



CONNECTIONS

SUPPORTING CRITICALLY-ILL CHILDREN AND THEIR FAMILIES

How do we fix this? What do we do first?

Chris Shares his Family's Story

My daughter Carter is three years old and in remission for leukemia. The remission is the promising news Chelsea (my wife), Carter's siblings Xavier, 17, and Dyleena, 14, and I couldn't imagine last April.

Carter had an on-and-off cold, cough and fever. We didn't think it was anything big. But when petechiae appeared on her skin and eye, we figured we should get her looked at.

The doctor took blood and we left. Less than 40 minutes later, she called and said to **get Carter to the emergency room**, but she wouldn't say why. It's a 90 minute ride to the hospital and despite how stressful it was, Chelsea and I promised we wouldn't jump to conclusions.

Carter was diagnosed with leukemia and immediately admitted into the hospital.

It was overwhelming and a blur. **All I kept thinking was how do I fix this? What do we do first?** The hospital social worker gave us binders of information, resources and books on caring for a child with cancer. They kept asking us if we needed anything...but we didn't know what we needed.

Even when I stopped getting paid, I kept thinking we can handle this...we'll figure it out.

The hospital suggested contacting Friends of Karen. Rhonda, the Friends of Karen Social Worker, soon visited and offered financial assistance.

We thought we were doing OK, but we lost one income and we were behind in everything. This is when Rhonda called again to say she hadn't heard from us and came to our home for another visit.

I call it the Rhonda Intervention. She made us aware of the severity of the situation and Rhonda steered us on a positive course. **That's when the full scope of what Friends of Karen does came into view. It's the first time we felt we could make it through this.** Rhonda became a cane to help support us...part of our team.

Chemo did not slow Carter down. She'd walk into the room for treatment with her purse and sunglasses ready to sign autographs. The only tough time was when her hair started falling out. She said **'Daddy, my hair is breaking.'** The clumps coming out were upsetting to her. I shave my head, so I asked if she wanted a haircut like daddy's. She did. Now the hair loss means she has a "daddy haircut."

Xavier and Dyleena had many concerns. Not just about Carter, but about money and family finances. That's when Melinda, a Friends of Karen Expressive-Arts Therapist became involved.



Chris with Carter

Melinda met with us, and then conducted sessions virtually, through Skype.

Time with Melinda meant time to check-in and sit down as a family in a way we could never do without her. She sent us art supplies, and we used them during sessions with her.

Friends of Karen has been helpful in ways I can't articulate. They provided Christmas for the entire family when we couldn't afford it. **Friends and family mean well but they don't get it. Rhonda and Melinda got it.** The future is super bright. Carter is responding to treatment. Melinda brought us all closer together in a way we didn't know we needed. Rhonda is a lifesaver.

Friends of Karen does all the big and little things you can't quantify, but mean everything to help a family survive.

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FROM OUR EXECUTIVE DIRECTOR

You Help Alleviate the Financial Impact of Childhood Cancer For Our Families



Dear Friends,

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
118 Titicus Road, North Salem, NY 10560
(914) 277-4547

Long Island Office
21 Perry Street, Port Jefferson, NY 11777
(631) 473-1768

New York City Office
205 E. 42nd Street, WeWork – 20th Floor,
New York, NY 10017
(212) 308-1378

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

A recent paper on “The Economic Impact of Childhood Cancer,” published by The National Children’s Cancer Society, confirms what Friends of Karen knows about the devastating consequences of a child’s cancer diagnosis on a family. Besides the emotional rollercoaster that’s overwhelming, parents must deal with the scary financial burdens related to the illness. The problem, so prevalent that it’s been termed Cancer-Related Financial Toxicity (CRFT),¹ encompasses indirect costs of cancer such as travel, co-payments, childcare and the like. On average, the cost of childhood cancer is an astounding \$833,000.² Additionally, parents often stop working to be bedside with their ill child, further compounding the problem. Imagine what this loss of income does to a family that is normally just getting by.

Researchers and policy-makers are searching for solutions to CRFT. They recognize both the disastrous financial impact on a family’s well-being, but also on a child’s chances of survival. The bleak reality is that “1 in 5 children who receive a new diagnosis of cancer are already living in poverty.”³

Our March 2019 snapshot of families served by Friends of Karen indicates 30% live below the poverty line of \$25,750 for a family of four. Altogether 60% of our current families earn \$50,000 or less and 29% are single parent households. It’s no wonder that the initial reason most families seek our help is for financial support.

In 2018, Friends of Karen covered \$1.2 million in direct expenses of 631 families, representing 1,500 children. Half of these dollars were dedicated to paying housing and utilities. The remainder enabled parents to feed their children, pay travel expenses to the hospital, cover co-pays, medicines, special treatments their child needed and more. At an unimaginably stressful time, families count on Friends of Karen to help keep them afloat.

With your support, Friends of Karen has this ability: Assisting tri-state area families financially, alleviating immediate problems and providing necessary stability. Our financial assistance, combined with the caring and knowledgeable guidance of our dedicated social workers, helps families gain the confidence to navigate the daunting world of illness and the complexities of their child’s care.

Because of you, we are able to help over 600 critically-ill children and their families each year. **Thank you for being part of the solution, standing with our families and Friends of Karen.**

Judy
Judith R. Factor



¹ Cancer-Related Financial Toxicity and its Pervasive Effects on Patients and Families: Solving a National Health and Economic Crisis Hiding in Plain Sight, Familyreach, <https://familyreach.org/white-paper/>, accessed May 3, 2019.

² The Economic Impact of Childhood Cancer. The National Children’s Cancer Society, November 30, 2018, <https://www.thencs.org/articles/>, accessed May 1, 2019.

³ Ibid.

Working to Overcome the Worry

A Sibling's Insightful Words

Meet Natalie, age 17. Interviewed by Melinda, our Expressive-Arts Therapist, Natalie describes the worries and challenges she has faced since her brother Nathan, age three, was diagnosed with rhabdomyosarcoma.



Nathan and Natalie

Will you talk about your relationship with Nathan?

Nathan came into my life late. I was the only child and I was upset at first, but then I saw him and I fell in love with him. **It's a love I never felt and it came out of nowhere.** I suffer from anxiety, but when I would see him it would just melt away. When he got diagnosed it felt unreal. **I didn't believe something like this could happen so close to me.** He was diagnosed in September and I remember everything about it.

As part of his treatment Nathan needed to receive radiation at a

hospital a good distance away from home. He and mom had to go and stay for eight weeks. Can you talk about what that time was like?

It took a lot to try not to be sad because I was in a really depressed state of mind. We are a unit and it was so hard to separate. He had to be put under general anesthetic every day for the radiation and it was really scary.

I know that you and mom worked really hard to make sure that support was in place before she left. It seems that planning was really helpful.

My mom is amazing. There is no one like her. She's unbelievable. Recently, she had someone watch Nathan (even though she never leaves him) so that she could come with me to get a prom dress. **It was such a special moment we got to share and it meant so much to both of us.** We really are trying to find a balance between always having Nathan with us and time together just the two of us.

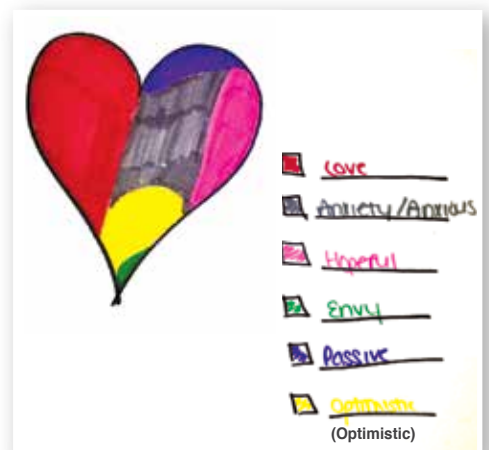
Can you share with us some tools you have used to help "quiet the anxiety?"

When I get really anxious I go through my five senses just noticing the things I can see, hear, smell, touch, and taste. It really keeps me in the moment and grounded. I also use drawing and writing. They are soothing and relieving even if you think you are a "bad artist" it doesn't matter, just get everything out on a piece of paper. And finally, music...sad or happy it helps me express a lot through the music.

Do you have any advice you would like to offer other siblings?

It's okay to talk to your parents during this time. Step up and talk about issues and feelings. Keeping it inside isn't going to help at all. Friends don't really get it like your parents because they aren't experiencing the same things. Be open with how you feel and know it's okay to reach out for help from others too. Everyone has a different situation they are facing. You shouldn't feel guilty or ashamed of how you feel. At first I was afraid to ask my mom to go out with friends because I felt I always needed to be there for her and Nathan, but I realized I can't just put my life on hold. **My mom really gets this too and always encourages me to go out and do things that make me happy.**

So don't hold yourself back. Try to maintain some of your "normal" from before.



Map of the Heart exercise that Natalie used to share what she was feeling inside.



Be Part of our Brick Walkway!

See details on your reply envelope, contact GabriellaDiSisto@friendsofkaren.org or visit our website for more information.

..... Because of You



The Long Island Black and White Gala honored Joe Romeo (L), founder of Industrial Coverage, and his family with the Humanitarian Award; Lou Karol, Esq. (C) received the Leader and Advocate Award, and Chris (R) a Friends of Karen young adult, was our celebrated guest speaker.



The Saturday Team (left) and the Sunday Team (right) for the annual Walk/Run for Friends of Karen at the LI Marathon. Luke (center), the inspiration for the Friends of Karen Walk/Run, took second place in the 5K.



Thanks to all the students, staff, friends, families, volunteers and sponsors who made the North Rockland Charity Sports Day such a terrific success. We are grateful to "Team LaBier" for organizing this special event and including Friends of Karen once again.

Jim Witt, President of the Hope for Youth Foundation, with Rhonda Ryan (L), and Judith Factor. Friends of Karen was the first charity supported by the foundation 30 years ago when Jim started selling his weather calendars to raise funds for children's causes.

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) 473-1768.

Where Are They Now? Priscilla – Motivated to Give Back



Priscilla: "I hope from my point of view I can offer a little insight..."

High school is stressful for every teen. Being a high school sophomore who has just been diagnosed with Hodgkin's disease rightfully elevates that stress level. At 14, Priscilla didn't plan to carry

this burden along with her books, but she wasn't given a choice. As she recalls from those days, "Friends of Karen was there helping. You helped my family financially and you helped us emotionally, something I didn't appreciate until much later in life."

Thankfully, those days were long ago. Now, more than 25 years later, Priscilla is in remission, and she's been giving back ever since. While in college, Priscilla volunteered for Friends of Karen. She stuffed envelopes, assisted at special events and ran errands. Priscilla also found comfort in speaking to teens that were coping with a critical illness, sharing her insight and experiences with them.

After earning her Bachelor's degree in psychology, Priscilla went on to get her Master's degree in education. With this background, she continued to help others as a special education teacher, a career path she stayed on for 13 years.

Now, instead of speaking to college students on behalf of Friends of Karen, Priscilla speaks to parents who are grappling with their child's critical illness. As a survivor, she brings a unique perspective to families...that of someone who has walked in their child's shoes. "I know what their child is thinking and afraid of," Priscilla says. "I hope from my point of view I can offer a little insight to help them out, even if only briefly."

When not helping Friends of Karen or others, Priscilla is a stay-at-home parent for her three-and-a-half-year-old daughter and 22-month-old son. And the drive to keep giving back? "From a personal standpoint, as a child with a life-threatening illness, Friends of Karen was a lifesaver for my family and me especially."

"That support from Friends of Karen meant everything to us. That's why."

Kids Helping Kids Meet Sophie

The future of fundraising is in excellent hands. It's wrapped in an eight-year-old package, attends third grade, stands less than four and a half feet tall and goes by the name Sophie. Inspired two years ago by The Blazer Pub selling shamrocks in support of Friends of Karen, Sophie wanted to help too. Sophie saved up her allowance and presented us with a terrific donation of just over \$30. The following year, she donated just over \$100, but Sophie was determined to do better.

This year, Sophie set a goal of \$1,000 and had a plan. With her parents' help, Sophie went door-to-door, played guitar at her taekwondo studio and even busked for change on the streets of Mount Kisco where she lives. When you ask Sophie why she's raising money, she says, "Friends of Karen works with sick kids and this helps them. The money helps families with basic needs." Isn't it hard asking strangers for money? "No,

I get excited by it all," Sophie notes. "I like making something out of something I love, like practicing and playing my guitar." Sophie didn't only fundraise from others, she chipped in from her allowance every week.

In her spare time, Sophie practices guitar, is a black belt in taekwondo and takes Ninja Warrior classes. She also, with a few friends, wants to start a school charity club. They will raise funds by "selling packs containing pencils, very cool erasers, a hairbrush and mirror combo, and slime".

When asked about her future, Sophie says, "I'd like to be an actor who gives to charity." If the acting doesn't work out Sophie, no worries. Friends of Karen will always have a spot for a formidable fundraiser such as you. The dictionary defines "precocious" as a child that is advanced, or "ahead of one's peers." The dictionary should also include a

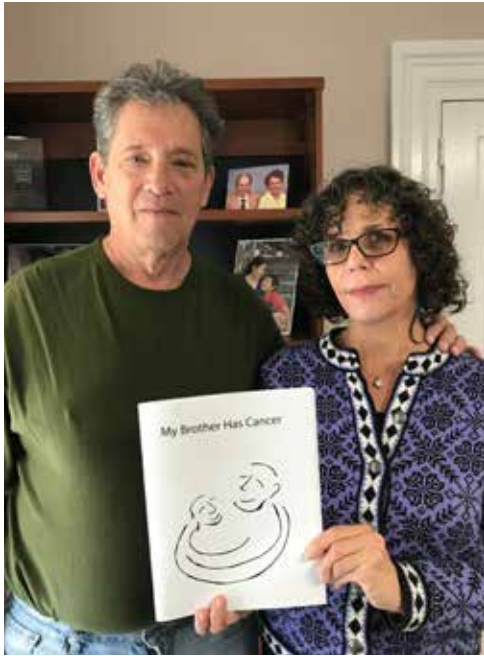
photo of Sophie. Ahead of one's peers? **She's ahead of a lot of adults and for that, we and our children and families are grateful.**



Sophie (r) presenting her \$1,000 contribution to Friends of Karen Executive Director Judith Factor.

From a Friends of Karen Dad

Thoughts on Life, Loss and Moving Forward



Mark and Donna Allen with the coloring book they created.

"You have a choice in life...you can live until you die or you can die until you die." Mark Allen shares this thought and it sums up his thinking as he looks back on a journey that started 25 years ago.

Back then, Mark, Donna, Jared and Perry Allen were living in the northern suburbs of NY as a normal family: Mark was running a restaurant as part of the family business; Donna was taking care of the kids and house; and Jared and Perry were typical youngsters. One day though, the untypical happened and Jared was diagnosed with leukemia. Thirteen months later, Jared died and following this tragedy, the family was at a crossroads. Now you understand Mark's quote above.

The Allens chose to live. Mark was adamant he didn't want Perry to be known in town as "the dead kid's brother," so needing a fresh start, the family packed up and moved to Arizona. Donna went back to work teaching and Mark became a chef at a gourmet deli. They wanted to LIVE, not just be pre-occupied. They soon opened up a pancake restaurant of their own, Flapjacks, which was an entire family affair. Mark cooked, Donna ran the

front of the house and Perry was a waiter. Over the 20 years the Allens were in Arizona, they LIVED. Mark, in particular, found "the day to day, the craziness... it was cathartic."

After leaving Arizona for a brief stay back in NY, Mark and Donna relocated to Florida. They had a loose plan to open a new Flapjacks, but pancakes weren't on the menu. "If I had a do-over in life," Mark shares, "I would be an artist." Educated in art and a member of the Art Students League, Mark shifted course and chose to use his talents to find purpose and inspiration as a way to maintain his own sanity and pay homage to Jared's well-lived life. He put down the spatula and picked up paint brushes again to pursue his passion.

Mark now creates art for his own gallery online—propermentalattitude.com—that features paintings, drawings and cartoons Mark originally created with Jared. The Allens also created a coloring book. My Brother Has Cancer was originally conceived for Perry while Jared was in the hospital. Only recently did the Allens publish it for the use of Friends of Karen's children, for which we are immensely grateful.

"They wanted to LIVE, not just be pre-occupied."

Mark's fear 25 years ago was that Jared would be forgotten over time. "Friends of Karen never forgets. Rhonda [their Friends of Karen Social Worker] and you were there during the darkest days and for that we're appreciative," Mark says. **"But Friends of Karen always remembers, year after year, that Jared lived, not that he died."** Where are the Allens now? Living.

In Loving Memory

Honoring the lives of our children who have died
January 1, 2019 – April 30, 2019

Jasiah	12
Peace	11
Karen	15
Alvina	22
Luke	13
Anya	2
Rachel	22
Yousef	10
Joel	1 month
Madelin	15
Ariana	2
Brooke	14
Joseph	18
Julisa	20
Gabriel	19
Asad	19
Amandalee	18
Adrian	14
Benjamin	16
Adrian	1
Scarlett	8
Jayce	2
Savannah	4

Thank you, Jay Fund!

A grant from the Tom Coughlin Jay Fund helps us cover emergency household expenses for some of our NYC families.

The mission of the Jay Fund is to help families tackle childhood cancer by providing financial, emotional and practical support.

www.tcjayfund.org



SAVE THE DATES!

Erin O'Connor Memorial Golf Tournament

July 15, Salem Golf Club, North Salem, NY

Crabtree Kittle House Sparkle for a Cause Fundraiser

July 23, Chappaqua, NY

Childhood Cancer Awareness Month Events

September – Details To Be Announced

15th Annual Journey of the Heart Bike Tour

September 21-22, Litchfield County, CT

Walk/Run for Friends of Karen at the Hamptons Marathon

September 28, Southampton Village, NY

5K Walk in the Park for The Adina's Angels Fund

October 6, Rockland Lake State Park, Valley Cottage, NY

Mamma Rosa Italian Dinner Party

October 7, Mamma Rosa Ristorante, Somers, NY

Gala 2019

October 24, Guastavino's, New York City

For more information about these and other upcoming events and programs, please visit our website at www.friendsofkaren.org/events

More ways to help

BACK TO SCHOOL

Help our children and their siblings start the school year with new backpacks and school supplies.

HOLIDAY ADOPT-A-FAMILY PROGRAM

You will be matched with a Friends of Karen child or children and can purchase one or more items on their wish list. What better way to celebrate the holidays than by putting a smile on the face of a sick child or sibling?

Details on these two programs are available on our website or contact Denise Tredwell at DeniseTredwell@friendsofkaren.org or 914-617-4052



HELP FEED OUR FAMILIES

Help parents provide healthy regular meals for their family. Gift cards in the amounts of \$25, \$50, \$100 are much needed from American Express, Visa, MasterCard, Shoprite, Key Food, Stop & Shop, Fairway, Trader Joe's, Walmart and Target. You can mail the gift cards to Friends of Karen, 118 Titicus Rd., North Salem, NY 10560 or 21 Perry St., Port Jefferson, NY 11777.



SHEILA PETERSEN LEGACY OF GIVING CIRCLE

Naming Friends of Karen in your estate plans will continue your commitment to caring for critically-ill children and their families. A bequest in your will or trust establishes a legacy of kindness and compassion, assuring Friends of Karen's support for generations of children to come. For more information contact JudithFactor@friendsofkaren.org.



You can make HOPE possible!

A monthly gift to Friends of Karen offers help and hope to children with life-threatening illnesses and their families.



When you become a Guardian of Hope, you are part of a caring community of supporters who understand that giving monthly enables us to guide a family, provide supportive counseling and provide financial assistance when one or both parents must stop working to be bedside with their ill child.



Choose to donate \$25 or more monthly on your reply envelope and you will help a family cover mounting expenses. As a special "thank you" for becoming a **Guardian of Hope**, you will receive a string bag, as our gift to you.

For more information, contact GabriellaDiSisto@friendsofkaren.org or call 914-617-4047.



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Approximately 85% of Friends of Karen children have been diagnosed with some form of cancer. **September is Childhood Cancer Awareness Month.** With awareness comes hope... Help us spread the word. **#AlwaysGold**

Gala 2019

Thursday, October 24, 2019 at 6:00 pm

Guastavino's at 409 East 59th Street
New York City

A gala celebration of providing help, hope and support to over 16,000 children and their families.

Honoring

Pauline (PK) and Richard Klein
Sheila Petersen Award

Patricia E. Vance, President,
Entertainment Software Rating Board (ESRB)
Humanitarian Award

To Be Announced *Corporate Support Award*

Master of Ceremonies
Lynda Baquero, NBC 4 New York Consumer Reporter

For more information and to reserve your tickets, please visit www.friendsofkaren.org or call 914-617-4051



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