



CONNECTIONS

SUPPORTING CRITICALLY-ILL CHILDREN AND THEIR FAMILIES

Meet Tova A Family Builds Resilience Together

Tova was a happy three-year-old toddler enjoying a family vacation when her father, Gedalia, noticed her smile was suddenly crooked. By the time they returned home to Rockland County, New York three days later, Tova was avoiding using her left hand and was limping on her left leg.

Their pediatrician sent Tova to the hospital, where she underwent emergency surgery after an MRI showed a tumor. Gedalia and Kayla, Tova's mother, soon learned that she was suffering from an extremely rare brain cancer called embryonal tumor with multilayered rosettes (ETMR). They also learned the heartbreaking news that only one in four children with ETMR survive.

It was a devastating blow, but Kayla became determined that Tova would be among that 25% that survive. So, the family followed the advice of the neuro-oncologist who immediately began aggressive treatment to fight the dangerous tumor: high dose chemotherapy, proton radiation therapy, and stem cell transplants. It's been grueling, but Tova is now five years old and continues to improve through rehabilitative services for the residual physical consequences of the treatment that have left her physically disabled.

Through it all, Kayla's optimism has built upon the example of her naturally resilient daughter. Kayla also attributes the family's faith and close knit community's support to helping them cope throughout Tova's diagnosis and treatment.

"I was a school principal and had stopped working to spend more time with Tova and her five older siblings just a week and a half before her diagnosis," Kayla said. "My school has a sign in every room to remind students and staff to pray for Tova, which is a comfort to us."

Another source of solace for the family has been Friends of Karen. The family learned from the hospital social worker that Friends of Karen could help with the cost of tolls and parking when they took Tova for treatment in New York City.

"Friends of Karen's social worker Beth reviewed all our expenses and asked us if we needed help with our utility bills, which I had not thought to mention," Kayla remembered. "We also received other things that we did not expect and meant a lot to the whole family, like money for clothing, and Hanukkah and birthday gifts. We had started working with Beth after the holiday wish lists were submitted, and we were amazed that Friends of



Tova, on Mom's lap, with her siblings

Karen picked the perfect gift for each of our kids."

Kayla says she was not always as resilient or open to this kind of support. She learned through a previous family crisis that she needs to embrace the reality that she is not in control of everything in her life.

"Once I let go of the need for everyone and everything to be perfect, it was easier to cope and to accept assistance," Kayla observed. "Sometimes we need to be able to accept help and then we can also give help to others."

The lessons Kayla learned that enabled her family to be resilient have led her to a new career path. She has completed a certificate to work as a family peer advocate to help support and empower other families facing life-shattering events.

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Celebrating Resilience

friendsofkaren.org



friendsofkaren.org

Our Mission

To provide emotional, financial, and advocacy support for children with life-threatening illnesses and their families, in order to help keep them stable, functioning, and able to cope.

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Sheila Petersen (1938-1990)

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FROM OUR EXECUTIVE DIRECTOR

Dear Friends,

Resilience, the theme of this newsletter, is a defining characteristic of our Friends of Karen (FoK) children and their families. Against what seem like insurmountable challenges, they tap into their strengths and support systems to weather the many hurdles of getting through a life-threatening illness like cancer. Add the threat of COVID-19 and you have some idea of what our families have been facing this past year. As if life wasn't already difficult enough for them! The stories we're spotlighting in this issue are a testament to their remarkable resilience and will inspire you for sure.



It is an understatement to say this year has been challenging for all of us too. One takeaway for me is an added insight into what our Friends of Karen families face every day — the feeling of isolation, the fear, disappointments, stress and anxiety that take over your life during a health crisis. Like FoK families, our lives have been turned upside down by an unforeseen health emergency. Truthfully, a year ago, I didn't know whether Friends of Karen would be able to fulfill our promises to the families who would need our assistance during the pandemic more than ever. It was a scary prospect, but I should never question the resilience of the FoK team.

Our Family Support staff kicked into gear. They quickly shifted to working remotely, connecting with families via Zoom or Skype because they could no longer visit them in their home or the hospital. Our administrative staff pulled together and has kept operations flowing smoothly these many months. Likewise, FoK's Board of Directors stepped up to help navigate the organization through the uncharted circumstances we faced. With careful financial planning, some steadfast volunteers, and a dedicated team working together, Friends of Karen never missed a beat. We even identified unmet needs created by the pandemic and launched new programs for children and families. You can read about them in this newsletter.

Reflecting back on this unbelievable year, I am filled with **gratitude**. Despite the challenges YOU were facing in your own life, you have kept Friends of Karen children and families in your heart and mind. YOU have been and continue to be the glue that unites us during this uncertain time. Your incredible generosity and kindness is overwhelming. Because of you, FoK was able to provide four-times the support for parents to feed their families at a time when nearly half have suffered a loss of income due to COVID-19. Your partnership empowers all of us at FoK to be resilient and focus on our core mission of helping families stay stable, functioning, and able to cope when their child is in treatment for a life-threatening illness.

To the amazing Friends of Karen team and all of you who have been by our side during these many months, my sincerest thank you. Be well and stay safe.

With a grateful heart,

Judith Factor
Executive Director

A Big Sister Finds Comfort through Support

At the end of 2019, Eden, now four, suddenly started to have difficulty walking and complained of pain to her mother, Victoria. Victoria took Eden to the hospital where it was determined the three-year-old girl had acute lymphocytic leukemia (ALL), a blood and bone marrow cancer.

The diagnosis was a shock to Victoria, and the single mother of three in the Bronx feared Eden's illness would break her. To her relief, the hospital social worker introduced her to Friends of Karen. "I could leave the hospital at ease knowing I'd be helped," Victoria said. "I don't have help from family members, but I learned that people were there for me."

Friends of Karen provided financial support for transportation to the hospital and childcare for her other children, Erin who is seven years old and Elam who is three years old, when Eden had doctor appointments. Victoria also knew her children needed support, so she and Friends of Karen sibling support specialist Jane discussed how the diagnosis would affect the entire family. Jane worked with Eden's sibling, Erin, virtually to discuss her feelings about her sister and the pandemic.

The Sibling Support program focuses on the emotional needs of the well siblings in the family, and sometimes the ill child

as well. Sibling Support is provided by child-life specialists and creative-arts therapists to help the ill child's sisters and brothers understand the illness and develop strategies to cope with changes in their family's life, using art, music, journaling, play and other appropriate means to work effectively with children from age five through the teens. While these services are usually provided in the home, during COVID-19 Friends of Karen staff has worked with children remotely.

"I don't have help from family members, but I learned that people were there for me."

During this time, Victoria recognized the need to take control over what she could control. Erin was going to be turning seven, and had shown a lot of progress and resilience. Victoria wanted to celebrate Erin, so she put together an art themed birthday party for Erin's siblings and cousin, and hosted a Zoom sing along for others to attend.

It wasn't just Erin who found inner strength through such a difficult time. Victoria is grateful for the help her family received,



and decided to follow Friends of Karen's example by supporting others. She recognized ways that she was able to comfort Eden during chemotherapy treatments and she gathered similar items to create Chemo Bags for five other ill children receiving treatment, and plans to help with more bags in the future.

"Each Chemo Bag contains a customized shirt, socks, beanie hat and water bottle," Victoria said. "The shirts have a zipper in the upper corner to allow access to ports easily, without having to change into a gown. I customize the shirts myself with empowering phrases. I want to give back because I have received help - because that's right thing to do."



Thank You, Nancy!

Nancy Mariano opened our Long Island office in 2001 and has been at the helm since then, building awareness and support for Friends of Karen in the NY metro area. A beloved colleague and champion of the organization, Nancy retired on March 31, 2021. She has had a tremendous impact on the lives of so many children and their families. Heartfelt thanks, Nancy, for your passion and dedication these many years. We will miss you.

Save The Dates

Long Island Roaring Twenties Gala:

July 21, 2021 — Stonebridge Country Club, Smithtown, NY

Walk/Run at the LI Marathon:

September 17-19, 2021 — Eisenhower Park, East Meadow, NY

Journey of the Heart Bike Tour:

September 25, 2021 — Bicycle Tour Co., Kent, CT

Adina's Angels Annual 5K Walk in the Park:

October 10, 2021 — Rockland Lake State Park, NY

Virtual Gala:

October 28, 2021

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

Because of You...



The Reifert Family joined in support of Friends of Karen's Virtual Long Island Walk/Run by running a 5K. Pictured are Christiana, Gary and Caitlyn.



Thank you to our dear friends at KPMG, who during the pandemic adapted their annual Thanksgiving program of purchasing food and gift cards for Friends of Karen families, to raising funds so families could purchase food for a Thanksgiving meal. Generous KPMG employees donated \$43,293, enabling 223 families to enjoy a special meal, and funds left over for many more families to have food for the holidays!



Nina, a 7th grader, created a unique project in preparation for becoming a Bat Mitzvah. She made 10 videos reading her favorite bedtime storybooks which we'll send to Friends of Karen children. Nina also donated twenty-four \$25 Barnes & Noble gift cards from contributions from her friends and family.

Nothing stops the Chi Omega's from helping Friends of Karen! They hosted their 27th Annual Tag Sale and raised \$3,136, the most ever since they began sponsoring tag sales in 1993 for Friends of Karen.



When Giselle, a high school junior, heard that food insecurity is a major problem for Friends of Karen families, she jumped on the idea of collecting grocery gift cards. She raised \$600 and donated Stop & Shop and ShopRite gift cards.



Nearly 100 people gathered at Rockland Lake State Park for the Adina's Angels 3rd Annual 5K Walk. Due to Covid-19, we split up the walk into two groups of 50. Even though Paula, who began the Adina's Angels Fund at Friends of Karen, could not join us in New York, she and her friends walked in Florida where they live to help raise a total of over \$34,076 for the Fund.

Would you like to hold a fundraising event?
 Call Gwen at (914) 617-4051 or email info@friendsofkaren.org.
 On Long Island, call Rebecca at (631) 473-1768.

A Family Stays Strong by Accepting Help

Gang and Lihong were living a parent's worst nightmare. Their teenage daughter Xingyu was more than 1,000 miles away in Florida during a hurricane, and she was suffering from a strange headache and visual disturbances that sent her to the hospital. The doctors there discovered she had a Clival Chordoma brain tumor.

Since the storm cancelled all flights, Xingyu's father Gang had to drive all the way to Florida to pick her up. As he drove, he felt numb and unable to cry. Gang reassured himself that maybe it was all a misunderstanding because his first language is Mandarin Chinese, and he had been told the news through a translator on the phone.

He rushed Xingyu home and his hopes were dashed when their local hospital confirmed the diagnosis and the need for treatment. She is now 15 years old and in the maintenance phase of treatment after numerous rounds of chemotherapy and radiation over the past year.

Xingyu's family connected to Friends of Karen through the hospital social worker and they were relieved when they were paired with social worker Sarah and sibling support specialist Naomi, a Mandarin speaker.

"My job is to devote myself to my children's needs, and I am so thankful to have Friends of Karen's support," Gang said. "It has made things more

comfortable for our family to have one consistent Mandarin speaking person working with us. Friends of Karen knows our story and we are comfortable with them."

This support has been vital as Xingyu's illness has had a profound impact on the entire family. Gang had to stop working



Xingyu smiles beneath her mask

as a taxi driver to be with her during inpatient treatment and doctor visits, while Lihong continued to work as a nail technician. Like so many families with a seriously ill child, the reality is that one salary was not enough to pay all their bills. Friends of Karen helped the family with financial assistance towards rent, car insurance, buying new furniture, providing gift cards for the kids for clothes, birthdays and the holidays.

And, it wasn't just their financial worries, the whole family was reeling from the life changes, and fear and anxieties of Xingyu's life-threatening illness. "After Xingyu was diagnosed, I noticed her moods were becoming unstable more easily," Gang shared. "Naomi helped Xingyu work through her feelings and helped the family understand and support her emotional needs."

Her younger brother Haokai, now 10 years old, had to deal with the upheaval of not just his family life, but the consequences of COVID-19 as he now attended school remotely. It created a mixture of feelings for him and Naomi worked with him to provide support and outlets for his emotions, which are typical for siblings of ill children.

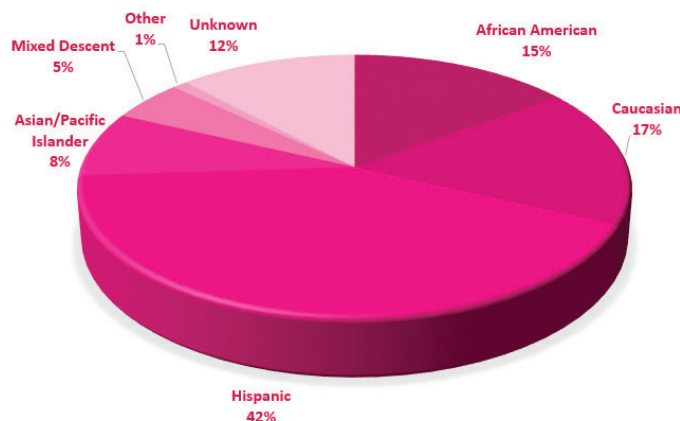
Gang is grateful that his family had the support of Friends of Karen to help his family persevere through this difficult time.

"Knowing that people cared about me and our family let me focus on Xingyu and her emotional and medical needs," Gang said. "It's not easy to stay strong when you are going through something like this. I learned that it's not just OK, but important to reach out for help so that you can focus on your child. It is important to think positively even in the worst case scenario to keep your hopes up and not give up."

DID YOU KNOW?

Friends of Karen offers its services at no cost to families and regardless of race, religion, gender, national origin or cultural heritage in compliance with all federal, state and local laws and regulations. We are committed to embracing and promoting diversity, equity and inclusion in all areas of our organization and are currently deepening our commitment by exploring ways to enhance this effort through Board of Directors and staff DEI committees.

2020 ETHNICITY OF FAMILIES SERVED



In Loving Memory

Honoring the lives of our children who have died from July 18, 2020 to February 28, 2021

Belinda12 years
Alexa17 years
Jeimy4 years
Mayah.....7 months
Ezio.....3 years
Gianna.....21 years
Lily4 years
Freddy15 years
Amara.....15 years
Shane12 years
Benjamin9 years
Andrew.....5 months
Thamara14 years
Jeremy.....8 years
Kaiden10 years
Jayden.....18 years
Emma15 years
Avery1 year
Jace6 years
Fatoumata18 years
Alondra.....6 years
Nashly4 years
Muhammad..2 years
Omar15 years
Tru.....15 years
Jocelyn7 years
Gabrielle.....5 years
Robert17 years
Eric.....16 years
Marsellus14 years
Angel.....5 years
Mizarahi.....22 years
Kleiberth.....18 years
Phoenix2 years

Our Resilience Brings New Ways for Families to Heal

The term resilience is an area of the health field focusing on people coming back from adversity due to disease or trauma. The ability to bounce back from a setback defines those who are best able to adapt to life-changing events and emerge as whole as possible. Friends of Karen's purpose is the essence of promoting resilience – helping every member of a family with a child undergoing treatment for a life-threatening illness to remain stable, functioning and able to cope.

COVID-19 has challenged everyone to find a level of resilience they never had to access. At Friends of Karen, we have seen our families pushed to their limits as they take on the added burden of COVID-19's far-ranging consequences.

The pandemic has brought changes to how Friends of Karen delivers our services as we transitioned from in-person visits to remote visits. These COVID-19 challenges came with a silver lining as we discovered new opportunities to help our families cope and heal. Through this process, Friends of Karen's talented, skilled and creative staff mined an even deeper level of resourcefulness that contributed to the resilience of our organization.

During the pandemic, our Family Support Program team identified that children and parents were feeling overwhelmed and stressed being at home all the time. So, in the summer of 2020, we initiated virtual Family Fun group meetups to provide a respite for parents and caregivers, while providing socialization, mindful engagement, diversion and fun for our Friends of Karen children and siblings.

While conducting the Family Fun group, our staff identified that the girls were struggling with self-esteem issues. In response, we developed a virtual six-week program called Connect and Create! Building Self Esteem Together. Connect and Create! kicked off this spring. The group serves girls ages 11 to 16, who are most vulnerable to low self-esteem. The girls will have an opportunity to discuss how the illness affects them and their families; create art that encourages leadership, creativity and reflection; and participate in teambuilding activities and unique art therapy opportunities.

Our Family Support staff knew that it wasn't just children that needed a special time to be together. Families who lost a child needed a place to gather too. With the wide availability of virtual meeting technologies during the pandemic, families no longer faced barriers to seeking mutual support. In late 2020, Friends of Karen started two online bereavement groups for our English-speaking and Spanish-speaking parents who have lost a child. Both groups are fully enrolled, with 12 families participating in each group. We held our annual memorial service virtually for the first time, which increased access and participation.

Friends of Karen's Family Support Program will continue to identify new ways to respond to our families' needs that will help them build their resilience as they face an arduous disease journey and COVID-19.

"As the sole pediatric palliative care physician, I have had the up close and personal experience of suffering made easier by Friends of Karen. They have the generosity of heart and foresight to really understand the experience of critical illness and ease burdens with such skill. They have the history and tradition at Friends of Karen to treat each family as they would a dear friend – always available, supportive and offering love through service."

— Sarah Norris, M.D., M.Ed., Children's Hospital at Montefiore

Staff Profile: Terri Sorrentino



My name is Terri Sorrentino, and I am the Director of Finance and Administration for Friends of Karen. This June will mark ten years that I have worked for this amazing organization.

The mission of the organization to help families cope with the unimaginable circumstances of having a child with a life-threatening illness is very compelling. It is what drives everyone on Friends of Karen's staff to give one hundred percent every day. While the social work team performs the "front line" work of supporting our families, the development team communicates news of the important mission to the wonderful donors that make supporting our families possible. Finance and Administration supports families by managing expenses to ensure they receive every dollar possible. We also manage internal processes to provide accurate and transparent reporting to our generous donors.

Ten years ago, I was excited for the opportunity to support Friends of Karen's efforts with children and families with a financial role critical to the mission's success. My goal was to find ways to balance great financial need with the processes and checks and balances required for financial accountability and transparency. Achieving this would be the best way to support the organization's needs, aspirations and impact.

Personally, my commitment to children has led me to write children's books on the value of kindness. My books speak to showing empathy and kindness to each other, the world around us and to the environment. I have found tremendous fulfillment in reading my books to groups of children. Reading is a great tool to advance the learning process for children. But reading also offers a chance to escape to another world where children can find comfort in other surroundings and recognize similarities to themselves in other characters.

My work at Friends of Karen has deepened my understanding of the struggles of families who deal with the crisis of a sick child and all the emotional and financial struggles that result. I am grateful for the opportunity to work for an organization providing critical support to families and witnessing the impact of our efforts.

Ways to Help

GIFT A BRICK IN OUR WALKWAY OF COMPASSION AND HOPE

Consider a brick contribution, a great way to celebrate a special occasion, Mother's Day, Father's Day, birthday, anniversary, graduation or in honor or in memory of someone special.



GUARDIAN OF HOPE

You can make an even greater impact with a monthly gift for our children by joining our Guardian of Hope caring community today! 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 each month.

SUPERHERO CHALLENGE

You can be a superhero too!

Run or walk 2.021 miles to 20.21 miles to help Friends of Karen children and their families. Your support means no family has to face their child's illness alone. And, that makes you a superhero too.



SUPERHERO T-SHIRTS

Get your superhero t-shirt today and help us raise awareness to support our critically children.

BACK TO SCHOOL PROGRAM

Help send our children off to school this fall with the tools they need for a successful school year whether they are learning in classrooms or online.

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.

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.

FEED-A-FAMILY

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.

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.



AMAZON SMILE

When you shop, don't forget to choose Friends of Karen as your charity on Amazon Smile.

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

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“Knowing that
 people cared about
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 let me focus on
 Xingyu and her
 emotional and
 medical needs.”

- Gang, Xingyu's father
 (see page 5 for full story)

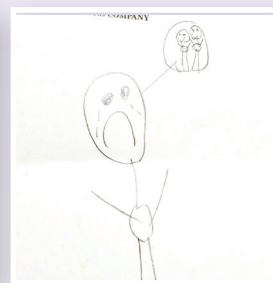
When you have finished reading this
 newsletter, please share it with a friend.

Sibling Support Program Nurtures Powerful Expression of Feelings



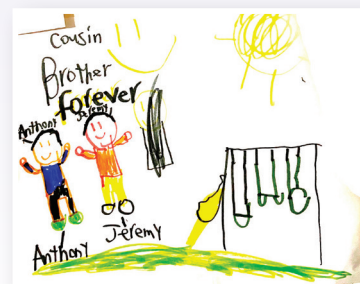
From Elianna:
 (above left) These are parts of my blood;
 red blood cells, white blood cells, plasma,
 leukemia cells.

(above right) These things help get rid of
 cancer; chemo, ginger pills, love, Jesus.



Julie and Johnny are twins (Johnny has Acute Lymphocytic
 Leukemia) and had to be separated when there was a COVID-19
 scare in their family. They missed each other very much but were
 able to express their feelings and create pictures for each other.

Anthony and his cousin Jeremy
 were the same age and spent
 a lot of time together. He loved
 him like a brother and misses him
 greatly. Jeremy died last year.



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 list and stay current on all our programs and activities.