



News from Friends of Karen

SPRING 2024

CONNECTIONS

SUPPORTING CRITICALLY ILL CHILDREN AND THEIR FAMILIES

A MOTHER'S STORY: Finding Help and Understanding

Finest is a 20-year-old college student being treated for a recurrence of Synovial Sarcoma, a soft tissue tumor, that first occurred when he was 15 years old. His mother Melissa was interviewed about how Friends of Karen has helped her, Finest and his 18-year-old brother Malik.

Connections: How has Finest's treatment changed your daily life?

Melissa: After the first time Finest was treated, he went about his life and went back to high school. Later he graduated and went on to Hunter College in Manhattan to study anthropology and was living a normal life until he had a car accident in April 2023. After the accident he noticed pain in his leg and he was limping. He had an x-ray but that did not show any problem. My mother's intuition kicked in and I insisted they give him an MRI, which showed a tumor in his knee. This time my world came crashing in on me. When he was diagnosed at 15, the doctor told me that if the cancer came back it would need to be treated aggressively. Now he needed chemotherapy, radiation, knee replacement and femur reconstruction.

Connections: How did you find out about Friends of Karen?

Melissa: During this recurrence, the hospital social worker gave me a list of organizations to call for support. I found out that because Finest is 20 years old he was not in the age range of most organizations that serve kids up to 18 years old or adults 21 years old and over. I was relieved that Friends of Karen would accept someone his age.

Connections: How has Friends of Karen been there for your family?

Melissa: I am thankful for everything Friends of Karen has done for our family. Without them, I believe I would have gotten into debt and not had some of my basic needs met. It was important that Friends of Karen was by our side because all our family is in Saint Lucia.

Friends of Karen sent their social worker Rhonda to visit. She made sure that Friends of Karen helped us with groceries, transportation to treatment, and some of our monthly bills. I did not know Finest could get covered under Medicaid and Rhonda told me about it and helped us through the application process. Friends of Karen gave Finest



Above: Finest (left) with his brother, Malik.
Top left: Finest with his mother, Melissa.

some gift certificates for games and clothing for him to be comfortable. They even found a volunteer to coach Malik through writing his college essays and applications.

Rhonda has been amazing in getting us whatever help we've needed. It's been heartbreaking for me to see my six-foot tall, healthy son go through surgery and treatment. Rhonda understood I was struggling and arranged for Jane, a Friends of Karen creative arts therapist, to come see us. Jane really listened to what we were going through, and we worked on art projects to help us emotionally. And Rhonda encouraged me to participate in the parents' virtual support group. It helps me to have hope when I hear other families that are going through this with good outcomes.

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friendsofkaren.org



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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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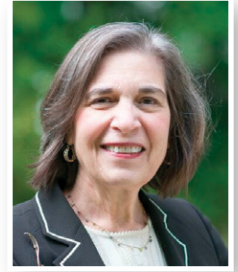
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FROM OUR EXECUTIVE DIRECTOR

What Makes Friends of Karen Special?

I am often asked what distinguishes Friends of Karen from other organizations that support critically ill children. This question usually follows: Is Friends of Karen like Make-A-Wish or Ronald McDonald House? While they are both great organizations with important missions, and Friends of Karen children and families utilize them, they do not offer the breadth and depth of services we do.



Friends of Karen's starting point is that a child's life-threatening illness affects every aspect of a family's life. Forty-five years ago, when our founder Sheila Petersen set out on her selfless mission, she innately understood that each family has their own needs and that whatever help is provided must be tailored to those unique needs. This principle continues to guide us.

That's why Friends of Karen does not have a "one-size fits all" approach. We personalize our comprehensive support based on a family's individual situation and address the impact of the illness on the whole family. This includes our special involvement with the sisters and brothers of ill children through our Sibling Support Program. Addressing their well-being deeply affects the family's ability to cope during the health crisis and impacts their future whatever the outcome of the child's illness. The article in this issue about mask making is an example of how our talented child life specialists and creative arts therapists support siblings.

Another unique feature of Friends of Karen is that our support continues for the trajectory of the child's illness, which can be months or years. Further, so long as a family resides in our tristate service area, our support follows the child, no matter if they are receiving the most promising treatment in New York City, Philadelphia, or Houston. Every Friends of Karen family is paired with an experienced, dedicated social worker who will guide them for the duration of the child's illness, and if bereavement support, unfortunately, is needed.

While Friends of Karen supports children with cancer (80+%), we also assist children with other life-threatening illnesses like sickle cell disease, organ diseases, various disorders, anemia, autoimmune and other serious illnesses. We often are the only organization that children with these other illnesses can turn to for help. Friends of Karen's lifeline of support is available for children birth through age 21. This is important because many other organizations provide support through age 18 only or begin at age 21, so we make sure no child falls through the cracks.

The stories in this newsletter describe in real time what makes Friends of Karen special. Thank you for your support which makes all that we do possible.

Wishing you a healthy and colorful spring,

Judith Factor
Executive Director



Friends of Karen is a registered 501 (c) (3) charity established in 1978. All contributions are tax-deductible.

SIBLING SUPPORT: Unmasking the Power of Self-Expression



Right: Friends of Karen children create masks to celebrate strengths, show feelings they keep inside and to have some much-needed fun.

The little children and teens that Friends of Karen Sibling Support Program professionals work with are carrying some big feelings. How can they not? They are experiencing unimaginable stress, change and worry. Those feelings are hard to talk about, but Friends of Karen's four licensed creative arts therapists and child life specialists know from experience feelings will only grow if kept inside.

Art is a natural mode of communication for children when words may not be there or may not seem enough. If asked directly "What are you feeling inside?" a child or teen will likely respond "I don't know" or a similarly short answer leading to a dead end in the conversation. Give the same child some paints, a paper mask and maybe some emoji stickers and you can watch what they learn about themselves and their thoughts and emotions as they make art.

Spanning centuries and continents, throughout art history, masks have been powerful tools for expression that

are functional, metaphorical and fun. Friends of Karen professionals help all children and their siblings by facilitating various mask making activities aimed at addressing their unique therapeutic goals.

During one-on-one therapeutic sessions that take place either in person or virtually, children explore the contents of a curated art bag provided by Friends of Karen and often reach for the masks as the material of choice.

Art therapy activities are chosen to match each child's specific needs. If a child has difficulty expressing themselves and seems to be keeping emotions bottled up, our professionals may guide them in creating an "inside/outside" mask, showing what they show to the world and what they mask from others and keep inside. They may create a mask of a feeling that seems overpowering to others, a feeling they wish they felt more often, or their alter ego or their "true self."

Another approach may be to explore a child's strengths with mask making, to follow the vein of positive psychology and focus on building what is strong as much as fixing what is wrong. The Friends of Karen professional might invite the child to create a mask answering the question "What is your superpower?" or highlight and celebrate character strengths. Mask making can also take the form of a self-portrait for an ego strengthening celebration of their uniqueness and worth in their family and in their world.

Lastly, it is hard for any child to resist the fun and imaginative play that mask making invites. All the incredible children Friends of Karen serves deserve those moments of playfulness tenfold, and our highly skilled Sibling Support Program professionals understand the positive impact of providing opportunities for fun.

Did you Know? Interesting facts about Friends of Karen...



79¢
of every
dollar supports
children and
families



32%
of families
are below
poverty line



18,311
children have
been helped
since our
founding in 1978

HELP US DECIDE

We're thinking of making this Connections newsletter digital only. You would be able to read it online. With savings on printing and postage, it would help us direct more funds to support Friends of Karen families and save trees.



Scan me

Scan the code and let us know what you think. If you prefer, reply by email to gabrielladisisto@friendsofkaren.org. Your feedback matters. Thank you.



Bruce and Denise Tredwell

Thank you, Denise!

For the past 25 years, Denise Tredwell has been Friends of Karen's Volunteer Coordinator. Among her responsibilities, Denise has managed the gift programs, including Back-to-School, holiday Adopt-a-Family, and birthdays. She has worked with hundreds of wonderful people of all ages and backgrounds who generously give their time and talents in a multitude of ways to benefit the children and families Friends of Karen serves. Denise knows how much this help matters because she was a Friends of Karen family when her son Josh was in treatment for a brain tumor. She has inspired countless volunteers with her passion for the mission and special understanding of the impact our support has on a family. Denise retired at the end of January, after wrapping up the 2023 holiday Adopt-a-Family program that filled the wish lists of 848 children. Looking back at her Friends of Karen career, she shared these reflections.

Connections: Who introduced you to Friends of Karen? How were you helped?

Denise: My sister found Friends of Karen for us. Josh was seven years old when we moved to Brewster. He had relapsed and we needed assistance. Susan Downes, then the Friends of Karen social worker, was beyond helpful. She got us equipment for Josh when he was in hospice care and arranged for important therapy to help us understand and cope with Josh's illness. We even went to a special camp that was wonderful for Josh's little sister, Sarah. Susan was always there to help us, no matter what we needed.

After Josh passed away in 1990, my husband Bruce and I, along with Sarah, participated in Friends of Karen's bereavement group. This turned out to be an amazing experience for us. I did not expect all the ways Friends of Karen supported us during this difficult time.

Connections: How did you transition from a "family" to an employee?

Denise: I had a job I loved at a project management firm when Susan Downes called to ask whether I would consider becoming the Volunteer Coordinator at Friends of Karen. How could I say no? That was in July 1998. The rest is history.

Connections: How did your experience as a family influence your work with volunteers?

Denise: Having been on the receiving end of Friends of Karen's support, I was committed to making our help meaningful to the children and their families. I love that Friends of Karen isn't a plain vanilla organization. We tailor our support to the needs of each family. I try to know each child as an individual by keeping track of what they like so their birthday or holiday gifts are what they want. I always express my appreciation to our volunteers to let them know how important their efforts are to Friends of Karen families. We can't do it all without them!

Connections: In 25 years, how have things changed? Are there some memorable moments?

Denise: Our volunteers are as kind, compassionate and giving as ever. They always ask what they can do. We have three generations of volunteers in some families. Our volunteers are the best.

It's the work that has changed most. Years ago, we needed volunteers to do huge mailings four times a year. They enjoyed the camaraderie of getting together and talking about Friends of Karen. Believe it or not, some of these volunteers are still involved, but now, most people are too busy working or pursuing other interests, so they want short-term commitments. We're working with more corporate groups that request a group project like putting together birthday bags or camp sacks for the children, or comfort bags for parents when they are with their hospitalized child.

My most memorable occasions were the annual Volunteer Recognition Dinners when we brought together volunteers of all ages. It was fun to recognize each person or group and applaud their efforts. We haven't held a dinner since the pandemic. Hopefully they will be revived in the future.

Connections: Are there words of wisdom you'd like to share?

Denise: I always say Friends of Karen is the glue that held my family together. They had our backs and held us up. I can never repay Friends of Karen for what they did for my family.

After 25 years, no matter how challenging my day at the office, when I walk out Friends of Karen's door, I always feel so good about what we did for the families.

Connections: Denise, enjoy your well-earned retirement!

A MOTHER'S STORY: Finding Consistent Support

Ellis is a five-year-old boy who was diagnosed in 2023 with Acute Lymphoblastic Leukemia (ALL), a cancer of the blood and bone marrow. His mother Jennifer shares how the diagnosis and Ellis's treatment affected her, her husband Eric, and their four-year-old son Jay.

"During the summer of 2023 things were going along well for our family. My husband Eric had just started a new job and I was doing well in my job as a physical therapist. Ellis got sick soon after, and there was a month of not having any answer to what was going on until a bone marrow biopsy came back conclusive for Leukemia.

Ellis's diagnosis meant medical bills we weren't prepared for, which in our case came with a complication. We

were paying for our family's health insurance out of pocket because we were on COBRA insurance until my husband's benefits started at his new job. That meant neither of us could stop working completely during Ellis's treatment.

Because this was a major issue, the hospital social worker encouraged us to apply to Friends of Karen for financial assistance. We had no idea that once we were connected to our Friends of Karen social worker Rhonda, they would be such an important support to us in so many other ways.

The best part of working with Rhonda is she calls often and it's nice having someone that understands what we are going through. From the start she had a concrete list of things she knew we needed and was always a step ahead to predict what we would need next.

Friends of Karen helped with everything from working with us on applying to Medicaid for Ellis and arranging for Ellis to have a volunteer tutor so he was on track for kindergarten, to making sure we had gift cards to shop for Thanksgiving dinner



Ellis

and wrapping paper for the holiday gifts they provided for Ellis and Jay.

Rhonda had Melissa, a Friends of Karen creative arts therapist, work with Ellis for additional emotional support. Melissa also worked with Jay to help him understand what was happening in terms he could understand and help him with his feelings. Both boys also benefit from participating in the *Friends Having Fun* weekly virtual activity group since they have few chances to socialize while Ellis is immunocompromised.

Friends of Karen also makes a difference because they are with us for the long haul. We are thankful because, without Friends of Karen, we'd be struggling to make ends meet and I'd have to work more and not be able to be with Ellis. I think of Rhonda as our director of traffic to keep things going as smoothly as possible and she always has suggestions of how to handle things."

— Jennifer



L to R — Ellis, mom Jennifer, younger brother Jay, and dad Eric.

2024 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 3-5, Eisenhower Park, East Meadow, NY

Summer Event: July 11, The Coliseum, White Plains, NY

Journey of the Heart Bike Tour: September 14-15, Bicycle Tour Company, Kent, CT

Adina's Angels 5K Walk: September 29, Rockland Lake State Park, Valley Cottage, NY

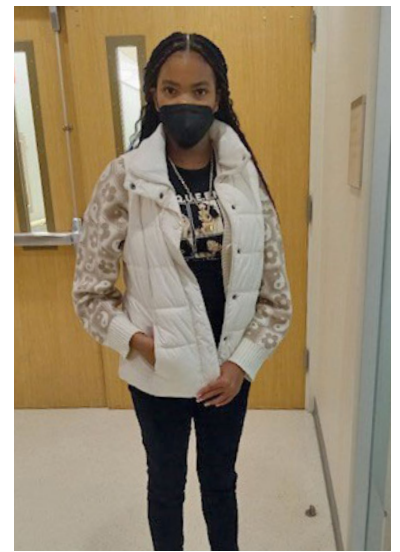
46th Anniversary Gala: November 8, Guastavino's, New York, NY

For more information, visit our website at [friendsofkaren.org](https://www.friendsofkaren.org)

In Loving Memory

Honoring the lives of the children who have died from July 15, 2023 to February 29, 2024.

Name	Age
Madaisha.....	12
Tommy.....	8
Jerry.....	18
Allison.....	7
Fatima	15
Ariadny.....	2
Angel.....	19
Eesa.....	1
Samantha	17
Xavier	13
Jaylen	15
Rashelle.....	16
Dunya.....	3 months
Jovanna.....	14
Mike.....	3
Melanie	15
Lea.....	4
Christopher	16
Kenny	15
Jaden	16
Fiona	15
Daviel.....	14
Matthew.....	2
Kenzie.....	2
Ian.....	7



Above: Amber (left) with her mom, Shameka. Above right: Amber at the hospital.

A MOTHER'S STORY: Finding Angels on Earth

Shameka is the mother of three: 14-year-old twins Ava and Amber, and their older brother Malachi, age 15. In 2023 Amber was diagnosed at 13 with Dilated Cardiomyopathy, a disorder in which the heart's main pumping chamber is enlarged. Shameka shares how Friends of Karen has been there for her family.

"Amber came to me complaining of chest pains which I thought were gas pains. When that did not go away, we went to the emergency room and she had some tests. The ER doctor arranged for her to be transferred to the children's hospital where she was in the Intensive Care Unit. There, they found that only one of the four chambers of Amber's heart was working, and her condition meant she needed a heart transplant to survive.

Before the transplant she needed two other surgeries, so many medications, and her care involved 23 doctors. At the time, I was working with patients as an anesthesia tech trainee in a hospital, but seeing your own child in the hospital with so many tubes in her was different and difficult. It was overwhelming but I knew I had to trust the doctors to help Amber, and she agreed to proceed with the surgery.

The hospital social worker could see that it was a lot to cope with, so I was referred to Friends of Karen. I was matched with their social worker Alyssa, who was amazing because she arranged for Friends of Karen

to help pay my rent and telephone bill, and the kids got holiday gifts and school supplies. Having Alyssa there for me is like a friend that is always taking time to listen and give advice and never judges. That kind of caring takes a strong spirit and not everyone is built for that.

Without Friends of Karen, I would be more stressed, and we probably would have been put out of our apartment. After I completed their application, everything fell into place. With Friends of Karen, things happened quickly so I never got behind on my bills. I did not have to worry about food because they gave me gift cards to the supermarket where I shop. We also had other emotional support to help us cope from their child life specialist Jenn.

It is amazing to see how much the surgery has helped Amber. She is full of energy now, and she likes to spend time cooking and baking with her twin sister Ava. She's back in school now, so things are getting back to normal.

I am thankful that Friends of Karen gave me peace in a troubled time while Amber was fighting for her life. They truly care about families and made sure I could focus on Amber, and it gave me time to be with my kids. Friends of Karen is truly like having angels on earth."

— Shameka

Because of You!



Chi Omega Tag Sale

Westchester Chi Omega Alumnae Association hosted their 30th Annual Tag Sale. Gwen Salmo, Friends of Karen's Special Events Coordinator, and her Chi Omega sorority sisters organized the tag sale for the 30th year!



2nd Annual Muscoot Cup Fundraiser

Joseph Kaiser organized a tennis fundraiser to benefit Friends of Karen for the second year in a row. The event took place at Chestnut Ridge Tennis Club in Mount Kisco, NY, and the top player took home the Muscoot Cup.

J&B Body Works Car Show, sponsored by Spectrum Painting Corporation

J&B Body Works and Spectrum Painting Corporation organized a car show in Armonk, NY to benefit Friends of Karen. More than 100 cars showed up at the car show and everyone who participated was very generous. Over \$73,000 was raised to help Friends of Karen's children and their families.



Toy Drive

Thank you to PS 46Q The Alley Pond School community in Queens, NY for holding a successful holiday toy drive for the Friends of Karen children.



NYC Gala

Friends of Karen's 45th Anniversary Gala hosted at Guastavino's in NYC, celebrated the contributions of Peter Iacovelli, Charles Avolio, and Laura Salerno Evans. CNN's John Berman served as the event's emcee, while Tess shared how Friends of Karen helped her and her family throughout her illness journey.



Long Island Advisory Board

The Long Island Advisory Board of Friends of Karen, which meets quarterly, has been diligently working to raise awareness and provide support for our fundraising endeavors on Long Island.

Mamma Rosa Italian Dinner Party Fundraiser

A former Friends of Karen family – Filomena, Fortunato and their son, Joseph Multari – organized their 10th Annual Italian Dinner Party for more than 80 guests. The event was held at Mamma Rosa Ristorante in Somers, which the Multaris own with their partner Rigo Giron. The Multari family has raised close to \$100,000 over the years for Friends of Karen families through their lively annual event.





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Family portrait created by bereaved Friends of Karen family during "Living Alongside Grief" retreat in 2023.

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

Ways to Help



Become a Monthly Guardian of Hope Donor

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 Allison at 914-617-4054 or email allisonwatson@friendsofkaren.org.

Follow us on:



Text "FRIENDS OF KAREN" to 22828 to join our email list and stay current on all our programs and activities.