge's Story: The Power of Feeling Understood

Jorge is a 17-year-old high school senior from Westchester County, NY, who was diagnosed with Osteosarcoma bone cancer in October 2021. Now, he is waiting for word on his college applications to study civil engineering after being inspired by what he observed at his father Jorge's masonry job. He is grateful for the support from his father, mother Lillia, and his younger brother Adrian and older brother Daniel. He shares his experience with Friends of Karen below.

"When I was told I had cancer, I felt like my head could not make sense of it. My ears would hear the diagnosis and everything the doctor was saying, but my head couldn't comprehend it.

Then I had to go through treatment, which meant I was in the hospital every day. I was tired and weak. I had no strength to get out of bed. My parents were always there for me. If it wasn't my mom, it was my dad. If they couldn't be there my older brother Daniel would.

Before I was diagnosed, I was really active. I played soccer, ran track, skateboarded, and hung out with friends.

Because the cancer was in my leg, I knew I couldn't walk properly anymore. I had doctors telling me that I wouldn't be able to run again or play sports. Then, I had a physical therapist tell me I would be able to run, so I focused on what I could do. Daniel pushed me to get outside and pass the soccer ball whenever I could, which helped a lot.

There were so many feelings. I felt annoyed, frustrated, upset, and then understood and hopeful. Thankfully, the hospital social worker told us about Friends of Karen, and then I had a sibling support specialist to talk to, first Naomi and then Jane.

It was really nice to talk to someone outside of my family and to hear other opinions. My parents are great and good problem solvers, but sometimes I was afraid that if I told them something it would stress them out. I just needed someone to talk to and to listen to me. I needed to talk about the fear of my tumor spreading to my lungs.

I was glad I had Naomi. We did art together, and painting allowed me to focus on



something other than being sick and feeling nauseous. It made a real difference. I started reading a lot more and journaling, which allowed me to feel productive. I felt mentally better after doing it. I also joined Friends of Karen's ill children's online support group, and I liked talking to other kids who went through what I was going through. I didn't have to explain everything because they understood.

It was also nice that Friends of Karen sent us art supplies and got me a guitar, which was so helpful for me when I was really sick. Then we got presents at Christmas and for our birthdays. My little brother Adrian loved it, and I still remember how excited he was when he opened his gifts. Our social worker Jackie also worked with my parents to make sure they had help to pay for groceries and for travel to my treatment.

I am thankful that Naomi, Jane and Jackie helped and that they understood the medical side of everything. I didn't have to explain to them what was happening, they got it. Without them, I would have been more isolated. Naomi pushed me to do more and told me to call friends and do activities instead of staying inside. I'm glad they knew the right way to give me that little push I needed."



Above: Jorge checking on his college applications

Left: L-R, Brother Adrian; mom, Lillia; Jorge; and dad, Jorge

2023 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.

Walk/Run LI Marathon: May 5-7, Eisenhower Park, East Meadow, NY

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

In Loving Memory

Honoring the lives of our children who have died from July 16, 2022 to February 28, 2023

Imani..... 13 yrs.
 Antwan 18 yrs.
 Gary 13 yrs.
 Adrian..... 9 yrs.
 Jeyden..... 14 yrs.
 Wynter..... 11 yrs.
 Alexandria 9 mos
 Yesica..... 14 yrs.
 Dylan 18 yrs.
 Jake 18 yrs.
 Mohamed..... 11 yrs.
 Laissa 11 yrs.
 Arianna 1 yr.
 Brandon..... 20 yrs.
 Ivanna 7 yrs.
 Javien 13 yrs.
 Greyson..... 1 yr.
 Justin 11 yrs.
 Caitlin 17 yrs.
 Ubaldo..... 14 yrs.
 Victor 20 yrs.
 Miguel 14 yrs.
 Ava 10 yrs.
 Alizah..... 7 yrs.
 Shikerra 20 yrs.



Above, the O'Connor Family at the 2022 Golf Outing. Right, the latest addition to the family – Erin.

Family Harnesses Community's Support to Nurture Child's Legacy

Since 2007, the Coldwell Banker-Realty Lower Hudson Valley Regional Office has organized and hosted an annual golf tournament held in memory of Erin O'Connor with proceeds benefiting Friends of Karen. Erin was diagnosed with an ependymoma brain tumor in June 1995 and died in 1999 at the age of 13. Erin's father Mike, a real estate agent at Coldwell Banker, and his wife Eileen, look back at that difficult time and Erin's legacy.

Mike and Eileen lovingly remember Erin as a strong willed, feisty and whip smart child, qualities that served her well as she battled cancer. She also was a thoughtful child who at 10, without her parents' knowledge, started a toy drive at her school so she could outfit the hospital's playroom with toys for the children to play with on days they were feeling up to venturing into the playroom.

While Erin was able to call upon her inner strength to fight, it still was a difficult time for the entire family. The family connected to Friends of Karen through a school social worker and were paired with Friends of Karen social worker Rhonda.

"Rhonda was always there for us, and we appreciated that Friends of Karen remembered our other girls by sending gifts for their birthdays and Christmas," Eileen remembered. "The candlelight ceremony we attended after Erin passed away was very moving. Unfortunately, there was no Sibling

Support Program back then and I think a program like that would have been helpful for Erin's three sisters."

It was providence when Mike joined Coldwell Banker Realty, where his co-worker Aliko was already a devoted Friends of Karen supporter. She held an annual tag sale for Friends of Karen at the agency that eventually outgrew the office property, so it was suggested holding a golf tournament could attract more support for Friends of Karen.

The golf tournament was an opportunity for the entire O'Connor family to put their hearts and souls into helping other children and families facing the same challenges. Mike, Eileen, and their daughters, and their growing families, have been able to keep Erin's memory alive through this wonderful outing held each year in her honor.

"Our involvement in the golf tournament has been cathartic and keeps Erin's memory alive," Mike said. "We are so fortunate for the tremendous contributions of time, effort and money by my co-workers, who help put the tournament together while working a very busy schedule. It could not have been done without my friends at the Yorktown Coldwell Banker office. The Outing has given us an even bigger circle of people who are there for us and who support Friends of Karen's important work."

Because of You!



Thank you to **St. Vincent Ferrer High School** students for hosting a very successful Holiday Toy Drive for Friends of Karen's children.



Regeneron Pharmaceuticals selected Friends of Karen to benefit from their annual "Day for Doing Good." A team from Regeneron purchased birthday supplies and created 135 Birthday Bags to help our children celebrate their birthdays.

Friends of Karen Junior Advisory Board – Junior Advisory Board President, Charli (Right) and Junior Advisory Board Member, Alexa (left), organized a restaurant fundraiser at Chris & Tony's Restaurant & Lounge in Syosset, NY, benefiting Friends of Karen.



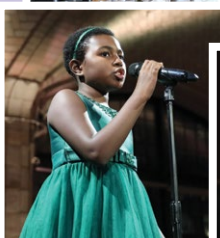
Joseph Kaiser and his friends organized their first annual Muscote Cup Tennis Fundraiser. \$1,800 was raised for Friends of Karen.



Friends of Karen Gala 2022, at Guastavino's in NYC, honored Dr. Sarah Norris, Paul Smadbeck, and the Insurance Industry Charitable Foundation, and was hosted by CNN anchor John Berman. Nine-year-old Daenerys shared her illness journey with us.

Enjoy Retirement Elvira Scollan!

Thank you Elvira for all of your hard work and dedication during your 21 years at Friends of Karen. You have been a valued member of our family and an incredible asset to our team. We are grateful for your loyalty and commitment to the Friends of Karen families in need. Best wishes for your retirement!



Super Volunteer Mary Cook

Whether she's selecting a birthday gift, packing school supplies, or assisting with the holiday Adopt-a-Family program, volunteer **Mary Cook** always does it with a smile. She may be busy with her grandchildren and two other volunteer jobs, but Mary is always ready to give her time and skills to Friends of Karen. Thanks Mary!

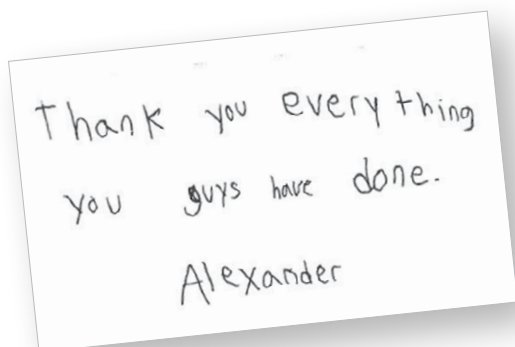
April is National Volunteer Month. Join us in honoring and celebrating volunteers like Mary who put others before themselves by sharing their time and talent with Friends of Karen. *We love our volunteers!*

For more information on volunteer opportunities, please contact Denise at 914-617-4052 or deniseredwell@friendsofkaren.org.



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A note from a 9-year-old child
helped by Friends of Karen

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

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 – especially their ill siblings – like making cards for them when they are away at the hospital.



Art by Abigail



Art by Ana, Ronald, and Elizabeth



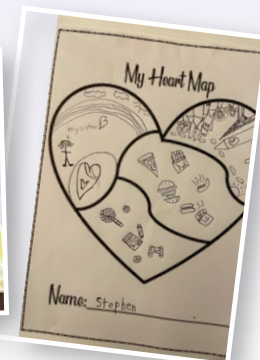
Art by Ana, Ronald, and Elizabeth



Art by Charlotte



Art by Hashimu



Art by Stephen

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list and stay current on all our programs and activities.