Meet Mighty Quinn

“Friends of Karen gave me hope when I felt hopeless.”

Quinn was just three months old when his mother Caravelle noticed something was wrong as he could not keep food down. Quinn’s mom went to the doctor frequently to find answers, but Quinn was still sick. The way Caravelle handled this illness is exactly the way she tackled all the challenges to come — she simply would not give up.

When she finally got an answer, the news was devastating. Quinn had a brain tumor and the prognosis was grim. He needed to be admitted immediately to the pediatric intensive care unit, where he remained for the next nine months.

At first, Caravelle admits, she did not understand how serious things were becoming so quickly. Soon it became apparent as Quinn needed surgery to remove the tumor and to place a shunt in his skull to relieve pressure on his brain that was affecting his blood pressure.

In addition to surgery to remove Quinn’s tumor, he underwent several months of chemotherapy and his little body had difficulty tolerating treatment. Caravelle was told to prepare for the worst, but with her unwavering faith she refused to accept that outcome.

He recovered from that episode, but Caravelle’s faith and Quinn’s toughness were tested when he was close to dying two more times. On top of these struggles, the COVID-19 pandemic emerged and made things much more complicated. Quinn’s treatment was able to continue, but under very trying and frightening circumstances surrounding them. Through it all she refused to give up on him.

Along with Quinn’s fragile health, Caravelle had to contend with her fragile finances. When Quinn was diagnosed, she left her job as a nurse’s aide in a nursing home near home in the Bronx so she could be by his bedside. She is a single mom to Quinn and his older sister Gabriella, and the pressure to care for Quinn, be there for Gabriella, and try managing her dwindling finances became too much to handle.

“I was trying to work out what to do,” Caravelle recalled. “Would I need to move in with my mother in Philadelphia? Would I have to give up my car or apartment, sell my furniture, or go back to work and not stay with Quinn at the hospital? Then the social worker at the hospital handed me a piece of paper with Friends of Karen’s phone number at the top of the page.”

At first, she was hesitant to call Friends of Karen for help, but held on to the paper for two weeks. When Caravelle realized she could no longer do this on her own, she called. After submitting an application, she was connected to Friends of Karen social worker Rhonda, and learned that the organization would help with her rent, car payment, and food.

Now that Quinn has finished chemotherapy, celebrated his first birthday and is more stable, Caravelle can look back at the difference Friends of Karen has made. “Without Friends of Karen, I might have ended up in a homeless shelter,” she observed. “And, it wasn’t just help paying my bills. Around Thanksgiving there was a box of food for our dinner and gifts for my kids for Christmas.”

Though Quinn still has to be closely monitored, Caravelle plans to go back to work by the fall. She is grateful that Friends of Karen has helped them get to a stable place financially and emotionally. “Friends of Karen gave me hope when I felt hopeless,” she said.
How Friends of Karen Helps Children with Cancer and Their Families

Friends of Karen started in 1978 with one ill child — 16-year-old Karen MacInnes — and our visionary founder, Sheila Petersen. Sheila’s goal was to help families of critically ill children with the vital emotional and financial support they need to emerge from their health crisis stable and whole.

The guiding principle for our work with families was beautifully articulated by Sheila:

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

Friends of Karen has fulfilled Sheila’s vision as a beacon of help and hope to families in the New York Tri-State region.

Our core belief is that no family should have to face their child’s illness alone. We are proud of our more than four decades of experience guiding families from all walks of life and all cultural backgrounds. Friends of Karen serves families with a child (newborn through age 21) who has been diagnosed with and is actively in treatment for cancer or another life-threatening illness. Because childhood cancer is a family disease, Friends of Karen addresses the impact of the illness on each member of the family.

We carefully match each family with one of our experienced social workers, who ensures they get the emotional support, financial assistance and practical guidance needed to cope during this crisis. We provide personalized concrete interventions and, prior to COVID-19, the majority of our services were provided during home visits. Today, these visits are conducted through video apps like Zoom and FaceTime.

Proudly, our Family Support Program exemplifies the current standards of psychosocial care for children with cancer and their families. All services are provided at no cost to families and they include:

- Individualized support for each family member from social workers, child life specialists, and creative arts therapists to prepare for and guide families through each challenge while their child is in treatment.
- Financial assistance to ease the enormous costs, which can include:
  - Travel costs to and from treatments and hospitals;
  - Childcare expenses;
  - Basic living expenses such as housing and utilities when there is a loss of income from illness-related work disruptions;
  - Gift cards and support to purchase food;
  - Medical expenses not covered by insurance.
- Assistance with issues that can overwhelm a family, such as insurance billing, changed family dynamics and special educational needs.
- Connecting families to organizations and government programs to ensure they receive help for which they qualify.
- Child life specialists and creative arts therapists to help the ill child’s sisters and brothers cope with changes in family life.
- End-of-life and bereavement support for parents and siblings.
- Gifts programs to enable children to mark holidays, birthdays, back to school and other milestones, helping families maintain a sense of normalcy.

Friends of Karen is a registered 501(c)(3) charity established in 1978. All contributions are tax-deductible.
Childhood Cancer Awareness Month
Friends of Karen Families in Their Own Words

Childhood cancer is a family illness. In recognition of Childhood Cancer Awareness Month, Friends of Karen is dedicating this entire issue to reflections on the impact of childhood cancer on our families.

A Dad Reflects: Helping his Princess Through Leukemia

“This time has been one of the hardest things I’ve been through mentally and physically in my life. This experience has caused so much heartache and pain. Our world got turned upside down in a blink of an eye. The first few months to present day I cry at night when I am alone thinking about my princess and her journey with Leukemia. Friends of Karen took a weight off our shoulders because they helped us with some of our bills and we could just continue to focus on Jenaye’s treatment. Friends of Karen has made an impact on our family that cannot be fully expressed in words.”

“Friends of Karen took a weight off our shoulders because they helped us with some of our bills and we could just continue to focus on Jenaye’s treatment.”

A Cancer Survivor Learns to Keep Climbing

Anastasia was 20 years old when she was diagnosed with cancer. She had surgery and numerous rounds of chemotherapy before she was considered cancer free and has had a very busy life since. Friends of Karen provided her family with financial support for daily living expenses. Our Creative Arts Therapist worked with Anastasia to help her understand the countless emotions that can go along with a diagnosis of cancer.

“I went to work at a cancer research lab in Cambridge, MA for two summers. I transferred and was accepted into my dream school (NYU), have had a few jobs and internships sprinkled in between, and went on a survivorship trip a few months ago in the Catskills. Who knew that climbing 60-foot frozen waterfalls could be so fun!”

Garfield is the father of 4-year-old Jenaye

Anastasia

FRIENDS OF KAREN
A Sibling Gives her Brother the Greatest Gift

Alexa, 11 years old, is the sister of Pedro, who was diagnosed with Leukemia in 2015 at age five and relapsed in 2019. Alexa was the donor for Pedro’s bone marrow transplant. A Friends of Karen Sibling Support Specialist, using art therapy, helped Alexa understand Pedro’s illness and prepare for her role as his bone marrow donor. She reflects on her family’s experience with honesty, wisdom, and hope.

“I love to read and I love Pedro. He is really strong and smart. I don’t understand why everybody thinks being a bone marrow donor is such a big deal. Anyone would do that for their brother. My Mom and Auntie had to stay at the hospital all the time. I missed out on school stuff and activities, but for very important reasons. My Mom and Auntie had to take care of my brother. There is more in my future that me and Pedro could do together.”

A Bereaved Parent Turns a Painful Loss into a way to Help Others

“For 10 years, pediatric cancer tried to take over our lives but we fought it every step of the way up to the very end. Despite the excruciatingly bad times, Bruce and I had a wonderful life with our beloved son Joshua and his adoring little sister Sarah. Joshua was diagnosed with a brain tumor at 11 months and died when he was nine years old in 1990. Not a day goes by when I don’t think about Joshi, and now, 30 years later, almost all my memories are the good ones. I always say that Friends of Karen was the glue that kept my family together, and when I had the opportunity to join the staff, I jumped at it.” — Denise, Volunteer Coordinator since 1998

“Friends of Karen was the glue that kept my family together.”
A Mom Stays Strong

“On July 13, 2019, my son was diagnosed with High Risk B-cell Acute Lymphatic Leukemia.

This is the day my family’s life changed and turned upside down.

Xavier is one of five children, my third born. He was born full term in November 2010. A normal happy and healthy boy, until he wasn’t.

“I am able to focus on my son Xavier’s care without having to be stressed about financial and emotional burdens.”

Despite the fact that I am a single mother, I have always been able to provide for my family. We have always managed to get by with everything we needed. After Xavier’s diagnosis this changed. The day my sweet eight-year-old boy was diagnosed, it was surreal. It’s something you never expect or want to hear. That day our journey and fight for survival began.

It has been a constant uphill battle. These past 12 months have felt like the longest 12 months of my life. There have been many setbacks, and hardships thus far. My family has been impacted emotionally, physically, mentally, and financially. We are unable to maintain a stable lifestyle due to so many doctor visits, hospital stays, and the possibility of complications. I am not able to work, and I hardly get to spend any quality time with my other children. My oldest son had to move back home to assist with the care for my two younger children when I am with Xavier.

Throughout this process I am doing my best to maintain my strength and sanity. There have been many sleepless nights since this began. Other nights I cry myself to sleep just thinking about the pain Xavier is going through daily. I have always considered myself to be a strong woman, but strength can only do so much when your child is ill. His strength and will to beat this awful disease is amazing and a true inspiration. It keeps me from falling to pieces.

Friends of Karen has been continuously helpful and supportive throughout this unbearable process of treatment. I am so grateful for the assistance we have received, and continue to receive through this difficult time. With the help of the oncology team at the hospital and with the support of Friends of Karen, I am able to focus on Xavier’s care without having to be stressed about financial and emotional burdens.

I know there is still a very long road of unknowns ahead of us, and it is not going to be easy. I am confident that we will make it to the finish line with all the wonderful people we have met supporting, and cheering us on through this difficult life-changing journey.”
A Social Worker Connects with Families Through a Common Language

Jackie is a bilingual (English and Spanish) social worker. Friends of Karen has two Spanish-speaking social workers and one Spanish-speaking case manager to serve the 29% of our families that primarily speak Spanish. We also have a bilingual (English, Chinese) Sibling Support Specialist to serve our families with cultural competence.

“As a bilingual social worker working with families who have just been told their child has cancer, I find that the word cancer is often frightening and overwhelming. It is my observation that non-English-speaking families seem to find it difficult to navigate what is yet to come for their child when he/she is newly diagnosed. I have the privilege of working with our Latino families. It is also my observation that when a non-English-speaking parent can connect with a social worker who is able to speak to them in their own language, you are able to eliminate communication barriers. This allows parents the opportunity to express their fears and concerns in their own language. The world has been going through challenging times these last few months, and our Latino families have been faced with new challenges, as a result of COVID-19. Job loss and a family member’s COVID-19 diagnosis, coupled with dealing with caring for a very ill child, has caused insurmountable stress. Now, more than ever, these families need to speak to someone in their own language, so that they can get accurate information in order to empower parents to care for their entire family. I find that giving them the tools and resources they need in their own language helps alleviate some of the problems they are facing.”

A Grandma Reflects on Pulling Through as a Family

“Alden and I have a close relationship because I have babysat him since he was born, and he is my first grandchild. In September of 2019, we found out that Alden had Adrenal Cancer. With that news, my world was turned upside down. When I found out about the cancer, I was emotionally distressed. I had many sleepless nights worried about how this cancer was going to affect him. It has been almost a year now, and Alden has been pulling through with flying colors! I am so proud of him! He has gone through chemo, stem cell transplants, and radiation. He will soon begin immunotherapy for the next few months. Alden has been such a little trooper! I am impressed on how brave he has been through all this. That bravery and confidence comes from his parents as well. Katy and Conrad have guided and communicated with him every step of the way. Our family has held each other up during this crisis. The strength and endurance of my grandson and the emotional support from my family has made me a stronger person.

After my daughter’s loss of salary due to COVID-19, Friends of Karen assisted with monthly household finances, which was a welcomed relief. Alden has been enjoying his virtual sessions with the wonderful Friends of Karen Child Life Specialist, who reads him books about dinosaurs fighting cancer and what it’s like to be a superhero going through chemotherapy. I was able to join one of their Zoom sessions. She has also sent fun care packages to keep him busy during his long hospital stays. Friends of Karen’s entire team has been there for Alden and his mom and dad, offering comfort and support throughout this difficult time.”
Besides the emotional rollercoaster that overwhelms a family, parents face a hefty financial burden when their child is being treated for cancer. Friends of Karen sees the impact on our families every day. The devastating consequences of a child’s cancer diagnosis on a family is so significant that The National Children’s Cancer Society and others have published papers on the economic impact of the disease.

The problem is so pervasive that it was given a name — Cancer-Related Financial Toxicity. The term refers to the disastrous financial impact of hundreds of thousands of dollars of costs of cancer care such as travel to treatment, co-payments, deductibles, childcare, medications and much more. The problem is compounded when, very often, one or both parents must stop working to care for their ill child. Layoffs and furloughs due to the COVID-19 pandemic add yet another layer to an incredibly stressful and unstable situation.

Imagine the impact this has on a family struggling to get by in the best of times? The majority of Friends of Karen families were vulnerable to financial instability prior to their child’s cancer diagnosis. In fact, a recent snapshot of families served by Friends of Karen reveals 29% live below the federal poverty line of $26,200 for a family of four, and 58% have income of $50,000 or less. About a third of our families are single parent households. It’s no wonder that many families ask Friends of Karen for financial assistance.

This past year, Friends of Karen provided $1.5 million in direct assistance to 638 families, representing over 1,500 children. The majority of these dollars covered basics like housing, utilities, food and medical expenses. Friends of Karen assists Tri-State area families financially, alleviating immediate problems and providing necessary stability. Financial assistance, combined with the caring and knowledgeable guidance of our dedicated family support team, empowers families to navigate the daunting world of childhood cancer and the complexities of their child’s care.

Financial Impact of Childhood Cancer

Sources: Friends of Karen, CuresSearch, and The National Children’s Cancer Society
"Friends of Karen gave me hope when I felt hopeless."
— Caravelle, Quinn’s mom

Did you know?

| Each year, the parents of approximately 15,300 kids will hear the words “your child has cancer.” | There are approximately 375,000 adult survivors of childhood cancer in the United States. | 12% of children diagnosed with cancer do not survive. |

Source: CureSearch