



# CONNECTIONS

SUPPORTING CRITICALLY-ILL CHILDREN AND THEIR FAMILIES

## Finding the Magical in the Unimaginable

When Matteo was four and a half years old, he started to go through a series of physical and emotional changes that his mother Jennifer knew were not normal. Matteo often complained that he was tired, and his head and stomach hurt. Soon after, he began vomiting a clear liquid. Then Jennifer noticed he was suddenly irritable and throwing unusual tantrums, and soon after his eyes began to turn inward.

Her persistence to find answers led to Cohen Children's Medical Center and a diagnosis of a brain tumor called an Astrocytoma. While Jennifer knew it would be a difficult road for Matteo during treatment, she also worried about the effect on her entire Long Island family's well-being.

She knew it would mean giving up her part-time job at a doctor's office, spending time away from Matteo's twin sister Nicolette and his older six-year-old brother Nico, and impact her husband Anthony Jr.'s work as a salesman. She also knew that because of COVID-19 they could not safely have anyone in their home to help.

"It was unimaginable news and our entire lives had to change drastically," Jennifer

noted. "There were so many things to consider. I was trying to figure out what everyone was feeling, and we did not have the words to explain it to our little ones. Then we had the added stress of the COVID-19 pandemic."

As the family worked to juggle the demands of Matteo's treatment and their lives, the hospital social worker recommended they contact Friends of Karen to help. Jennifer describes the help that followed from social worker Marla and sibling support specialist Siobhan as life changing.

"Marla gave me support as a mother by constantly texting and calling," Jennifer recalled. "She arranged for us to get help with travel expenses to the hospital. Siobhan knew how to explain what cancer is to the kids at their level and gave them books to learn more. She helped them explore their feelings about the illness through artwork and other activities. I did not have proper language for that. Our family could not have gotten through Matteo's illness without them."

Jennifer fondly remembers that Friends of Karen always made their children feel extra special by surprising them with birthday and holiday gifts. She is grateful



*From left, Matteo, Nicolette and Nico*

that during a difficult time the children had Friends of Karen virtual activities like "Friends Having Fun" to enjoy being with other kids.

Despite the impact of Matteo's illness on the family, the brightest spot in their journey was Matteo himself. Jennifer is amazed that he never complained and how strong and brave he was throughout treatment, which he completed in August 2021.

"Matteo got us through it all," Jennifer said. "And we are so proud that despite his own illness, he thought of helping other kids in the hospital by starting what we called Matteo's Magical Toy Drive at Cohen's for the holidays. He gave out gifts to the children at the hospital the past two years with a big smile on his face. He really is our superhero."

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[friendsofkaren.org](http://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)

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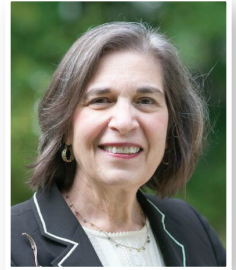
## FROM OUR EXECUTIVE DIRECTOR

*"Spring adds new life and new joy to all that is."*

— Jessica Harrelson

Dear Friends,

Spring is a time of renewal and hope. At Friends of Karen, April signals the beginning of our fiscal year and a new cycle of special events, gift programs and outreach. These activities are the lifeblood of Friends of Karen that enable us to assist more than 550 families who seek our support each year.



This spring, we are taking a cautious but hopeful deep breath that after a two-year hiatus due to the pandemic, Friends of Karen's amazing team of social workers may be able to meet with families in person once again. Our staff is looking forward to regularly working together in the office after being home for so long and holding our special events in person. What a joy to be together to share our passion for helping critically ill children and their families! I'm crossing my fingers that soon the isolation we've all experienced will be in the rearview mirror.

In this spring newsletter, we celebrate finding those moments of hope and joy expressed by Friends of Karen children and families, even amid the challenges they are facing. The "Friends Having Fun" group that you'll read about on page 4, has helped form bonds of friendship among the children at a time they desperately needed these connections.

We're also so proud to spotlight our unique Sibling Support Program and how our talented team of creative arts therapists and child life specialists have adapted to working remotely with the children, bringing them comfort and hope. The art bags described on page 3, jam-packed full of arts and crafts, make each session meaningful and fun.

April also marks "Volunteer Recognition Month," which has special significance for Friends of Karen and offers another opportunity for feeling hopeful. Our caring community of dedicated volunteers has played a vital role in every aspect of our program throughout our 43-year history. We've missed having our dear volunteers working alongside us these past two years, but we're optimistic that as we adjust to the new normal, they'll be back with us in force.

Friends of Karen has weathered these many dark months because of the kindness and generosity of you, our supporters. As we emerge into the sunlight of springtime, your continued partnership is the greatest joy of all. Thank you for all you have done and continue to do in support of Friends of Karen's children and their families. Wishing you and your loved ones a healthy, hopeful and joyous spring!

With a grateful heart,

Judith Factor  
Executive Director



# How Art Bags Help Children Cope Through Remote Support

By Siobhan Casey, MA, LCAT, ATR-BC, Sibling Support Specialist



When the world shut down during the first wave of COVID-19, Friends of Karen's Sibling Support Program had to be adapted to deliver all sessions remotely—something done occasionally before. Prior to the pandemic, the Program's licensed and certified art therapists and child life specialists would visit siblings, and sometimes the ill child, in their home. These sibling support specialists would tote with them bags of art supplies, books, materials for medical play and an occasional surprise gift or two.

With the help of several grants, our sibling support specialists developed activities that would be effective for virtual sessions and created thoughtfully curated bags of art supplies to complement the new curriculum. As the initial two-week lockdown extended and the pandemic lingered, it became apparent that we needed to do more than adapt, we had the responsibility to the Friends of Karen

families to make the program great. Over the past two years, we have been able to identify emerging needs and create "art bags" to address them.

Currently, there are specific art bags for elementary-aged children, teens, and the youngest who benefit from sensory stimulation and play, as well as for those children experiencing bereavement/end of life challenges. Additionally, we can include doctors' kits, cuddle bears or favorite toys in the package based on a child's unique needs. When a new child begins to receive services, a package is shipped to the family. Once the family receives the art bag, often within a few days, sessions may begin.

The art bag is a critical part of each child's healing as art and play are natural modes of communication for children and they allow them to open up, understand and express far more than they would be

capable of with words alone. These materials and supplies are also integral tools in the sibling support specialists' work of providing illness education and emotional support.

**"The art bag is a critical part of each child's healing as art and play are natural modes of communication..."**

Art bags have helped Friends of Karen to continue offering a space, albeit virtual, where the most vulnerable children can feel safe to ask questions, feel things deeply and connect with their loved ones. Below is a peek into some of the key items children receive for their sibling support sessions.

## WHAT'S IN AN ART BAG?



**1 Paper, Clay, and Drawing and Painting Supplies** – Common materials used in Sibling Support Program activities.

**2 Stickers** – Glittering heart stickers may be used to create a beautiful poster to remind siblings of their support system and all those who their heart is connected to when they are separated due to long hospital stays.

**3 Journals** – Teens may collage the cover of a journal, making it their own and using it to safely share whatever feelings they are keeping inside.

**Body Outline** – Siblings may complete a body outline sheet and indicate where they feel anger, sadness and worry in their bodies.

**4 Mask** – Children may decorate the outside of a mask to express the feelings they show to the world and the inside to illustrate feelings they keep hidden.

**Worry Stones** – An ill child may make worry stones and use them as a way to cope with growing fears.

**Memory Box** – A grieving family may work together to create a memory box for a brother or sister who has died – decorating it with care and filling it with treasured mementos and memories.

Photo: Jacob Gerrish



# Friends Having Fun!

**W**hen the realization came that the pandemic wasn't going away any time soon, it became clear that there were brand new challenges that Friends of Karen families were facing. Children were scared and even more isolated than before, with longer stretches of separation and strict policies prohibiting visitors at the hospitals. Parents were overwhelmed and stressed. *We wanted to help and we needed to offer new support for these new challenges.*

With the guidance and support of the Family Support Team at Friends of Karen, *Friends Having Fun* was born. This weekly virtual group for Friends of Karen children engages participants in creative art, movement, games, storytime and our signature finale, Freeze Dance. It's a light, fun way to connect during an isolating and uncertain time.

Recognizing the great importance of play, our goal was to both create a space for them to simply feel like kids and to offer a small respite for parents who may have needed a break from the around-the-clock caregiving that a tandem of a

pandemic and caring for an ill child brings.

*Friends Having Fun* debuted in June 2020 and the group is still going strong, having celebrated the first 'birthday' this past summer with a virtual party, creating party hats and, of course, an epic round of Freeze Dance.

Zoom has now become second nature and the group has evolved in some ways, but what we are most proud of are the bonds of friendship that have formed during this otherwise very lonely time. As always, the resilience of these children inspires us. They are truly experts in making lemonade out of an unprecedented amount of lemons.

Please read below what our most loyal attendees have to say about the group.



Philip: "It is just so much fun!"

Johnny: "I like to freeze dance."

Stephan: "I like doing different creative stuff that you come up with."

Julianna: "I usually like it when we do the art."

Marlee: "Me too!"

Jack: "I like seeing my friends in group."

Show your support by joining us at one of our **Spring and Summer events**, a great opportunity to meet our staff, board members, and the families we serve.

**Walk/Run LI Marathon:** April 29 - May 1, 2022, Eisenhower Park, East Meadow, NY

**Magic on the Sound:** June 16, 2022, The Point at Norwalk Cove, Norwalk, CT

**Erin O'Connor Golf Outing:** July 18, 2022, Salem Golf Club, North Salem, NY

**FoK Night at the Mets:** August 4, 2022, Citi Field, Queens, NY

**Journey of the Heart Bike Tour:** September 17 - 18, 2022, Bicycle Tour Co., Kent, CT

For more information, visit our website at [friendsofkaren.org](http://friendsofkaren.org)

**Would you like to hold a fundraising event?**

Call Gwen at (914) 617-4051 or email [info@friendsofkaren.org](mailto:info@friendsofkaren.org).

On Long Island, call Rebecca at (631) 473-1768.

# A Mom Finds New Way to Say "Thank you" 30 Years Later

*The Friends of Karen Family Support Program social workers develop strong bonds with the families they work with for months or years. When Friends of Karen social worker Rhonda picked up the phone in 2021, she was pleasantly surprised that Pat, whose daughter battled acute myeloid leukemia 30 years before, was calling. We asked Pat, who lives in Queens, to share her memories of that time and what prompted her to contact Rhonda.*

"When my daughter was 10 years old, she was diagnosed with leukemia. When that happened, I was in big trouble because I had to be at Memorial Sloan Kettering Cancer Center all the time with my daughter and could not work. The hospital social worker referred me to Friends of Karen so I could get help with some of my bills.

I will never forget Rhonda; she was a godsend. She arranged for me to get help paying the electric bill and my rent. Rhonda was there for anything I needed, and she showed us so much love and support.

That time in our lives was exhausting and I almost never left the hospital in the one and a half years my daughter got treatment. I found ways to make it bearable for us both. I cooked all



*Pat enjoying a relaxing moment*

my daughter's meals for her on a little stove near the children's playroom in the hospital.

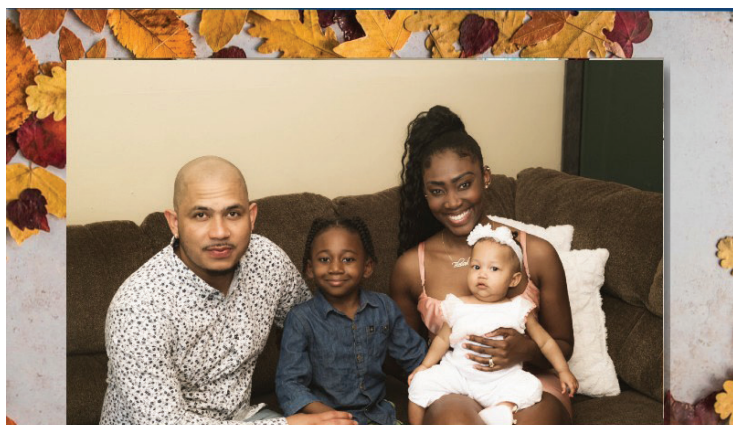
Children who didn't enjoy the hospital food and the staff would come out and tell me that the food smelled good. So, I began cooking lentil soup for the staff two days a week, as well as writing down the other children's favorite foods and cooking them.

After her treatment ended, my daughter got stronger and healthier. Years later she graduated law school and today she is an attorney with a busy practice and life. We have so much to be grateful for and I always dreamed of the day I could give to Friends of Karen what I received. I am now retired and in a better place to help.

Last summer, I decided to reach out to Rhonda. I was so happy when I heard her voice that I started to sob. We had a really nice conversation and I told Rhonda I had not called just to catch up, but I was going to make a contribution to help others. It felt great to give back and it is something I look forward to doing again and again."

– Pat

## 8th Annual Thanksgiving Food Drive for Friends of Karen Families



**Thank you to our friends at Heidrick & Struggles, KPMG, Mastercard, and Wood Smith Henning & Berman LLP for helping to provide nearly 200 families with a food check or supermarket gift cards to make their Thanksgiving extra special!**

**Friends of Karen**

**Magic on the Sound**

**THURSDAY, JUNE 16, 2022**  
**6:30 PM – 10:00 PM**

The Point at Norwalk Cove  
48 Calf Pasture Beach Road  
Norwalk, CT 06855

**Honoring Drs. Gina Lodolini and Neil Capolongo**



# In Loving Memory

Honoring the lives of our children who have died from July 16, 2021 to February 28, 2022

April.....	13 years
Mahlih .....	7 years
Amely .....	1 years
Genevieve .....	15 years
Zachary.....	2 years
Joseph.....	17 years
Dream.....	16 years
Violet .....	3 years
Johnny.....	7 years
Moshe .....	16 years
Camryn.....	20 years
Lindsey .....	16 years
Noah .....	1 month
Winston .....	22 years
Mahogany .....	18 years
Alyce.....	4 years
Joseph.....	18 years
Madison .....	9 years
Jose .....	18 years
Fairouz.....	5 years
Alayda .....	2 years
Hussam.....	19 years
Bladimir .....	18 years
Carli .....	19 years
Syed .....	20 years
Zemirah .....	6 years
Liam.....	7 years
James .....	8 months
Deysi.....	5 years
Liam.....	6 years
Alexander.....	6 years
Izabel .....	15 years

# Guiding Families While COVID-19 Complicates Already Difficult Days

By Marla Krellenstein, MSW, Social Worker, Family Support Program



Life takes a lot of turns you don't expect. When I was in college studying art, I never expected to become a social worker.

I received my undergraduate degree, got married and raised my three children. When

they were grown up enough to be more independent, I was ready to get back into the workforce. Thinking about what I might do next, I thought of culinary school or social work. My husband is a psychologist, and I was always around a lot of mental health professionals, so I knew how meaningful it was to help in that way.

I went back to school and graduated with a Master of Social Work degree from the State University of New York at Stony Brook. Around that time my best childhood friend was dying from breast cancer, and I would help her out with whatever she needed. Soon after, Friends of Karen social worker Rhonda was visiting a family she was working with at Stony Brook Hospital. While Rhonda was there, she asked if the staff knew anyone looking for a job as a Long Island social worker and they recommended me.

It was amazing how this job just materialized that would bring together my experiences with my friend, my knowledge of the field through my studies, and things I learned helping in my husband's practice.

This job has been a gift. It is now 20 years later, and it has been gratifying work that allows me to give back to help families deal with the most difficult time of their lives.

When a child is diagnosed with a life-threatening illness, it is likely the first time parents find they have no control over what is happening. Parents turn to us because they know we will be there when they need us. Friends of Karen social workers, child life specialists, and creative arts therapists have the skills and experience to know how to put families at ease and what help is likely to be needed. We do this because, ultimately, we want parents to be able to spend time with their ill child.

The COVID-19 pandemic was another unexpected turn in my life. I worked with families in person before the pandemic, which allowed me to directly observe families' situations and needs. Now I stay connected to them virtually, and it is clear the need for the Family Support Program is greater than ever. Every family tells me how much more difficult the pandemic has been for them emotionally and financially. I make sure they know about what Friends of Karen can do to help, and that I will be here with them every step of the way.

It's been 20 years and I still love my job because I know the difference Friends of Karen makes. In all those years we have never turned a family away, which I think is just incredible.



## 137%

The percentage increase in dollars we provided in food assistance during the first year of the COVID-19 pandemic.

# Super Volunteer

## Harriet Savitz



For a dedicated educator like Harriet Savitz, volunteering for Friends of Karen is second nature. She has been giving her time and talents to the organization for more than 20 years.

Harriet learned about Friends of Karen when staff member, Gwen Salmo, visited the elementary school in Manhattan's Chinatown where Harriet was teaching. Harriet's class was participating in a community service program and they selected Friends of Karen as a beneficiary of their grassroots fundraising activities. What impressed Harriet then and still does now is "Friends of Karen's commitment to helping the whole family, not just the ill child. What makes the organization so special is the art and music therapy for the siblings, the birthday bags and holiday gifts for all the children in the family."

You can count on Harriet to handle every volunteer assignment with a smile, whether packing school supplies or holiday gifts, greeting guests at special events, tending the gardens at the North Salem headquarters, or calling donors to thank them for their contribution.

"As a volunteer, whatever I do for Friends of Karen, Friends of Karen does MORE for me," explains Harriet. "To be able to directly help, in some small way, has filled my heart with purpose and joy. I am never conscious of the hours spent at Friends of Karen. Instead, I am gratefully aware of the dedication and professionalism of the staff I have been privileged to know."

Friends of Karen celebrates Harriet and all the remarkable volunteers who make a difference every day. We LOVE our volunteers.

*Interested in volunteering?* Contact Denise Tredwell, at [denisetredwell@friendsofkaren.org](mailto:denisetredwell@friendsofkaren.org); in Long Island, contact Rebecca Plant at [rebeccaplant@friendsofkaren.org](mailto:rebeccaplant@friendsofkaren.org)

# Ways to Help

## GIFT A BRICK IN OUR WALKWAY OF COMPASSION AND HOPE

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. To order fill out your reply envelope or visit our website.



## 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.

**You can help put a smile on the face of a critically ill child by participating in one of our Gift Programs listed below.**

Kid projects, scouts, and school groups are welcome. For more information, email [denisetredwell@friendsofkaren.org](mailto:denisetredwell@friendsofkaren.org) or call Denise at 914-617-4052.

## SUMMER SACK PROGRAM

Send a child off to camp with a summer sack filled with a beach towel, sun hat, sunscreen, and water bottle.

## BACK TO SCHOOL PROGRAM

Help send our children off to school this fall with the tools they need for a successful school year. We are looking for donations of new backpacks and school supplies and **are accepting donations now.**



## 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 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](mailto:info@friendsofkaren.org)**

“We have so much to  
 be grateful for and I  
 always dreamed of  
 the day I could give  
 to Friends of Karen  
 what I received.”

– Pat, Friends of Karen mom  
 (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

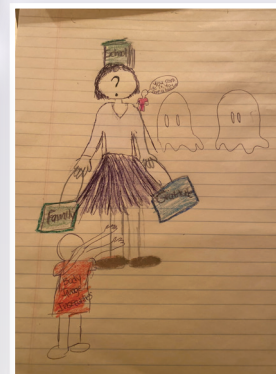
From  
 Cindy, this  
 is a drawing  
 of her  
 ‘Feeling  
 Heart.’



This is a drawing created  
 by Belinda. She was asked  
 to create an image of before  
 she was diagnosed with cancer  
 and after her diagnosis.



Roberto drew his cat Princess. She is  
 his mascot. He is going through  
 radiation, and he identified her as  
 being calming, cute and able to  
 communicate her needs. All things  
 he needs when receiving treatment.



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