



BUILDING RESILIENCE AND PROVIDING SUPPORT,
COMPASSION AND HOPE TO FAMILIES CARING
FOR A CRITICALLY ILL CHILD

ANNUAL REPORT 2022



FISCAL YEAR



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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.

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(1938-1990)

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



BECAUSE OF YOU!

Friends of Karen has not missed a beat during these many months since the worldwide pandemic began. Although the consequences of COVID continue to affect the lives of Tri-State area families we serve, we continue to fulfill our mission. With your partnership, we have not wavered in responding to the pressing financial, emotional, and practical needs of ill children, their parents and siblings who turn to us for help year-round.

Families need Friends of Karen more than ever. The economic effects of the pandemic linger and inflation makes the cost of daily living expensive. Life is more complicated in every way when you have a seriously ill child. Frequent work interruptions, a deep concern juggling treatment while trying to make ends meet, add to parents' intense financial and emotional struggles. Imagine a parent's relief in knowing that Friends of Karen will assist them during this unimaginably difficult time. Because of you, they know that they can count on us. Their words throughout this Annual Report speak volumes about the impact your helping hand provides.

This past year, we have done some juggling ourselves, venturing to establish a new normal at Friends of Karen. We have only recently resumed some in-person home visits with families, as the majority continue to be conducted remotely. Some parents even discovered they prefer a Zoom or FaceTime visit when managing their hectic, illness-focused schedule.

Adversity in our case has spawned innovation. Our creative Friends of Karen staff has stepped up to the challenge and developed all sorts of new program offerings. The success of the many online groups we have introduced to address the isolation experienced by ill children and their siblings, as well as the needs of parents grieving the loss of their child, is among the unanticipated silver linings of the pandemic.

Looking ahead, our Family Support Team of social workers, child life specialists and arts therapists are working with a greater intensity to respond to the complex issues Friends of Karen children and their family members are struggling with today. As a result, we are adding two more staff social workers to give our team the additional capacity necessary to support children and families effectively. A new clothing fund, and special grants to extend housing assistance for families and offer educational workshops focused on children and grief are among other new offerings.

With innovative programming giving breadth to our services and additional staffing providing depth to our professional team, Friends of Karen continues to build upon our 44-year legacy of support for the hundreds of families that seek our help every year.

Our most important partner in this life-changing work is YOU, our donors, volunteers, and friends in the New York area and across the country. Because of YOU, Friends of Karen has thrived these past few difficult years. It is heartening to witness your caring, compassion, and dedicated support.

On behalf of the Board of Directors and staff of Friends of Karen, thank you for standing with our children and families, and with all of us. Your steadfast support assures that no family will face their child's life-threatening illness alone. They will have Friends of Karen by their side every step of the way, bringing them help and hope.



RICHARD SGAGLIO
Board President



JUDITH FACTOR
Executive Director



JULIA'S STORY FROM ANXIOUS TO AMAZING

Julia is an effervescent, grounded, and wise 17 year old who is in remission from Hodgkin's Lymphoma. Julia shares how Friends of Karen supported her after her January 2021 diagnosis.

"When I got the diagnosis, I wasn't just worried about my health. I worried about my younger brother Xavier and how all of this would impact him. I'm a person who loves to talk about everything and put it all out there, but my brother is more closed off. I worried about the burdens this would place on Xavier and on my parents.

My parents are both extremely hard working and I worried about the time needed to bring me to the hospital. I also knew treatment is expensive when things aren't covered by insurance. My mom is an ER nurse and she had to take six months of family leave to be with me during treatment. It was a tremendous toll on my parents, but they were great. My mom was always positive and fun, and my dad would cook for us.

I was being treated during my junior year, the most important year and I really had "chemo brain" that made it difficult to concentrate and study. I have a little of that Type A personality so I thought 'OK, I can do this. I have treatment from 8:00 AM to 6:00 PM, then I have three hours to do all my work, I'll sleep a little and then I'll get up early to finish studying.' But that did not work because I couldn't think straight.

I learned that to be positive, you first have to accept your reality. Even though I'm here and healthy now,

I did go through some sort of grieving process and went through all the stages including denial and anger. I was isolated sometimes because I didn't feel like anyone knew what I was going through and I didn't want to make my parents sad, stressed or more overwhelmed. Some people shut me out because they didn't know how to approach me. I had also just moved, and it was the pandemic, so I had no friends for support. Even post treatment I still missed a lot of school for appointments and sickness, so it was really hard to form connections in my new school.

It was great having Melissa, a Friends of Karen sibling support specialist. I am so grateful for Melissa. I could open up to her and call her on my worst days. It was an amazing experience, and I don't think I would have the mindset I have today if it were not for her.

I really liked participating in the virtual art therapy Create and Connect Group for teen girls. I was home and completely isolated because of COVID and being immunocompromised, so it was cool to hear other people's stories and relate to others my age. It had a fun element to it, which was the art. I learned another way to pour in my emotions rather than just talking alone. I still remember the activities that had an impact on me and have that art hanging in my room. For one activity, we made an affirmation mirror and I wrote 'You are amazing'. Every day, before I go to school, I look at that mirror and think 'Yeah, you are amazing!'"



A MOTHER'S STORY

LUIGINA

Luigina's late son Joseph was diagnosed with a diffuse intrinsic pontine glioma (DIPG), a tumor in the part of the brain that controls many basic functions like breathing and swallowing and affects speech and eye movements. There is currently no effective treatment for these aggressive tumors.

"Before Joseph was diagnosed at 17, I was working part-time as a childcare worker and was the PTA President at Joseph's high school. Joseph was an active teenager and played soccer on his high school team in Queens.

In July of 2020, Joseph kept losing his balance and I thought he had a bad ear infection. It was a shock when we got the terrible news that he had a brain tumor.

At that point I had to stop working to care for Joseph. Soon after, I was coming up short every month for our household bills. I looked at a DIPG group on Facebook to see if any parents had posted other resources. I found information about Friends of Karen and filled out an application. Soon after, they assigned Rhonda to be our social worker.

Friends of Karen's support helped pay travel expenses to Joseph's treatment, before I arranged Access-A-Ride, and in emergencies afterwards. They helped us pay for clothing, Joseph's medical expenses that insurance did not cover, and helped with our rent.

Things got tough fast, so having Rhonda by our side was important for us. Joseph's tumor was aggressive, and he became less independent. Over time he could no longer walk, feed, dress or bathe himself. I was devoted to his care around the clock because he did not want anyone else to help him but me.

As a mom you will do anything to take care for your child. Still, it was very stressful, and I am grateful that I had Rhonda to talk to. I could talk to her about things we were going through and that were hard to speak about.

During Joseph's illness Rhonda made sure he and his sisters Rosemarie and Alexis got to celebrate their birthdays and had gift cards to buy something special. Rhonda even arranged for Joseph to have his 18th birthday party at a local restaurant, and to attend a professional wrestling match, which made him very happy.

Rhonda was there to support our family emotionally after Joseph passed in November 2021, and Friends of Karen even helped with some of the cost of Joseph's funeral. When Friends of Karen began hosting a monthly online bereavement group for parents, Rhonda encouraged me to participate. I wasn't sure I would feel comfortable in the group, but over time I saw it was helpful for me to share our story. Losing a child is like no other loss and the other parents in the group understand what that is like.

Looking back, I know that without Friends of Karen's help we would have become homeless. I am thankful Rhonda was there for anything we needed and listened to me whenever I needed support. Most of all, I am grateful that they brought Joseph comfort and happiness in so many ways."

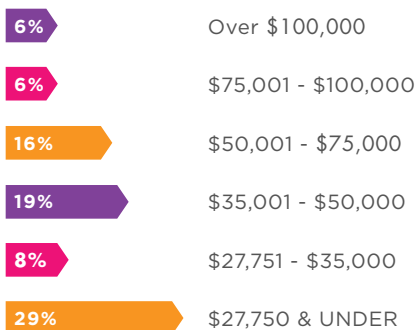


A LOOK AT FAMILIES SERVED

IN FISCAL YEAR 2022

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.

FAMILY INCOME



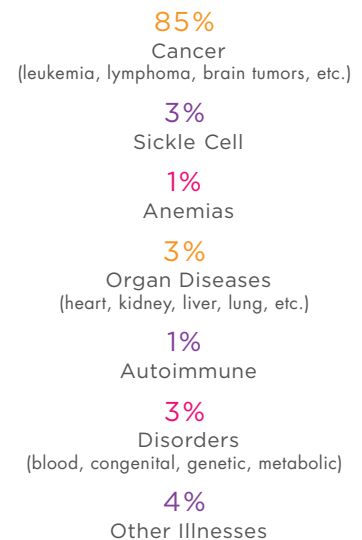
The Federal guideline for poverty level is \$27,750 for a family of 4.

*16% Unknown

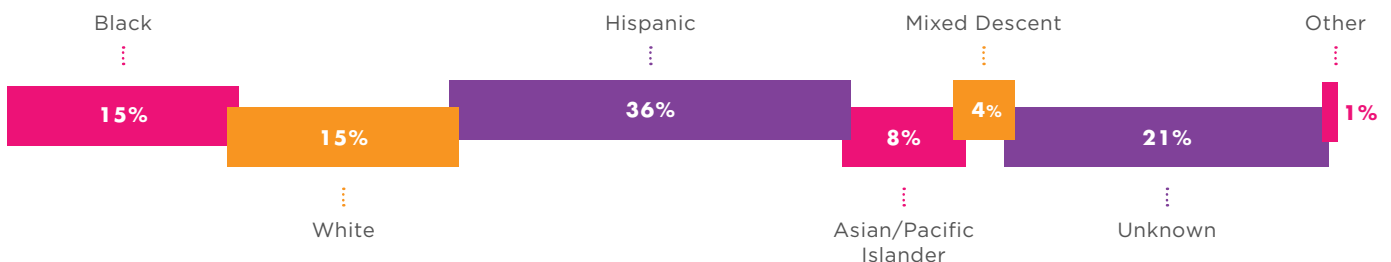
AGE OF ILL CHILD



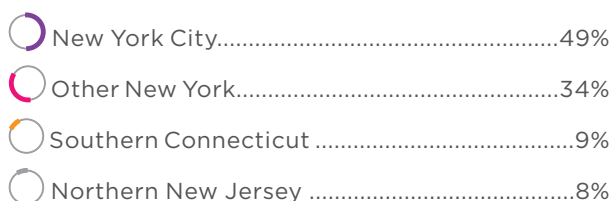
ILLNESSES



ETHNICITY



RESIDENCE



FAMILY STRUCTURE



32% of Friends of Karen families are single-parent households

NOTABLE NUMBERS

IN FISCAL YEAR 2022



\$1,479,164

The amount spent covering family bills for medical expenses, hospital travel, and basic costs of living for housing, utilities, internet and food. An 11% increase over FY'21.



17,496

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



2,102

The number of hours our volunteers dedicated to helping Friends of Karen achieve our mission.



1,289

The number of children whose lives we have touched through emotional, financial and advocacy support in FY22.



824

The number of children that received holiday gift cards from our generous donors to the annual Adopt-a-Family program.



757

The number of children who received birthday gifts and birthday cards. We want birthdays to be happy and celebrated even amidst illness.



710

The number of children who received gift cards for school supplies and clothes through our COVID-19 modified annual Back-to-School program.



347

The number of views of the Friends of Karen Livestream Candlelight Memorial Service bringing healing and comfort to families that have lost a loved one.



318

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



152

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



140

The number of Arts Bags provided to children for Sibling Support sessions and online group fun activities like Connect and Create!, Siblings Week and Friends Having Fun.



22

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



17

The number of hospitals we partner with that have a pediatric oncology department and/or pediatric transplant unit. Among them:

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 NJ, and New York-Presbyterian Morgan Stanley Children's Hospital.



1

44 years ago, Friends of Karen began with one child, Karen MacInnes, and one caring neighbor, Sheila Petersen

A BEREAVEMENT STORY ALEXIS'S FAMILY



Alexis was diagnosed with Acute Lymphoblastic Leukemia when he was 17 years old. He was a good student, loving son, devoted brother to Giovanni and Jessica, and an avid soccer player. Despite three years of treatment, Alexis passed away in 2018. His parents Josefina and Gerardo participate in Friends of Karen's virtual bereavement group specifically for Spanish-speaking parents, which runs concurrent to one for English-speaking parents. Josephina spoke to their Friends of Karen social worker Natalia, from her home in the Bronx, about the impact of Alexis's illness and working through their grief.

Natalia: How was it to have Friends of Karen in your life during your child's illness?

Josephina: Friends of Karen means the world to me because they really cared about my Alexis and all of us. Sometime after the diagnosis, we realized we needed help more than we expected. What we see now is that every parent, every family with a seriously ill child needs their financial and emotional help.

Friends of Karen helped with hospital travel, food assistance, and our cell phone bill. A couple of times when Alexis was in the Pediatric ICU, and at the end of his life, they paid our rent so we didn't have to worry about paying the bills. That helped us so we could be together as a family in those crucial moments. The financial part was important, but I will always be grateful for their kindness. They called or came to visit my home to check on Alexis and all of us. They always thought about everything. The kids had school supplies for their first day of the new school year and got to open Christmas and birthday gifts.

Now, after years since Alexis died, Friends of Karen is still present in our life. A few months after Alexis died people went away, went back to their lives. Sometimes you feel alone, but it is comforting knowing Friends of Karen is still present in our lives.

Natalia: Why did you decide to join the online bereavement support group?

Josephina: Our social worker Natalia invites us to the group, and my husband Gerardo and I wanted to be part of it right away. I liked the idea of being able to talk with other parents about Alexis and share our experience. I love when we all remember our kids' smiles.

In the beginning, it was not easy to share. I was afraid to talk about my feelings but hearing other parents and their stories gave me the strength to start talking. The group understands what me and my family are going through. I find peace knowing it's okay to remember Alexis, say his name, and smile at our memories of him.

Natalia: What in the group experience has been most helpful to you?

Josephina: I don't want to forget my son, so I want to continue talking about him and have someone to listen. Sharing stories about his life in the group fills my heart every time.

We have bad days and good days though all this. It's was a tough three years after his diagnosis, and during the treatment and his the last days. Sometimes I don't like to remember or speak about the bad things, but when we talk about it in the bereavement group, I feel peace. It helps us to share our experiences with newly bereaved parents. We let them know that they will survive and the pain they feel is meaningful. It's impossible to think that we are going to give up when the kids fought so hard.



A SIBLING STORY

YASIR, YUSRA, & MUHAMMAD

When siblings Yasir, Yusra, and Muhammad are in a Sibling Support session or participating in the Friends Having Fun virtual group they exude an immediate jolt of exuberant energy. They bring their vibrant personalities, friendly competition, and passion to whatever they do, whether it is drawing their feelings, discussing their struggles or breaking out their best moves in a freeze dance.

Yasir is eight years old and has Sickle Cell Disease (SCD), a group of disorders that cause red blood cells to become misshapen into a characteristic crescent shape. This condition can cause anemia, pain, fatigue, and infections. Yasir had a bone marrow transplant to treat his condition, and his donor was his older sister Yusra who is 10 years old. His five-year-old brother Muhammad also has SCD and is doing well, but currently has no donor match for a transplant. The children participate in Friends of Karen's Sibling Support Program with Jane, a licensed creative arts therapist.

Jane sat down with Yasir and Yusra to discuss what they enjoy about the Sibling Support Program.

Jane: How has the illness changed your days?

Yusra: Yasir wanted to go to school, but he couldn't do that or to other activities because he couldn't be around many people. It was hard for our parents because we don't have any family around to help whenever Yasir was sick.

Yasir: I was happy not to go to school. I was able to stay home all day and be with Mom, and not do homework.

Jane: How has it been to have your sibling support specialist work with you?

Yasir: Jane and I would meet when my brother and sister were in school. I liked to have my own time with her. We talked about things I was missing, like music and art classes. One day I played my keyboard, and we wrote a song about being home. I liked doing the online group and playing games. It was good to be around other kids.

Yusra: We get to meet and do art together. It was fun to do the activities with Yasir and Muhammad because we could all do it together.

Jane: What things big and small has Friends of Karen done to help you and your family?

Yasir: Jane helps us because we had activities to do.

Yusra: Our family is back home in Nigeria, so Friends of Karen has been like family. They make sure my brothers and I have fun, send us presents and school supplies. We share the gifts, but Muhammad is not very good at that. We share with him, and he doesn't share with us. But, he's little and will learn.



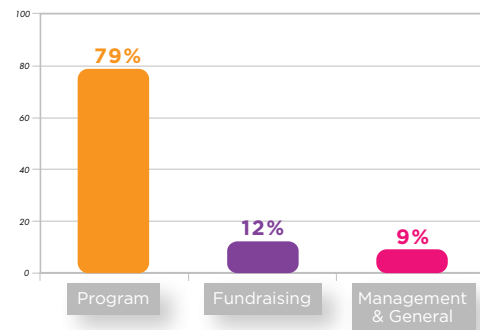
FISCAL YEAR 2022

FINANCIAL SUMMARY

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.

Total Operating Expenses

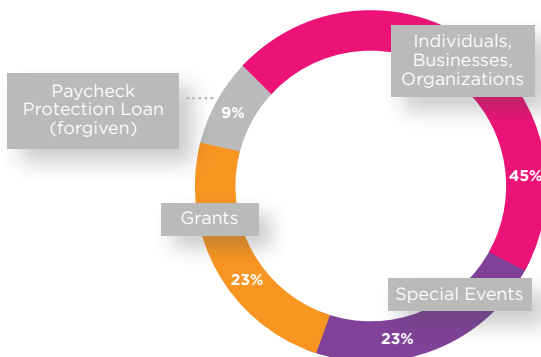


MANAGEMENT & GENERAL (9%): The areas of the organization that enable the Family Support Program to meet the urgent needs of the families we serve, and Friends of Karen as a whole to operate.

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.

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.

Total Support & Revenue



Support and Revenue

Contributions (from individuals, businesses, etc.)	\$1,943,078
Grants	\$979,485
Special Events (Net of Direct Costs)	\$1,022,626
Paycheck Protection Program	\$399,535
Administrative Fee	\$17,843
Total Revenues and Other Support	\$4,362,567

Operating Expenses

Program Services	\$3,112,650
Management and General	\$357,479
Fundraising	\$482,231

Total Expenses.....\$3,952,360

Change in Net Assets Before Other Changes	\$410,207
Investment Return	\$64,637
Loss on Disposal-Property & Equipment	(\$1,500)

Change in Net Assets	\$473,344
Net Assets Beginning Of Year	\$5,638,662
Net Assets End of Year	\$6,112,006

PROGRAM SPOTLIGHT

SIBLING SUPPORT



Since its inception in 2009, the Sibling Support Program has been a signature program of the Friends of Karen Family Support Program. The Sibling Support Program is delivered by Licensed Creative Arts Therapists and Certified Child Life Specialists to help siblings and the ill child cope with the stresses and changes in their daily lives. These professionals use a range of interventions such as art, music, movement, journaling, play and other appropriate means to work effectively with children from age five through the teens. These interventions provide an outlet to children for their complex feelings and a means to develop coping strategies.

Friends of Karen's holistic view of treating the entire family has grown and evolved with exciting new additions to the Sibling Support program to meet the varied needs of the children and parents we serve. This includes a line-up of virtual programs that promote joy, connection, and self-esteem. The team has launched the Instagram handle @familysupportteamfok to share their knowledge and provide insights for ill children, siblings, survivors, parents, groups and other professionals. The following are the reflections of our four experts on the impact of this vital program.



Jennifer, Certified Child Life Specialist

A veteran Child Life Specialist for nearly two decades, Jennifer is consistently our team's "go-to" when it comes to explaining a complicated medical diagnosis and treatment.

"One of the areas we are trained in as a child life specialist is how to explain a diagnosis or hospitalization to a child at their developmental level and in the appropriate language that they can understand. How we explain something to a five year old will look different than how we explain it to a 10 year old or a teenager.

At Friends of Karen, we are able to use our training and skills to not only help the child going through treatment, but also help explain it to their siblings. This has always been an important part of the work, because not every sibling has the opportunity to visit the hospital and receive illness education. At Friends of Karen, we are able to reach beyond the hospital walls and directly work with the siblings.

Illness education has become even more important since the pandemic, because many hospitals have no visitation policies in place, so many siblings have never met with a member of the health care team to learn about the diagnosis or reasons their brother or sister is in treatment."

Jane, Licensed Creative Arts Therapist

Jane brings a contagious energy to any virtual group she hosts at Friends of Karen, particularly the weekly fun group. The continuously popular Friends Having Fun began during the pandemic as an opportunity for isolated children to socialize and as a respite for overwhelmed parents.

"I love facilitating these groups because I get to see our kids having fun while playing games, being creative while making art, and challenging themselves in movement activities. What they typically don't realize is that I also see them learning skills to problem solve, to persevere, to collaborate and all the while increasing their confidence."



Siobhan, Licensed Creative Arts Therapist

Creative Arts Therapist, Siobhan has a passion for working with families, whether throughout treatment, bereavement or survivorship.

"Whether it is the initial diagnosis, treatment, survivorship or bereavement, art therapy is the perfect modality to use when working with Friends of Karen children and families. The arts are powerful and natural ways for children to communicate big feelings when words are hard to find or may not be enough.. We utilize different creative modalities to help regulate emotions, improve coping skills and strengthen relationships by acting as a bridge for communication within a family.

Expression through art is a way to help these children feel a sense of normalcy without judgment. Using imagination and creativity feels good and improves self-esteem. It often allows the children to feel seen in a beautiful new light.

I hold a tender place in my heart for families who are bereaved. Art therapy is a means to celebrate memories, explore feelings and try to make meaning out of the unimaginable. The mementos created in these sessions become heartwarming treasures for the family."

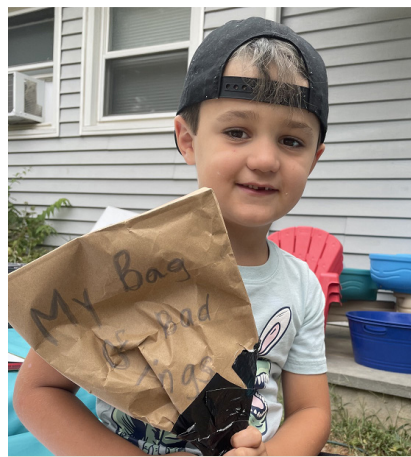


Melissa, Certified Child Life Specialist

Though our program is called "Sibling Support," we provide many resources for the ill children as well, in the form of individual and family sessions, and most recently a group for adolescents experiencing a serious illness. Melissa has the honor of leading the ill child group.

"Friends of Karen Sibling Support Specialists are in a unique role to meet the very specific needs of the ill children they serve. The COVID-19 pandemic made ill children even more isolated, which was particularly hard on teens. It became clear we needed a way for ill teens to have a way to meet one another for mutual support. The new online group provides an opportunity for socialization and to talk about the issues they have in common."

GALLERY OF SIBLING ART





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