



# A SPECIAL WAY OF CARING

45 YEARS OF IMPACT ON FAMILIES  
CARING FOR A CRITICALLY ILL CHILD

FISCAL YEAR 2023  
ANNUAL REPORT





**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.



**FAMILY SUPPORT SERVICES**

Friends of Karen provides Family Support Services to any child with a life-threatening illness, and their family, that meets our guidelines. Our work embraces diversity as a core value that represents inclusiveness, mutual respect, multiple perspectives, and serves as a means to achieving health equity. We provide services that consider family members' experiences and circumstances, including their socioeconomic status, race, ethnicity, language, nationality, sex, gender identity, sexual orientation, religion, geography, disability and age.

**FOUNDER**

Sheila Petersen  
(1938-1990)

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EXECUTIVE DIRECTOR

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Mike Nieves  
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J Durst, Beth Leventhal, David Rosenberg,  
Arnold Ursaner, Sharon Weiner

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

Cover photo: Christa and her mom Georgette





# 45 YEARS OF CARING BECAUSE OF YOU

In 45 years of service to the New York metro area community, Friends of Karen has demonstrated time and again a special way of caring. The legacy of kindness and compassion that our founder Sheila Petersen exemplified when she brought a quality of life to a gravely ill teen, Karen MacInnes, and her family so many years ago has been replicated thousands of times. Today Friends of Karen provides its services to a diverse and ever-expanding population that needs our help. We are proud of our commitment to never turn away a qualified family when their child is desperately ill. There are no waiting lists at Friends of Karen, no matter how we must stretch our own resources or weave together a safety net for a family with help from other partners. When your child is in treatment for cancer or another life-threatening illness, a waiting list won't cut it. That's what we mean by a special way of caring. Always going the extra mile, or sometimes two, to fully embrace a family whose life has been upended by a child's illness.

In this 45th anniversary annual report, you will meet some of the children and family members who the Friends of Karen team has been privileged to know this past year. They chose to share their story so that you understand how deeply everyday life for a family is affected when illness strikes out of nowhere and what having Friends of Karen by their side meant to them. Whether we paid the rent, provided gift cards for food and clothing, offered guidance on planning for a child's long-term treatment, helped parents find the words to speak with their children about a sibling's illness or myriad other ways, Friends of Karen continues to tailor assistance for a family so that it is most helpful to them. Ours has never been a "one size fits all" approach. That is among the distinguishing characteristics of Friends of Karen.

Another is that our programs are always evolving to address the pressing concerns we hear from families. We recently added a survivorship component for children who have ended their formal treatment but who still have significant medical and emotional needs. We also piloted a program to build a community of support for families who have lost a child to illness, offering two grief education workshops this past year, something we plan to continue. This flexibility to be creative and test innovative support services for the children and families we serve is a testament to our dedicated staff. Their focus on Friends of Karen's mission never wavers. The leadership of our Board of Directors, combined with the commitment, passion, and generosity of our remarkable community of volunteers and supporters are the engines that make it all possible.

Forty-five years of service is a milestone to celebrate, yet we know that Friends of Karen's special way of caring is needed as much now as ever. The resilience and bravery of the children and the strength of their families facing the most difficult circumstances move us to focus on the future while we acknowledge the achievements of the past year detailed in this annual report. With your continued confidence and support, Friends of Karen will be well-positioned to bring help and hope to children and families for years to come. On behalf of the whole Friends of Karen team, thank you for inspiring our work and keeping us strong.



*RS*  
Richard Sgaglio  
Board President



*Judith Factor*  
Judith Factor  
Executive Director



## A SIBLING STORY

# THE UNBREAKABLE BOND OF SISTERS



When Christa was being treated for Leukemia, she and her beloved sister Skylia participated in Friends of Karen’s Sibling Support Program. Her mother Georgette, thinking it was a stomach bug, brought Christa to see the doctor. He told mom that Christa’s blood count was low.

In 2021 five-year-old Christa began to complain of frequent stomach aches. Her mother Georgette, thinking it was a stomach bug, brought Christa to see the doctor. He told mom that Christa’s blood count was low. Georgette was working at Memorial Sloan Kettering Cancer Center, so she had knowledgeable coworkers to consult, and they urged her to bring Christa back to the doctor as soon as possible. That doctor’s visit brought devastating news. Christa was diagnosed with Acute Myeloid Leukemia, a bone marrow and blood cancer. Christa’s diagnosis forever changed her life and the lives of her mother, older sister Geneil, and little sister Skylia. When Christa was hospitalized, Georgette took medical leave from work and was constantly by her side, and Skylia was at home missing her mom and sister. “Skyla would cry for her sister all the time and did not want to leave the house,” Georgette said.

When Christa came home from the hospital the family faced additional challenges. With all the time they had spent apart juggling hospital visits and doctor’s appointments, they yearned to be together again as a family. Skylia, Geneil, and Christa struggled to connect with one another after such a long time separation. Then Georgette was laid off from her job at the hospital and the bills began to pile up. The family was in crisis. The hospital social worker suggested that Georgette contact Friends of Karen. After completing an application, she was contacted by Beth, a Friends of Karen social worker. Friends of Karen helped Georgette with paying her rent to ensure the family could stay safely in their home.

Beth also referred Skylia and Christa to Jane, a creative arts therapist in the organization’s Sibling Support Program. Jane created a safe space for the sisters to play games and work on art projects together. They participated in the “Friends Having Fun” virtual group every Thursday, never missing a chance to make new friends and have fun. Georgette credits Jane with helping the family become whole again.

“Friends of Karen was here when I needed them the most,” Georgette said. “Jane is a gem and the activity group got kids together and provided a special world to be a kid again and interact with other kids in the same situation.” The children’s circumstances have improved with Friends of Karen’s support and the support of their extended family. During the summer of 2023, Christa left the house for the first time since returning home from the hospital to attend a special summer camp the family was connected to by Friends of Karen. Skylia sat right beside her filled with excitement on the bus ride to their first day of camp, together again and ready to just have fun.





A FATHER'S STORY

# EMBRACING SUPPORT WHEN THINGS GOT TOUGH

Celeste is 3 and 1/2-years-old and in the maintenance phase of treatment for Acute Lymphoblastic Leukemia that was diagnosed in October 2022. Her father Rafael shares how he and his wife Gwen coped through Friends of Karen's support.

"Everything was going well for us. We were expecting a new baby and we decided to send Celeste temporarily to my parents' house before the baby's arrival. Things got very difficult very fast. Our new son, Mael, was born early via C-section and Gwen was recovering in my care while we were nursing our son from the Neonatal Intensive Care Unit (NICU) at Jamaica Hospital. In the meantime, Celeste had developed a slight limp while in the care of her grandparents, which was showing no signs of letting up and quickly worsening. Unlike many kids her age, Celeste was rarely sick, so when my parents told us she was looking pale and limping we thought maybe it was a bit of separation anxiety or an injury from roughhousing with her cousins.

The orthopedist was unable to find anything to worry about, nor did the general physician. We didn't think much of it, until my mother informed me Celeste was pale and unwilling to walk or eat. Then, she developed a mild yet unrelenting fever. We flew her back earlier than planned as a precaution. When she arrived at the airport in my mother's arms and unable to stand, we quickly knew something was really wrong. Celeste had developed bruises and complained of pain everywhere. We thought she might have an infection from a potential knee or hip injury, and we were shocked when she was diagnosed with Leukemia. This was just five days after my wife gave birth and now our children were in two different ICUs in two different boroughs of New York City. I quickly found myself shuttling from one hospital to the other, while also taking care of my wife. It was all a whirlwind of meetings about the children's care, and it was hard to retain all the information. Fortunately, the social worker at the hospital introduced us to Friends of Karen a few weeks after Celeste's diagnosis. Our Friends of Karen social worker Rhonda has been available whenever we need her, and she has helped support us emotionally. I have participated in Friends of Karen's online group for parents of newly diagnosed children. It's helpful to speak with other parents who understand our situation.

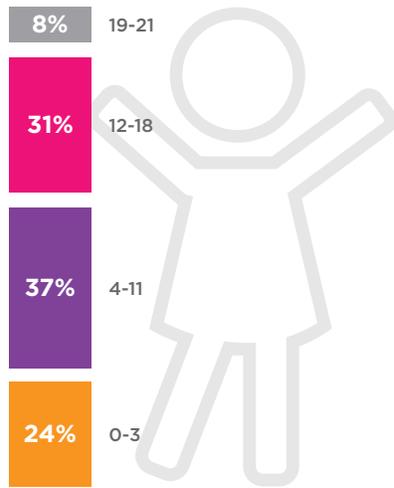
My wife and I both work in the hospitality industry and with her maternity leave and Celeste's illness, I worked when possible. The loss of income has meant we needed Friends of Karen's financial support to pay some bills like our rent, which allowed us to breathe easier and set aside a lot of worries. Things have improved quite a bit since those dark days in 2022. Celeste is doing better and in partial remission. Gwen and I are back at work and only need to take time off for the kids' doctor appointments.

We are thankful that Friends of Karen got us through a tough year. Gwen and I don't have much family in the United States and Friends of Karen has come to feel like an extension of our family. Without Rhonda we would not have fully understood much about Celeste's treatment and what the experience would be like for our family. It would have been an even more stressful time." – Rafael

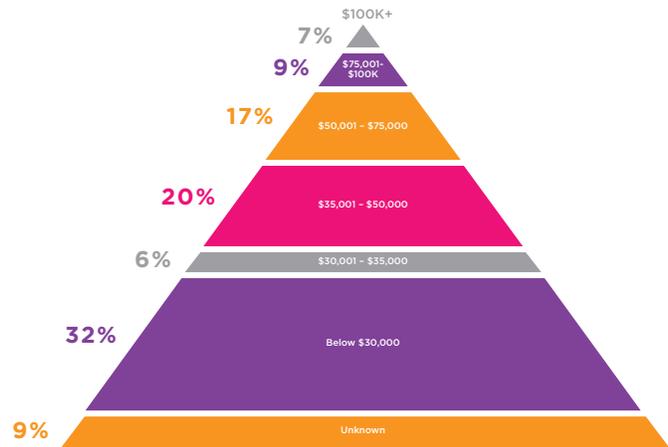
FY 2023

# FAMILIES SERVED

## AGE OF ILL CHILD

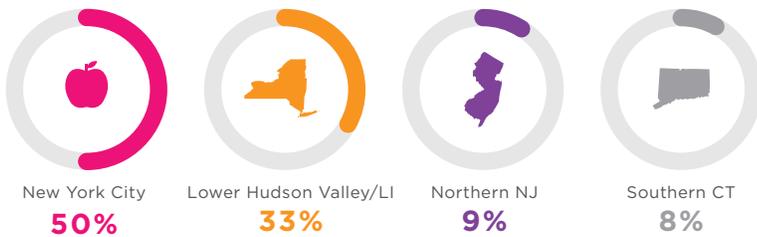


## INCOME

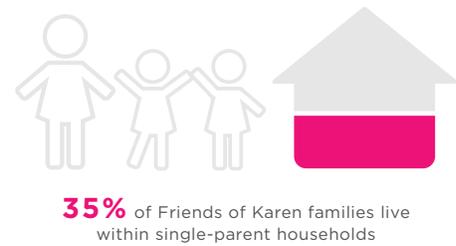


32% of Friends of Karen families live below The Federal Guideline for Poverty (\$30,000 for a family of 4)

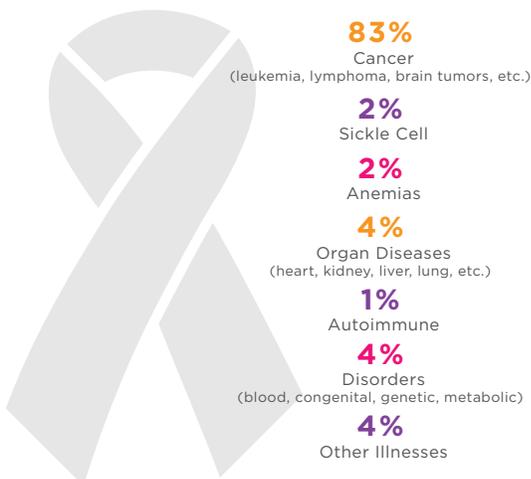
## RESIDENCE



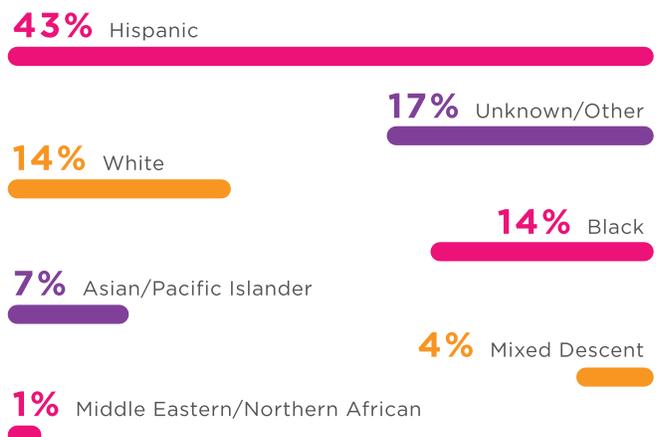
## FAMILY STRUCTURE



## ILLNESSES



## ETHNICITY



# NOTABLE NUMBERS



**\$1,605,655** The amount spent covering family bills for medical expenses, hospital travel, and basic costs of living for housing, utilities, internet and food. An 8.5% increase over FY'22.

**\$32,650** The recently established Seymour Tutelman Memorial Clothing Fund at Friends of Karen provided \$32,650 in gift cards that enabled 261 children to purchase new clothing and shoes.

**17,938** The total number of children that Friends of Karen has helped since our founding in 1978.

**2,688** The number of hours our volunteers dedicated to helping Friends of Karen achieve our mission.

**1,298** The number of ill children and siblings whose lives we have touched through emotional, financial and advocacy support in FY23.

**808** The number of children's holiday wish lists filled by our generous elves through our annual Adopt-a-Family program.

**738** The number of children who received backpacks, school supplies, and storybooks through our annual Back-to-School program.

**708** The number of children who received birthday gifts and birthday cards.

**318** The average number of families Friends of Karen assisted each month.

**200** The number of ill children and siblings receiving one-on-one support from our Child Life Specialists and Creative Arts Therapists.

**22** The number of counties and boroughs in NY, NJ, and CT served by Friends of Karen.

**17** The number of hospitals and hospices we partner with that have a pediatric oncology department and/or pediatric transplant unit. Among them are Memorial Sloan Kettering Cancer Center, Yale-New Haven Children's Hospital, Cohen Children's Medical Center/Northwell, Maria Fareri Children's Hospital, Children's Hospital of New Jersey, and NewYork-Presbyterian Morgan Stanley Children's Hospital.

**1** How it all began in 1978... 45 years ago, with one child, Karen MacInnes, and one caring neighbor, Sheila Petersen.





A MOTHER'S STORY

# PICKING UP THE PIECES AFTER A LOSS



Long Island couple Liz and Theodore attended the Living Alongside Grief Retreat in April 2023 to address the impact of losing their only son Jeyden one year ago. The Retreat is a new family bereavement education program on the range of experiences that grieving family members may go through. Jeyden was 13 when he was diagnosed and treated for an Astrocytoma brain tumor and passed away at age 14. Liz shares how her Friends of Karen social worker Marla and the Family Support Program helped, and continue to help, her family.



“Jeyden was the kind of boy that everyone was drawn to. He had a beautiful heart and always stepped in to defend other kids from bullies. Through all our ups and downs we had each other and he knew how to make me laugh - and we laughed a lot. It was terrible to see our strong boy go through chemo, but he even went through that with a smile on his face.

Jeyden really tried to keep our spirits up, but Theodore and I were trying to cope and having a hard time facing the reality of his condition. All this was happening during COVID, and my husband was a chef and wasn't working during the pandemic. I had to stop working to help care for Jeyden, so things started to get difficult quickly. Thankfully, our hospital social worker referred us to Friends of Karen, and we were paired with their social worker Marla.

Working with Marla and getting Friends of Karen's support was like having them as part of our family. You just don't find that kind of humanity everywhere. I can call Marla anytime if I need to talk or if we need help. She was there for us throughout Jeyden's treatment and has been since he passed away. At that time Theodore and I just fell apart, and we have been holding it together with Friends of Karen's help.

When Marla encouraged us to attend the Living Alongside Grief Retreat, we were hesitant about going. We had already cried so much and we were scared we would just sit there and cry. We took Marla's advice and read through the retreat information and decided to attend. That was a good decision.



Our family has been so supportive, but being at the retreat with other families who went through the same thing was something we needed. This program helped us to cleanse our souls. My husband expressed his feelings in ways he had not shared before because he had wanted to support me and not burden me with what he was feeling.

When we got home after the retreat, we felt like we were in a better place than when we left home that morning. I learned that day it is OK for us to go on and live and have some happiness. It is a long process, but we are making progress in adjusting to our 'new normal.' We could not have gotten to this point without Friends of Karen.” - Liz

A TEEN'S STORY

# RUNNING TOWARDS BETTER DAYS



Xavier is a 17-year-old from Westchester County, NY who is on maintenance treatment for T-cell Acute Lymphoblastic Leukemia. He lives with his mother Antheya and his 15-year-old brother Zach and shares how Friends of Karen helped him and his family.

“I love to run and am on the cross country team at my high school and the season had just ended when I noticed over the next few weeks that it was getting harder to breathe. I started wheezing just sitting still. Things kept getting worse and even my friends noticed I looked sick. Then, a few days after Thanksgiving in 2022, I was in the shower and noticed that every time I took a breath there was a pain in my shoulder.

Soon after I couldn't sleep, and suddenly there was an orange-sized growth on my neck, so my mom took me to urgent care. The doctor there thought I might have a collapsed lung, so I went to the hospital where I had a ton of tests. The test results showed a grapefruit-sized mass pushing against my heart and my lungs were filled with fluid. The doctors were amazed I had been so active with all this going on.

I was transferred to the children's hospital, and they tested the fluid in my lungs and found that I had cancer. I had been hoping it was just an infection, so this news

left me numb. I didn't have much time to think as the next day they had a roadmap for my treatment and they started by putting in a chest tube, a PICC line in my arm, and I had to go through a spinal tap which was the worst pain of my life. Then I was able to start chemotherapy.

For weeks I was afraid to tell my friends because I knew that if a friend told me they had cancer I'd be devastated. I did not want anyone to worry about me or treat me differently.

My mom learned about Friends of Karen from a friend. Our Friends of Karen social worker Rhonda has been there for my mom. Whatever makes my mom feel better makes me feel better, so I am glad that Rhonda helped her deal with my health insurance which seemed to be very confusing. Friends of Karen also helped my mom pay some of the bills for my doctor visits, surgeries, and chemotherapy which can add up fast.

Friends of Karen sent Zach and me gifts for Christmas which came at a very dark time for us after my diagnosis, so it was appreciated. I spoke weekly to my Friends of Karen sibling support specialist Melissa who has helped me quell any anxiety I am feeling. Without Friends of Karen our lives would have been a lot sadder, and things would have been tougher for my mom.” - Xavier

# FINANCIAL SUMMARY

FY 2023



79 cents of every dollar raised

by Friends of Karen goes directly to providing emotional, financial and advocacy support to our critically ill children and their families.

## APRIL 1, 2022- MARCH 31, 2023



### SUPPORT AND REVENUE

Contributions.....	\$2,020,025
(Individuals, Businesses, Organizations)	
Grants.....	\$970,056
Special Events (Net of Direct Costs).....	\$1,248,223
Other - Administrative Fee.....	\$19,739
<b>Total Revenues and Other Support.....</b>	<b>\$4,258,043</b>

### OPERATING EXPENSES

Program Services.....	\$3,408,287
Management & General.....	\$408,797
Fundraising.....	\$510,433

**Total Expenses.....** \$4,327,517

Change in Net Assets From Operations.....	(\$69,474)
Investment Return.....	(\$265,216)
Gain on Disposal-Property & Equipment.....	\$40

Change in Net Assets.....	(\$334,650)
Net Assets Beginning Of Year.....	\$6,267,006
Adoption of New Lease Accounting Standard..	(\$3,814)
Net Assets End of Year.....	\$5,928,542



### PROGRAM SERVICES (79%)

Friends of Karen is the only organization that provides comprehensive financial and psychosocial support and advocacy to families in the New York Tri-State region caring for a child battling cancer or another life-threatening illness. This assistance is provided at no cost to families, who receive these services from diagnosis through treatment, survivorship, and bereavement.

### FUNDRAISING (12%)

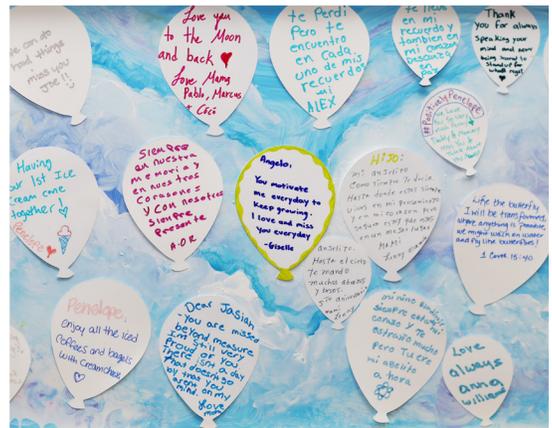
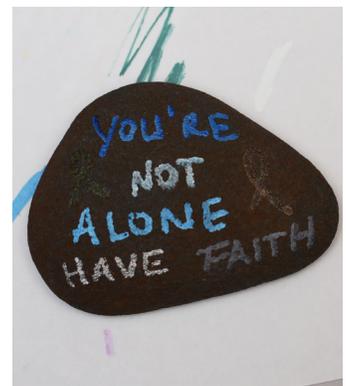
Our comprehensive services for families are made possible by our donors and funders. Our fundraising efforts work to maximize the dollars directed to the Family Support Program.

### MANAGEMENT & GENERAL (9%)

The areas of the organization that enable the Family Support Program to meet the urgent needs of the families we serve, and Friends of Karen as a whole to operate.



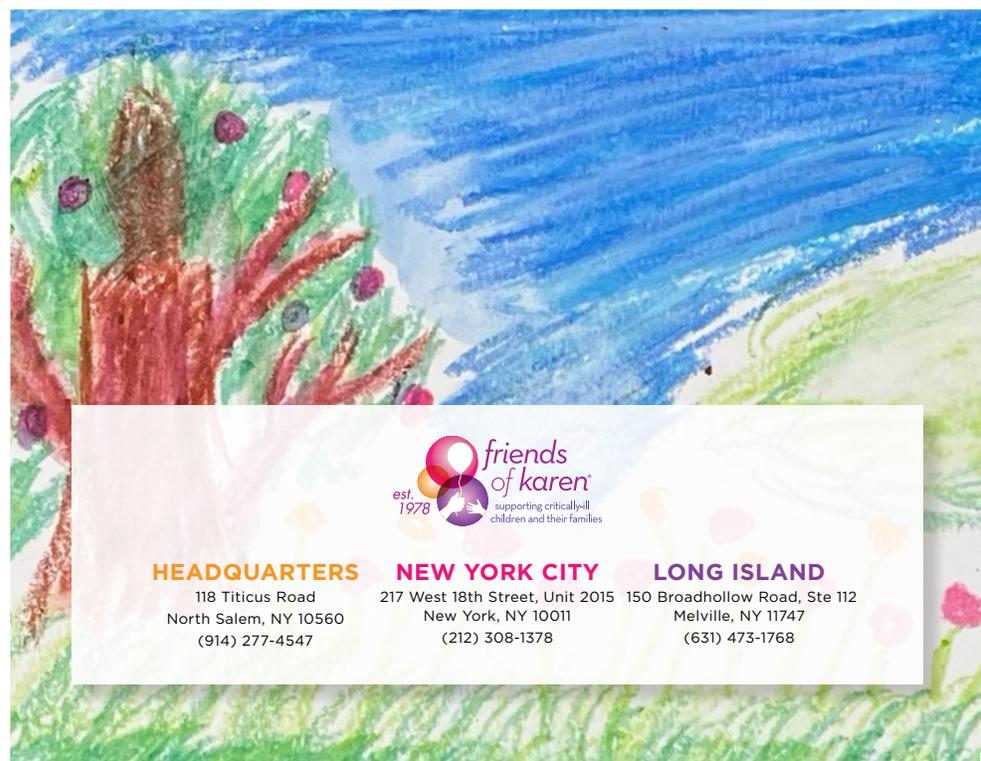
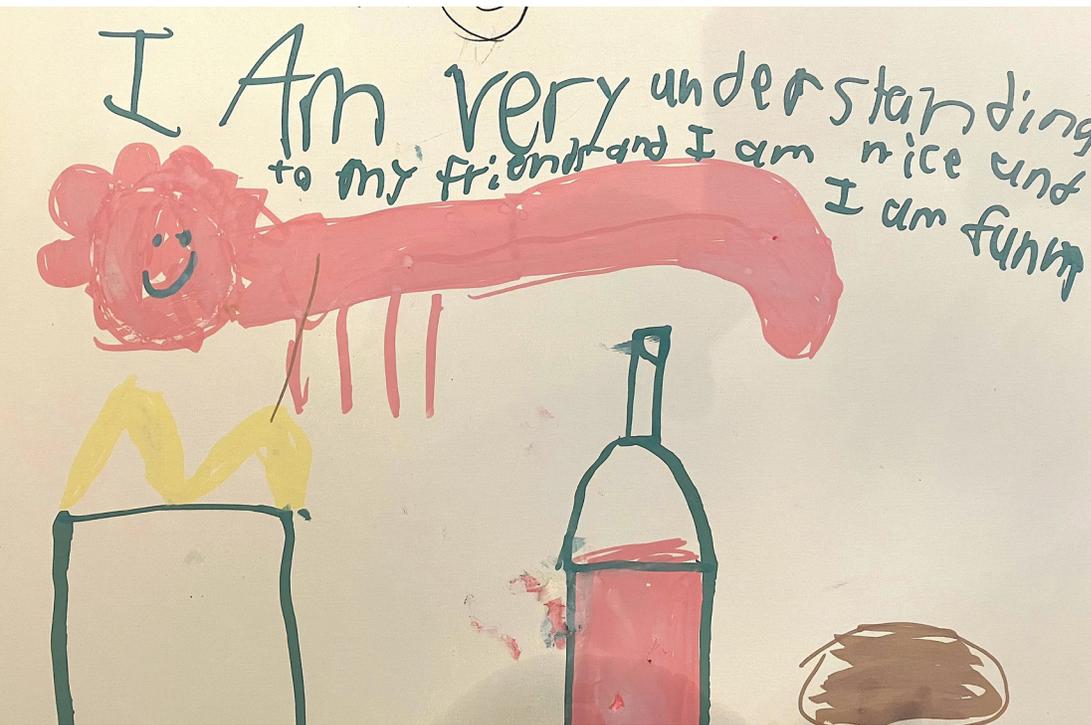
Friends of Karen’s Living Alongside Grief Retreat is a new program that invites bereaved families to participate in a unique one-day in-person grief workshop. The workshop was developed to address families’ uncertainty if what they were experiencing was “normal grief.” Two retreats, funded by a grant from New York Life Foundation, were held in spring 2023 and their goal was for bereaved children and parents to connect with each other and create new family memories while working on healing from their loss. The programs engaged 43 bereaved families in a program developed by our Family Support Program staff that included family memory crafts, support groups, and age-appropriate activities for children, tweens, and teens. The day was designed with times of heaviness and times of levity to emphasize that it is normal for grief and joy to coexist. These successful retreats helped family members reconnect with each other and created a sense of community among a group of bereaved families. We plan to build on and continue this support for families.



# SIBLING ART

SIBLING SUPPORT PROGRAM NURTURES  
POWERFUL EXPRESSION OF FEELINGS

Art is a natural way for children to express themselves, especially when the words get stuck or language isn't enough. With the guidance from our Sibling Support Specialists (Licensed Creative Arts Therapists and Certified Child Life Specialists) Friends of Karen children use art to tell their stories, to act as a bridge to communicate with their families.



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