We felt like our world crashed.
That’s how Iryna describes the way she and her husband Yuroslav felt when they received the diagnosis that their daughter Sophia, just shy of three years old, had stage 4, high-risk neuroblastoma, a rare cancerous tumor that almost always affects children. It was the beginning of a very bumpy road for the family that included not only intense treatment for Sophia, but additional trials for the family. Throughout their rough journey, Friends of Karen provided much-needed support that Iryna calls, simply, “priceless.”

Sophia’s treatment included six cycles of chemotherapy, surgery, two stem cell transplants, 12 sessions of radiation, and six cycles of immunotherapy. She spent nearly seven months in the hospital. Compounding the situation was another unexpected tragedy. There was a fire in the apartment directly above the condo where they lived – and their home was destroyed from water damage. They came home from Sophia’s first chemo session to find they had no home, on top of everything else.

“It was very tough on us,” Iryna recalled. “At first, we felt like we were alone. Someone told us about Friends of Karen. When I first heard from Sarah, our Friends of Karen social worker, we just talked. I told her about Sophia and what happened to our home, and she said they could help us.”

Iryna had stopped working to care for Sophia, so Friends of Karen was able to provide valuable financial support for the family, including copays for doctor visits and medications, and help with transportation to the hospital for treatments. Friends of Karen also successfully obtained a grant for the family, which allowed for the purchase of new towels, bedding and other household necessities.

“The financial support was vital, but it meant so much to just have someone to talk to; someone who understood,” she reflected. “Sarah has been a spark of light in our life! She was in the hospital with us almost every session. She would come and sit with me and just listen. Sophia loved when Sarah came. Sarah would call us, sometimes in the middle of the day, just to see how we were. What we were going through was a process and not everyone understands or knows how to talk to you. Sarah is one of the only people I could talk to who knew just what to say at the right time. She is amazing!”

Thankfully their bumpy road has come to an end. The family is in a new home and Sophia’s last treatment was in July 2017. All of her scans came back clear. According to her mom, she is doing absolutely great! “She’s back to normal again,” Iryna said with relief. “She’s now four-and-a-half. She has gained weight, she started pre-K, she’s doing arts and crafts and drawing, she even started horseback riding. And she and her little brother, Luka, they are best buddies. They do everything together – including making trouble!”

“We made it through. And Friends of Karen has been tremendously helpful. They reminded us that there are people who really care and who help to make this road easier. What they did for us truly was priceless. And now, our sunshine is shining again!”

“What they did for us truly was priceless .” — Sophia’s mom
FROM OUR EXECUTIVE DIRECTOR

Thank You for 40 Years of Kindness

Dear Friends,

Each new year marks an opportunity for reflection and growth. This year, as we celebrate a milestone anniversary at Friends of Karen, we’re looking back on not just one, but 40 years of giving families more time to love.

In 1978, Friends of Karen was born when one kind-hearted soul, Sheila Petersen, couldn’t sit idly by and watch her neighbors care for their terminally-ill daughter, Karen, alone. Sheila urged her community to pitch in to help Karen and her family at such a difficult time. It didn’t take much urging. People responded to Karen’s plight and eagerly offered their support. This small, grassroots effort started in Westchester County has grown steadily over the years, thanks to the compassion and generosity of a caring community.

Forty years later, we annually serve well over 600 families, each caring for a child with cancer or other life-threatening illnesses. Friends of Karen’s diverse families live in the 5 boroughs of New York City and in 17 surrounding counties in the Tri-State region. We are only able to assist so many children and families because you stand with us.

They say a lot changes in 40 years. That’s certainly true. Most notably, according to Curesearch, “In the last 40 years, the overall survival rate for children’s cancer has increased from 10% to nearly 90% today.” Children, fortunately, now have many more therapeutic options, though some treatment protocols may last two or three years. You can imagine how challenging this can be to normal family life. We have readily been able to adapt Friends of Karen’s support so that we may best serve families throughout their child’s treatment, whether for a few months or a few years. We remain steadfast by a family’s side.

There have been many changes within our organization. In this newsletter, you’ll read about Joseph, a Friends of Karen child, who has grown to become an advocate, even hosting fundraisers for us. You’ll also hear from Susan Downes, who became our very first social worker in 1986. She helped families in that role for more than 12 years and now has transitioned to being one of our most valuable volunteers.

But one thing hasn’t changed at all. When given the opportunity, people will step up and make beautiful things happen. In my 10 years as Executive Director, I’ve seen this at Friends of Karen practically daily. This extraordinary kindness and caring never ceases to amaze me.

Throughout 2018, we’ll be hosting events to celebrate our 40th year. We hope you’ll join us to help mark this meaningful milestone.

Judith R. Factor
Executive Director

I’ve been trying to figure out, “why her?”, “why our family?” but I think I finally figured it out. It’s probably so that we could do just what we are doing... spreading the word about the disease, the hospital, the doctors and organizations such as yours. — Mia’s mom
As we celebrate our 40th anniversary in 2018, we’re pleased to spotlight Susan Downes. Susan has the distinction of being the very first social worker hired by Friends of Karen.

Susan recalled her initial interview. “When I met with Sheila Petersen, she was so enthusiastic and so committed! I left my interview feeling like I really, really wanted this job! And I was so pleased to be hired. In those early days, Sheila worked from a tiny office nearby her home, with just a small part-time staff and a few volunteers. But she laid the foundation and was able to build this big organization.”

Over the years, Susan developed wonderful relationships with many families during their time of crisis. “We worked so closely with them, sometimes just sitting with them; sometimes going to be with them after their child passed away,” she reflected. “We were fully immersed in their lives.”

Susan stayed on as a social worker until 1998, and she and her husband, Jim, have continued ever since as loyal supporters and volunteers. “I never felt a separation from them after I left the job,” she said. “I always stayed in touch. A few years ago I volunteered at a memorial service and balloon launch. It brought back a lot of memories of families I worked with. It also reminded me of the tremendous commitment of the staff at Friends of Karen. In spite of the emotionally demanding work, they still have passion for the organization and what they do. Someone wrote that Friends of Karen is an organization that does exactly what they say they do. And that’s so true! Their mission is very clear and they’re very transparent. You know exactly where your money is going and what it’s doing. They are always finding ways to enrich the work they do; to help a family, beyond the financial. They never say that’s it; we’ve figured it all out. They always go the extra mile to meet the needs of families.”

Joseph was almost through his sophomore year in high school when the headaches started. “For about a week or two I had a headache and I wasn’t eating,” he recalled. “My mom finally said, ‘We’re going to take you to the hospital, because this doesn’t make sense.’”

Joseph ended up at the hospital the day before Mother’s Day, scans found a growth on his brain. Doctors performed surgery immediately. A few weeks later, he was diagnosed with glioblastoma multiforme, a malignant tumor affecting the brain. He underwent treatment for over three years.

Early on, a social worker from the oncologist’s office suggested to Joseph’s mom, Rosa, that she contact Friends of Karen. “I assumed we were not eligible for support because we had a home and a business,” Rosa recalled. “But when I exhausted all our savings on copays and medications, I decided to reach out. Friends of Karen treated us like family, providing the emotional and financial support we needed during this difficult time.”

Joseph is now doing well in his third year at SUNY Dutchess, where he’s active with his studies and other activities, including a student LGBT club which he helped form. His ultimate goal is to earn his doctorate in clinical psychology. Giving back to Friends of Karen has become a part of Joseph’s life. “I like to volunteer when I’m home from college,” he said. “My family has been involved, too — we’ve had fundraising events for the past five years at our family restaurant, Mamma Rosa, in Somers. It feels good to help out, because they’ve been so helpful to us. When you get to that point of dealing with cancer in a family, everything changes and it’s easy to lose grasp. Friends of Karen is so valuable when it comes to helping a family maintain stability.”
An Evening at Tribeca Rooftop was a celebration of Friends of Karen honorees and supporters, The Impagliazzo Family, John Berman and Diana E. Lemon with her daughter Dream. CNN anchor/ correspondent, Randi Kaye, was Master of Ceremonies.

The Brewster High School Varsity Girls’ Lacrosse team held a lacrosse clinic and bake sale to raise money for Friends of Karen. Thank you to junior Lauren Craft, who organized the event, and all her team members who participated!

Friends of Karen bike team endured the 13th annual “Journey for the Heart” bike tour on the picturesque back roads of Connecticut September 2017. New riders are always welcome. Each rider dedicates their journey ride for a Friends of Karen child!

To benefit Friends of Karen and raise awareness, Ultramarathon Runner Byron Lane (left) next to his trainer Dan Turturro, completed 183.03 miles on a treadmill in 48 hours to break the U.S. Record and is now 7th place in the World.

In memory of Friends of Karen child Erin O’Connor, the 11th annual Erin O’Connor Memorial Golf Tournament was held at the Salem Golf Club. The event raised $70,000 to help Friends of Karen children and their families. A very special thank you to Mike and Eileen O’Connor and their family as well as Coldwell Banker Real Estate LLC for going the extra mile for Friends of Karen and our families.

Would you like to hold a local fundraising event?
Contact Gwen Salmo at GwenSalmo@FriendsofKaren.org or (914) 617-4051.
On Long Island, contact Rebecca Mowl at RebeccaMowl@FriendsofKaren.org or (631) 473-1786
Congratulations to Beth Ferrari, who is celebrating her 15-year anniversary as a Friends of Karen social worker! Beth earned her undergraduate degree in social work and began working with Friends of Karen in 2002.

“I’ve always had a place in my heart for children who are ill,” Beth shared, “so when I found out about the work Friends of Karen was doing to help critically ill children, I knew working for them was a career path I wanted to pursue. Although it has been 15 years, I continue to have the same passion I had for this work when I first started at Friends of Karen. I know our organization impacts families and children in a way that allows them to remain stable in the midst of so much uncertainty.”

Beth covers a wide territory that ranges from the Bronx up to Ulster County, with parts of New Jersey and Connecticut, as well. At any given time, she is working with 35-40 families.

“Over the years, I have helped over 1,000 families of children with cancer or other life-threatening illnesses. Honestly, it is not about what I have done for them, as much as what they have taught me about strength, resilience, patience and love. While it is my job to provide financial and emotional support to families, I am acutely aware of how difficult it is for families to ask for help. Making it easy for families to open up to share their worries and concerns is also a critical piece of my work. I am honored and humbled each time I meet a new child and their family, knowing they are allowing me into a very sacred place — their family’s life. Hope is evident in all of our work, as I believe that Friends of Karen allows parents to have hope — now and into their future.”

For anyone thinking about supporting Friends of Karen, Beth has some encouraging words. “This is a very special organization with a special mission. The money and efforts go directly to families, who benefit so much and appreciate the support — and often end up giving back themselves. It’s my honor and privilege to work here, to be able to help such incredible families, and to learn so much from them, as well. Ultimately, we’re here to offer hope. That’s really what the organization is all about.”

We’re delighted to have Beth on staff and thankful for what she does at Friends of Karen to bring help and hope to so many children and families!
Meet Kunga

Like many young boys his age, Kunga likes playing video games, creating things with Legos, and playing soccer with his friends. But Kunga's typical childhood was interrupted in the summer of 2015, when he was eight years old. He began to exhibit symptoms of what appeared to be a cold with fever. On his first of four visits to the doctor, Kunga was told Dolma she needed to bring Kunga in immediately. He was diagnosed with ALL (acute lymphocytic leukemia), a cancer in which the bone marrow makes too many immature lymphocytes. Kunga was sent to Sloan Kettering to begin his treatment and started chemotherapy immediately. He was inpatient for five months as doctors worked to find the best treatment and medications for him, and was in isolation multiple times.

Shortly before Kunga was discharged, a social worker at the hospital encouraged his family to call Friends of Karen for support. Dolma found the organization to be an "amazing support," helping the family in many ways. Utility bills were paid, as well as emergency travel expenses for cabs whenever Kunga had to go to the emergency room. Friends of Karen was able to provide school supplies, birthday and holiday gifts, and gift cards to help with family food expenses. And when Kunga returned home, Friends of Karen provided an art therapist to work with him and help him better understand his illness through the use of art, books and conversation. Kunga looked forward to her visits!

As a Tibetan immigrant to the U.S. who speaks limited English, Dolma has had some difficulties adjusting to a new country where everything is different. She is so thankful that she can rely on Friends of Karen for help. “I know that if something goes wrong or something is needed, I have someplace to turn to get help,” Dolma said. "The emotional support has been so important. I will never forget all that they provided for me through Kunga's illness.”

Dolma reports that Kunga is doing well now. He is in the maintenance phase of treatment, which is less intense than in the beginning. He has been homeschooled since his diagnosis, but Kunga's doctors are hopeful that he will be able to go back to school in January. Best of all, he is feeling like a kid again! He's back to eating his mother's traditional Tibetan foods, like thenthuk, a noodle soup. When asked about Friends of Karen, Kunga said, “They helped me through lots of trouble!"

“Saying thank you for the support and help is not sufficient,” Dolma expressed. “What they have done for me and my family is so amazing. I cannot express in words my gratefulness. Friends of Karen touches so many people. It truly is amazing.”

“I know that if something goes wrong or something is needed, I have someplace to turn to get help.”
– Kunga’s mom

As soon as a child is diagnosed with a life-threatening illness, a family’s world is turned upside down and it affects the entire family.
SAVE THE DATES!

The Masquerade Gala at Stonebridge
March 9, Stonebridge County Club, Smithtown, NY

The Walk/Run for Friends of Karen at the LI Marathon
May 5-6, Eisenhower Park, East Meadow, NY

40th Birthday Party for Friends of Karen
June 8, Rye Playland, Rye, NY

The Erin O’Connor Memorial Golf Tournament
July 16, Salem Golf Club, North Salem, NY

14th Annual “Journey of the Heart” Bike Tour
September 22-23, Litchfield County, CT

40th Anniversary Celebration
November 2, Chelsea Piers, New York, NY

Ways to Give

BIRTHDAY PROGRAM
Bring the “happy” to every birthday by helping provide gifts for every child in the family. Gift wrap needed too! Please see our “Wish List” at www.FriendsofKaren.org/gifts-for-children.

HELP FEED OUR FAMILIES
Did you know that Friends of Karen has a Feed-A-Family Gift Card Program? Many families encounter a loss of income due to lengthy and frequent hospitalizations and this leaves parents unable to provide healthy regular meals for their family. Gift Cards in the amount of $25, $50, $100 from American Express, VISA/Mastercard, ShopRite, Key Food, Stop&Shop, Trader Joe’s, Walmart and Target will enable parents to feed their family. You can mail gift cards directly to Friends of Karen, 118 Titicus Road, North Salem, NY 10560.

HONOR A LOVED ONE
Celebrate important milestones or express your sympathy with a gift in honor, memory or in appreciation of a special person. With your gift, we will notify the person(s) you designate with a special letter and include your personal message. It’s a wonderful way to remember a loved one and ensure that families caring for an ill child have Friends of Karen by their side. Please call (914) 617-4040 or visit www.FriendsofKaren.org to make a gift.

LEGACY CIRCLE
Be part of our Sheila Petersen Legacy of Giving Circle. As a member, 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. Including a bequest to Friends of Karen in your will or trust may be as simple as adding a single sentence. Here’s language that you can take to your attorney or estate planner: Thank you for supporting our future!

“I give, devise, and bequeath _________ (a certain sum, a percentage of the estate, or the remainder of the estate) to Friends of Karen, 118 Titicus Road, North Salem, NY 10560.”

GIFTS OF APPRECIATED STOCK
Giving a gift of appreciated stock is an easy and effective way to support Friends of Karen. You will have the satisfaction of investing in a cause important to you while possibly realizing tax savings. Call Kathleen Ryan for more information: 914-617-4058

SHAMROCKS FOR FRIENDS OF KAREN
March brings St. Patrick’s Day and the “sale” of shamrocks to benefit Friends of Karen children and families. Check the listing on our website for the restaurants or other locations where you can find our shamrocks and dedicate one to that someone special in your life.

Call Gwen Salmo at 914-617-4051 or Rebecca Mowl at 631-473-1768 (on Long Island) for more information.

Emotional, Financial and Advocacy Support

BECOME A MONTHLY SUPPORTER.
Use the enclosed reply envelope or contact Gabriella DiSisto at 914-617-4047 to sign up today!

Friends of Karen
“The past year and a half have been tough for us, but nonetheless, we have a lot to be thankful for. Especially for people like you and Friends of Karen that have been so good to us. ”
– Friends of Karen Mom

Friends of Karen turns 40 this year!

We remember Sheila Petersen, our founder, and Karen MacInnes, our first child, for whom Friends of Karen is named. Their strength and compassion inspire us to this day.

“When the parents of a terminally or catastrophically ill child received financial and emotional help, they have more time to love.” Sheila Petersen, founder

Please join us to celebrate this milestone year with many special events and remembrances planned throughout 2018.

Left: Founder Sheila Petersen
Right: Karen MacInnes for whom Friends of Karen is named

Follow us on:

Text “FRIENDS OF KAREN” to 22828 to join our email list and stay current on all our 40th anniversary activities.