

News from Friends of Karen Supporting critically-ill children and their families SEPTEMBER 2022

CONNECTIONS

CHILDHOOD CANCER AWARENESS MONTH ISSUE

#alwaysgold

A Father's Story

Manuel is the father of 14-year-old Rashelle, who recently completed treatment for Rhabdomyosarcoma, a disease in which cancer cells form in muscle tissue. Rashelle was diagnosed in 2021 and relapsed in July 2022 after this article was written. The family lives in New York City.

"When you hear the words, 'your daughter has cancer,' your world turns upside down. I couldn't believe it. After the news, the doctors gave me all that information about the illness and about the treatment. They tell you you must travel to the hospital three or four times weekly for chemotherapy, checkups, blood transfusions, etc. At home, you must pay attention to side effects or fevers. It was overwhelming.

Then, you arrive home, still in shock, looking at the mail and seeing the bills. I couldn't sleep thinking, 'how am I going to do this?' I am a single father and Rashelle's mother, Emilia, lives in the Dominican Republic. I have family in New York, but everyone is busy with their jobs and lives. Suddenly I couldn't work anymore because the idea of leaving Rashelle alone at home or in the hospital was unimaginable.

I kept thinking, 'how would I pay the bills if I couldn't work? What happens to others in my situation? How do they manage?' On top of all my worries, things are a little more complicated for me because I have hearing problems and my primary language is Spanish. I explained my situation to the hospital social worker, and she told me to call Friends of Karen because they would help me.

I was so relieved when Friends of Karen paired me with social worker Natalia, who speaks Spanish fluently. Natalia is like an angel. It is not only about the financial assistance Friends of Karen provides, but Natalia also cares and always made sure that we are okay. Natalia made sure we could speak on video calls so I could read lips and we texted every week.

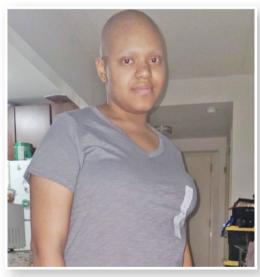
From the first time we connected, Natalia made me feel comfortable. During our first video call, she reassured me that from now on Rashelle's health will be my only concern, and Friends of Karen will help take care of the bills. When Natalia asked me to send her the bills for our rent, electricity, and cell phone, I got quiet for a minute because I got very emotional. Friends of Karen took a weight off my shoulders, and I felt relieved.

Because of Natalia's work, Rashelle always had what she needed during her treatment, from clothes to a new bed. Natalia also ensured that Rashelle received emotional support through other programs at Friends of Karen, including one-on-one sessions with the sibling support specialist Naomi and participating in the virtual teen groups.

Without Friends of Karen, we would have lost everything I had worked for, including



Rashelle during treatment with her father, Manuel, by her side



Rashelle

the apartment where Rashelle grew up. We felt safe because we knew Friends of Karen was there to help us. Natalia knew how to guide me through any question, concern, or problem; and how to find us resources. She took the time to be there for us every step of this journey."

— Manuel



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.

Founder

Sheila Petersen (1938-1990)

Headquarters

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Marla Krellenstein





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

Why Riding is so Rewarding

"I have supported Friends of Karen by riding in the Journey of the Heart Bike Tour since 2013. I ride for the children, their families, and for me.

Obviously, the children and their families need all the support they can get. They are dealing with life-threatening illnesses that tear at the very fabric of their family life.

Every year, we are fortunate enough to hear firsthand from a family member of a Friends of Karen child speak at our dinners during the ride. They describe the trauma of being in that situation and the lifeline that Friends of Karen provides.



Richard Feldman, Journey of the Heart Bike Tour

They receive support for the siblings, school supplies, medical payments, and social work for the families. They make coping with this awful situation palatable.

For me, I feel it is my duty to give back, to do something that truly matters. My reward, and it is truly a gift I give myself, is that I know I am making a difference. Also, the camaraderie that all participants share is unlike any other feeling I have ever felt. That feeling has not diminished in all the years that I have ridden for Friends of Karen. I ride because I can and because I could not dream of missing the experience. Join us and see for yourselves!!!"

- Richard Feldman

YOU Bring Help and Hope

Friends of Karen supports families that have a child (birth through age 21) undergoing treatment for a life-threatening illness like cancer and facing the ongoing emotional and financial repercussions of the COVID-19 pandemic. The needs of these fragile families have grown during this tumultuous period that has also seen the rise in the cost of everything from groceries to gasoline. Friends of Karen has been responding by providing a greater intensity of service, as well as extending the period of assistance to ensure the stability of families.

How is Friends of Karen able to provide these comprehensive support services for children with cancer and their families at NO cost to them?

The answer is YOU. We depend on compassionate and generous friends like you to make Friends of Karen's assistance possible. Your contributions give us the capacity to help New York Tri-State area families with a blend of financial and emotional support so they can function and cope during this tremendously difficult time.

During Childhood Cancer Awareness Month – or at any time – please support Friends of Karen so no family will have to face their child's life-threatening illness alone. Every dollar matters when a child has cancer.

Contributions may be made online at friendsofkaren.org or in the contribution envelope in this newsletter. Thank you for caring!

A Mother's Story: Turning Loss into Help for Others



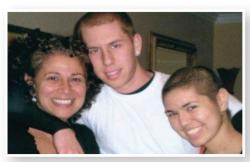
Adina's Angels Walk 2021

In 2010, Paula experienced a lifetime's worth of loss in less than four months. First her husband Steven, a non-smoker, passed away from lung cancer. A few months later, her son Justin died unexpectedly. Then, just two weeks later, Paula's 17-year-old daughter Adina lost a four-year battle with leukemia.

Paula faced these overwhelming losses by leaning on her trusted Friends of Karen social worker Rhonda and her family and friends. Paula knew she needed to do something positive to get through this heartbreaking time. Her good friend Sheri suggested hosting an event to keep her beloved family members' memories alive and benefit Friends of Karen, which had been so helpful when Adina was ill.

Once she made up her mind to do an event in their honor, Paula was determined to pull off the fundraiser with just two months planning. Paula and Sheri pulled together an event at an indoor amusement center and over the years held a comedy night, dance party, and magic event all to support Friends of Karen. Since 2018, Paula and friends have sponsored a 5K Walk in the Park (see details in box on this page)

Not only was she motivated by honoring her family, but Paula was fueled by her drive to ensure Friends of Karen could



Paula, Justin, and Adina

help other children like Adina and Justin and other parents like her. She and Sheri went to every business owner they knew in Westchester County and New York City and created a Facebook page to ask for support of their new effort, which they dubbed Adina's Angels.

Paula recalls that she found Friends of Karen on her own and with the first call found a very different response from other places she called to help her with the issues surrounding Adina's cancer.

"It was 2008, and Adina was getting a transplant and my husband was sick," Paula noted. "I didn't need financial help, but I needed help to get through all this. I reached Rhonda at Friends of Karen and she was the first person that immediately said, 'this is what we will do.' She helped me through all the obstacles we faced, including helping me get a second opinion for Adina."

Paula remembered that Rhonda even helped with small things that made a difference for the family. She brought Adina gifts for Hannukah, her birthday and just because; visited Steven; and helped Justin through some obstacles.

"Friends of Karen was my go-to place, and they never said no – Friends of Karen was always by my side," Paula said. "Now it feels good to help the organization from my heart so that it helps others and keeps my children's and husband's memories alive."

The impact of the emotional and practical support the family received was deep and Paula remained connected to Friends of Karen. Rhonda and Paula spoke periodically after Adina passed away, so Rhonda thought of Paula as the perfect

person to come to a Friends of Karen's Board of Directors meeting to speak about her experiences and what families need from the organization.

"I remember the Board asked what I thought would be helpful to families with ill children," Paula said. "I said 'If they had more sibling support for Justin, he might have dealt better with his dad's and sister's illnesses.' "

That clarity was one of the reasons the fundraising proceeds of Adina's Angels support the now expanded Sibling Support Program. Today, the program is delivered by four creative arts therapists and child-life specialists who provide both one-on-one sessions and group activities targeted to siblings, ill children, and parents. Adina's Angels has also thrived and the group has raised more than half a million dollars cumulatively since 2010 for sibling support and other assistance for children and their families. Paula sums up her fundraising success with Friends of Karen as "a great relationship that really works, but I am a cheerleader who is only as good as the marching band."

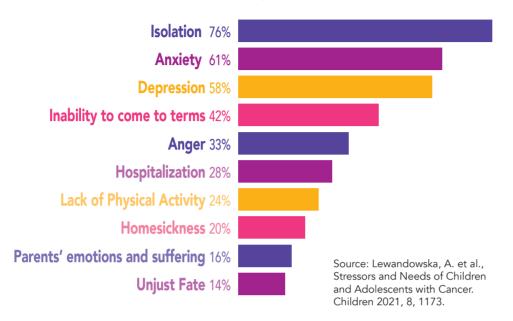
Join Us...

for Adina's Angels' 5K Walk in the Park on Sunday, October 2, 2022 beginning at 9 a.m. in Rockland Lake State Park in Valley Cottage, NY. The Adina's Angels Fund helps Friends of Karen provide vital, practical and comprehensive support, at no cost to families caring for a child with cancer or another life-threatening illness. It particularly strengthens support for siblings coping with their brother's or sister's illness. For details on how to join or support the walk, visit our website at friendsofkaren.org or contact Gwen at 914-617-4051

FRIENDS OF KAREN

Cancer's Emotional Toll on Children

Psychological problems and negative experiences related to the disease are experienced by 82% of children with cancer. Below are the most common concerns experienced by those surveyed.



Faces of Childhood Cancer





Kiarales, age 16

Benjamin, age 8





Christian, age 6

Charlotte, age 6

Because of You...



The Northern Star Quilters Guild members and Friends of Karen volunteers helped sell lots of raffle tickets for this beautiful quilt. Proceeds of \$8,500 benefitted Friends of Karen.



Educator Jennifer LaBier and the North Rockland High School sports teams honored Friends of Karen at their Annual Sports Day and raised \$2,625 to support our services.



LI AlwaysGold Gala honored Jacqueline Clancy and Andrew Lagnado. Friends of Karen child Johnny and his family were our honored guests.



Magic on the Sound honored Drs. Gina Lodolini and Neil Capolongo. Friends of Karen mom Maggie was our celebrated guest speaker, pictured here with son Benjamin and family. *Photo credit: Claudia Boyle*

Gwen Salmo with FoK board member Tom Jocelyn. Tom and the Somers Lions orchestrated "Night at the Races," a very successful event to benefit Friends of Karen. The proceeds are part of a fundraising effort for a match from the Lions International.

David Feldman and Rachel Pastuch of Imperial Cleaning accepted the Friends of Karen's Corporate Challenge trophy for their company's participation in the FoK LI Marathon Team on April 29, 2022.



Siblings Committed to Helping Others

Marisa and Arlene, two Friends of Karen Board Members

Marisa's Story

"Thirty-two years ago, the day before my 16th birthday, our lives changed forever when my sister Erika was diagnosed with Acute Lymphoblastic Leukemia (ALL) at the age of 13. Our life was a rollercoaster ride for two and a half years with daily visits to the hospital for chemo treatments, checkups, and lots of visits to the emergency room.



Marisa and younger sister Erika

Fortunately, our mom was introduced to Friends of Karen and all their wonderful resources. Not only did Friends of Karen assist my mom financially, but they also provided her with a supportive social worker who was able to gently guide her through the nuances associated with a life-threatening cancer diagnosis for her child.

I am happy to report that my "little" sister is now 45 years old, a cancer survivor and thriver, and founder/CEO of The Brain Bodega, an online tutoring and mentoring company which focuses on critically ill children.



Erika and Marisa in 2021

As the sibling of a cancer survivor, I am inspired every day by her journey and strength. Inspiring others and being able to pay it forward have become a priority in my life. As a result, I chose to pivot my career and now work by Erika's side as her COO and as an Academic Mentor for some of our remarkable students. I have also come full circle, 31 years

later, as a proud board member for Friends of Karen. There is no better feeling than sitting in a board meeting, or on a bike in FoK's Journey of the Heart ride, knowing firsthand that your decisions and actions are impacting the lives of children, their siblings, and their families each and every day."

Marisa Carson-Bibens
 Friends of Karen Sibling and Board Member

Arlene's Story

"Growing up as a teenager with a younger brother Ben who battled leukemia, I had many questions and concerns. My family did not have access to the holistic support that Friends of Karen is able to provide as we didn't live in the New York area. When I first discovered Friends of Karen, I thought about how different our family's experience could have been. Having the

opportunity to serve as a board member now is truly rewarding as I witness the powerful impact that Friends of Karen has on its children and families."

- Arlene del Mundo, Chief Nurse Anesthetist, Northwell Health -Lenox Hill Hospital; Sibling and Friends of Karen Board Member



Ben and Arlene

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. For details and to order, fill out the enclosed reply envelope or visit our website. Order by September 30, 2022 to be included in the next phase.

SAVE THE DATE: NOV. 2, 2022 at Guastavino's, 409 E. 59th St., NYC



HONORING SPECIAL AGENTS

Sheila Petersen Award: Paul Smadbeck Humanitarian Award: Dr. Sarah Norris Champion Award: Insurance Industry Charitable Foundation

FRIENDS OF KAREN 5

In Loving Memory

Honoring the lives of our children who have died from March 1, 2022 to July 15, 2022

Eric	10
Daniel	14
Christian	16
Rharie	6
Charlotte	1
Joe	5
David "DJ"	16
Sebastian	19
Noah	2
Andy	18
Kyrie	5
Astor	8
Joseph	23
Jahsean	5
Cameron	9
Wendy	10
Tania	5



Finding Strength in Asking for Help

Queens, New York mother Stacey shares the many ways Friends of Karen helped her family. Her son Stephen, 12, is under treatment for the extremely rare Inflammatory Myofibroblastic Tumor.

"When we first learned Stephen had cancer, I feared whether he would make it and what would happen if he did not. My husband Sudesh and I always thought of ourselves as independent and self-sufficient. We taught Stephen and his older sisters Sarah and Kimberly to get back up if you get knocked down.

When Stephen was diagnosed, it was difficult for us because his tumor was a rare one. First, it took a long time to really understand what was going on with his illness. Then, everything was going along smoothly, and I thought we were managing well. We are grateful to have close family and friends that helped us with whatever we needed.

When the pandemic hit, it made things much harder. That's when things hit rock bottom. My husband is a woodworking joiner and jobs were hard to come by for a while. Our finances were getting tight, as relatives also lost work because of the pandemic and could no longer help us. Then, Sarah was selected out of 60 students to start a combined high school and junior college program. We were so proud, but we did not have the money to buy the program supplies and a computer printer she needed.

I remembered that the hospital social worker had given me some places to call for help, but I had not needed it before. I prayed on who to call first and I swallowed my pride and called Friends of Karen. I was surprised how fast the social worker Rhonda called. All I was focused on then was getting help to pay for Sarah's school supplies, but Rhonda took the time to ask questions to see how we were coping.

Rhonda helped Sarah get the school supplies, but she kept in touch and always wanted to make sure we were adjusting and coping, which was something we did not expect. The warmth Rhonda showed us was different from other experiences we had and that really touched me, especially her concern for Stephen and his siblings' well-being. She even arranged for Sarah to get some spending money so she could get food while she spent long days in her advanced program at school.

"Friends of Karen has been there for us, we really appreciate that everyone looked after us as people."

Rhonda encouraged Stephen and Sarah to join Friends of Karen's weekly *Friends Having Fun* virtual group, and for Stephen to join the peer support group for ill children. Both have been helped by working with Friends of Karen sibling support specialist Naomi in group and one-on-one sessions.

Along with the many ways Friends of Karen has been there for us, we really appreciate that everyone looked after us as people. The love and support we gained by this helped us feel normal during a time when nothing is normal."

Stacey



Stephen when he was younger

Sibling Art



Michelle participated in remote learning this past year and recently returned to school. She is so happy to be back and created this painting of her school.

Nadine's drawing shows her love for kittens.





This is an image created by Julia after being given the prompt "create an image of your heavy load," "the weight you carry."



Belinda's drawing depicts her before and after her cancer diagnosis.

Ways You Can Help

GUARDIAN OF HOPE

You can make an even greater impact when you join our Guardian of Hope caring community of monthly donors. Because of you, Friends of Karen can keep families secure in their home, put food on the table, pay for medical expenses and so much more.



SHEILA PETERSEN LEGACY OF GIVING CIRCLE

Leave your imprint to benefit future generations.

Naming Friends of Karen in your estate plans will continue to impact the lives of critically ill children and their families well into the future.

PUT A SMILE ON THE FACE OF A CRITICALLY ILL CHILD

You can help by participating in one of our Gift Programs listed below. Kids' projects, scouts, and school groups are welcome. For more information, email denisetredwell@friendsofkaren.org or call Denise at 914-617-4052.

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.

FEED-A-FAMILY

Food insecurity is a significant problem for Friends of Karen families. Help parents provide healthy meals for their family. Gift cards in the amounts of \$25, \$50, \$100 are much needed from Stop & Shop, ShopRite, Key Food, Target, Walmart, Mastercard, Visa and American Express. Spread the word and host an online fundraiser, ask us how.

BIRTHDAY PROGRAM

Every child looks forward to their special day. Please help us provide a gift for every child in the family, so that birthdays remain a happy occasion even in the midst of illness.

For more information about our programs or events call (914) 277-4547, or email info@friendsofkaren.org

Why I Choose To Give and Not Receive

"I choose to give the gift of happiness, compassion, and love to others that are in need. During a time of illness of a child, the last thing a family needs to worry about are the basics: food, shelter, and transportation. Spending time with the child that is living with cancer is all that a family member should have in mind.

During the year I give a monthly monetary donation to Friends of Karen, in memory of my nephew David. On my birthday to celebrate his life and all that Friends of Karen did for him and his family, I ask my friends to donate to Friends of Karen in lieu of gifts. I feel it is always better to give than receive. I hope this will inspire others to do the same."

- Janice Williams

FRIENDS OF KAREN



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"We felt safe because we knew Friends of Karen was there to help us. Natalia knew how to guide me through any question, concern, or problem; and how to find us resources."

- Manuel, Rashelle's dad

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

