JUNE JESSEE
MEMORIAL FOUNDATION

2023

IMPACT REPORT

Our mission is inspired by the bravery of June Jessee, a young girl who fearlessly faced chronic, life-limiting conditions with no specific diagnosis.

Dear JJMF Friends and Supporters,

I am excited to share our 2023 Impact Report with you, highlighting the breadth of our programs that provide vital support to children with complex neurological conditions and their families. Because of the generosity of our supporters, the JJMF has been able to reach more families each year, and we are incredibly grateful for the opportunity to do so. I hope you enjoy reading about the growth and impact of our mission and will consider getting involved in this important work. Whether you support the JJMF as a donor, volunteer your time, or connect our organization with additional resources in the community, you will help provide relief and assistance to families as they face the challenges of their child's conditions.

With heartfelt gratitude,

Jenny Jessee

Executive Director and Co-founder

The June Jessee Memorial Foundation (JJMF) is a nonprofit organization dedicated to supporting children with complex neurological conditions and their families, aiding their physical, emotional, and financial needs. By providing services and support to children with these conditions, the JJMF affords families the ability to have more time to love their child with fewer worries.

Our compassionate community is a place where families feel supported and understood.

The JJMF seeks to empower families through building a supportive community of people who understand the unique challenges of caring for a child with a complex neurological condition. By growing and strengthening the community we serve, families find comfort and support within a welcoming group.

Community Growth through Partnerships

We value connections with partner organizations that help build awareness and enable impactful community growth.

Sharing information about our programs at events like **St. Louis Children's Hospital's Cerebral Palsy Family Day** and **Tri My Best Adaptive Triathlon** provides opportunities for families to learn about resources available to them.

Genny Jessee presented to a group of families at the Rett Spectrum Family Conference on the topic of **"Finding Caregiver Wellness Through Community, Support and Joy"**, serving as an introduction to JJMF's programs.

Digital Reach

The opportunity to connect with our community online helps extend the impact of our mission further, ultimately enabling more families to connect with needed services.

138,000
Organic Impressions
DISPLAYED CONTENT
ACROSS NETWORKS

121,000
Organic Post Reach
UNIQUE VIEWS
ACROSS NETWORKS

3,265
Fans & Followers
ACROSS NETWORKS

20% Increase in Email Subscribers

Family Connections and Support

Virtual Music Therapy

Monthly virtual music therapy sessions make it easy for children with complex neurological conditions and their siblings to engage in a lively and fun activity together from the comfort of their own homes. Led by a specially-trained neurological music therapist, each session is customized to be inclusive for all participants' unique needs.

MIDWEST MUSIC THERAPY

Moms' Night Out at Topgolf

Providing a connection opportunity along with an evening of respite is one of the most important ways we support parents and caregivers. This group of moms enjoyed a fun evening at Topgolf while engaging in meaningful conversation and finding common ground in parenting their children with complex neurological conditions.

it's your birthday!

More than 175 birthday cards sent to children in our community celebrating special milestones

Normal Broken Book Launch Connection Event

JJMF was proud to partner with author and advocate Kelly Cervantes for the launch of her grief companion book, *Normal Broken*. This unique occasion provided an opportunity to host a group of parents and caregivers for dinner and fellowship before the book event, during which Genny Jessee led an honest and vulnerable conversation on grief with Kelly.

"Our family moved to St. Louis this year and we feel very lucky and grateful to have found the JJMF. It has been great to be able to meet other families that have experienced a journey similar to ours. It has helped us understand that we are not alone, and the support and encouragement we have received from this community has been inspiring and beneficial."

– ANDREA AND JAKE SCHIMKE, JJMF COMMUNITY PARENTS

"Not-So-Haunted House" Halloween Party at The Magic House

Recognizing that a traditional Halloween celebration doesn't work well for all children, our annual gathering at The Magic House provides a fun opportunity for children with complex neurological conditions to engage in activities and collect trick-or-treat goodies selected just for them. This event is a fun outing that enables families to enjoy Halloween together.

100% of families

surveyed expressed that the after hours private event made it easier for their families to explore the Magic House, while enjoying opportunities to connect with other families and JJMF team members.

Family Connections and Support

Family Holiday Party

Gathering for holiday-themed activities in a festive environment allowed families to connect while their children enjoyed participating in the fun. Coordinated by the JJMF's Youth Board members, activities included holiday crafts, a winter-themed photo booth and gifts of sensory and adaptive toys.

Celebrating the Month of June

Throughout this special month, we honor our June by delivering care packages and hosting connection events to bring families together. Through June's legacy, we value this opportunity to grow and strengthen our courageous community.

CARE PACKAGES

Over 200 care packages were delivered to families, including distribution at St. Louis Children's Hospital, as well as home deliveries, both local and mailed nationwide.

PARENT CONNECTION EVENT

Parents enjoyed an opportunity to connect with friends, old and new, within our understanding community.

IN-PERSON MUSIC THERAPY & FAMILY PICNIC

Following a lively music therapy session, families gathered for lunch and connection.

"One of the leading reasons I love working at the JJMF is being able to watch firsthand the connections and friendships formed between families. It's truly beautiful to watch them feel seen, heard and validated in a world that often doesn't acknowledge or understand families like ours. It's a glaring reminder of just how important having a community like ours is."

– KARLITA BLACKWELL
JJMF COMMUNITY ENGAGEMENT ASSOCIATE

Meet Karlita Blackwell

JJMF COMMUNITY ENGAGEMENT ASSOCIATE

Karlita Blackwell has been a member of our JJMF community for several years, even serving as the featured parent speaker at An Evening of Joy in 2022. She and her husband, Ryan, are parents to Ezra, an adorable seven-year-old boy who has Krabbe Disease, a rare genetic condition that affects the nervous system. In 2023, Karlita officially joined the JJMF team in the position of Community Engagement Associate. Through her role, Karlita passionately grows the heart of our mission by furthering connection and support for families of children with complex neurological conditions.

Engaging within our community and expanding supportive initiatives are roles that perfectly suit Karlita. As Ezra's mother, Karlita understands firsthand the unique challenges families face in caring for children with a variety of needs. She has a natural capability and desire to genuinely connect with fellow parents and caregivers, and she openly shares advice and knowledge gained from her experiences. Meeting Karlita is like making an instant friend - her warm and infectious personality makes others feel comfortable and welcome.

In addition to her personal experience, Karlita has a professional background in social work and counseling and possesses a high level of knowledge on resources and services. Her well-rounded perspective helps fulfill our mission to provide relief and assistance to families along their journeys while strengthening a growing community of others who understand. With Karlita on our team, we're grateful to have additional opportunities to extend our network of support, making a difference that can be felt by families.

Mental Healthcare

Since its founding five years ago – in partnership with St. Louis Children's Hospital and Washington University's Perinatal Behavioral Health Service – our mental healthcare program has provided anxiety and depression screenings, free therapy, community support, and education regarding the importance of parent and caregiver wellness.

Children's HOSPITAL • ST. LOUIS
BJC HealthCare

This vital program has continued to grow through incrementally increasing JJMF funding, with more parents and caregivers gaining access to free mental healthcare. As the program provides for a dedicated licensed professional counselor on unit at the hospital, the JJMF's commitment to continued development of the services has allowed for parents of children ages 0-18 with any complex neurological diagnosis to receive needed support.

The JJMF's program partnership is aimed at reducing the heightened levels of anxiety, depression and psychological distress experienced by parents and caregivers of children with complex neurological conditions. Through an emphasis on accessible mental healthcare, parents and caregivers are able to focus on their well-being, enabling them to better care for their children. As emerging research shows that parent and caregiver wellness is influential in positive medical outcomes of children facing the challenges of complex neurological diagnoses, the JJMF's unwavering support of this essential program endures.

296
FREE THERAPY SESSIONS

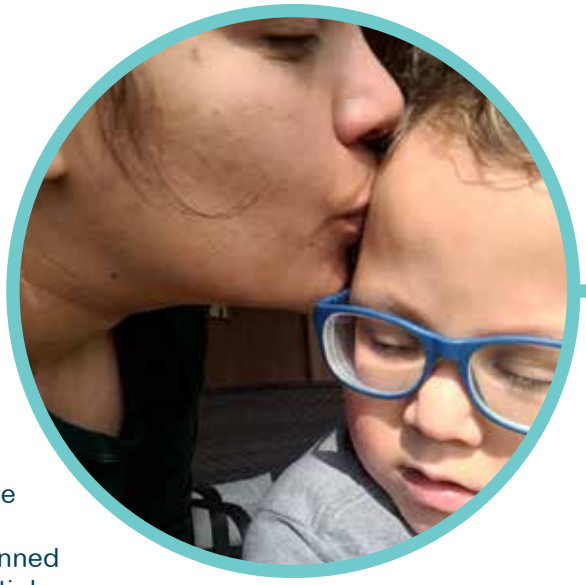
Initial research data shows that parents and caregivers whose screening indicated high anxiety and depression attended more therapy sessions, suggesting that therapy proves to be helpful to parents who need it most.

2023 Program Highlights

- **Provided outreach to more parents and caregivers** with co-located screenings in Epilepsy Monitoring Unit, Neurology Inpatient Floor, Pediatric Intensive Care Unit, and Pediatric Advanced Care Team Family Rooms
- **Offered free therapy sessions** via telehealth, bedside and in-person clinic hours based on parent/caregiver preference
- **Continued community-building initiatives** including Parent Cafe support groups and a new Pediatric Intensive Care Unit support group
- **"Caring for the Caregiver"** research presentation given at CSNK2B Foundation

FAMILY SPOTLIGHT

Meet Anita and Thor



When Thor was born unexpectedly at just 22 weeks, new mom Anita found herself facing an unimaginable path of challenges. In addition to living moment to moment in a world of new anxieties, worries and fears, Anita gave birth to Thor during the height of the Covid-19 pandemic. With strict restrictions in place to give tiny Thor the best possible chance of survival, Anita was often very isolated from the outside world while she focused on being the best advocate and caring for her son.

While Anita felt a sense of relief when she knew Thor would survive once he reached three months of age, their journey was far from easy, and many challenges lay ahead. Thor's initial NICU stay spanned 5 months. He experienced grade 4 brain bleeds and required multiple treatments to resolve them. After being extubated and having a shunt placed, Thor was luckily able to go home on only a little supplemental oxygen. However, after a year, Thor had a seizure, resulting in being airlifted to St. Louis Children's Hospital for shunt replacement. He experienced 8 additional shunt failures and replacements over the span of a couple months. Finally, after several months of trials and tribulations, Thor's doctors placed a VA shunt, which ultimately proved to be a successful treatment.

"Therapy is an invaluable hour to myself and serves as my dedicated self-care time. I don't know how I could have lived this last year without the support of my therapist. She has helped me navigate situations in a way that made me feel important, heard, and supported."

- ANITA, JJMF COMMUNITY PARENT

It was during Thor's stay at St. Louis Children's Hospital that Anita first met staff therapist Bianca. The roller coaster Anita was experiencing with many ups and downs left her feeling incredibly scared as the doctors tried everything they could to save Thor's life. When Bianca informed her that she could receive ongoing therapy funded by the JJMF, Anita felt reassurance in her ability to navigate the road ahead, enabling her to focus on her hopes and beliefs for Thor's life. From the moment she met therapist Katherine Aravamudan, Anita felt relieved by the emotional support and guidance provided by the partnership of a therapist who cared for her own well-being while she continued to serve as Thor's advocate. She felt heard and understood, which is vital for parents of children with complex medical needs as life often revolves solely around the child(ren).

Thor has been defying odds since the day he was born, and he's grown into a remarkable little boy. Today, three-year-old miracle child Thor continues to thrive. Undeterred by any difficulties that face him, Thor remains motivated and accomplishes what he wants to do on his own timeline. He loves to explore and go on walks, and he began school this year. As for Anita, she feels lucky everyday to care for such an amazing child, attributing her positivity and ability to face each new challenge to the dedicated time she spends focusing on self-care through regular therapy sessions.

Family Financial Assistance

Recognizing the financial demands families face in caring for their children's needs, the JJMF provides grants to help pay for essentials that are not covered or only partially covered by insurance. By relieving some of the stress associated with high out-of-pocket expenses, JJMF affords families the ability to focus on what is most important - loving their children.

Families receive assistance for expenses such as:

- Medical care
- Medications
- Home medical equipment
- Adaptive seating
- Respite care
- Intensive therapies

37
financial assistance grants
extended to families in 2023

"...they don't ask for tons of referrals or letters from doctors and therapists; they're just here to help families in need, families of children whose needs require a never-ending list of things for their extra care."

- KATE, JJMF COMMUNITY PARENT

19%
increase in number of grants
extended over previous year

FAMILY SPOTLIGHT

Meet Kyle

Four-year-old Kyle Fitzgerald was born with pontocerebellar hypoplasia type 2 (PCH2), a very rare genetic disorder that affects development of the brain. His parents, Eric and Kate, didn't know about Kyle's condition until he was born with symptoms, including stiff muscles and tremors, that led to genetic testing. While they waited 2 months for the results that determined his diagnosis, Kyle's symptoms unfortunately continued to worsen. He was unable to be comforted and cried at all times of the day, especially in the evening, and he made no eye contact, missing developmental milestones for infants of his age. During this incredibly difficult first year, Eric and Kate took Kyle to many doctors, desperately seeking any help for their baby. Then, at age one, Kyle was hospitalized with seizures and aspiration pneumonia, requiring intubation. After this incident, Kyle experienced similar complications over the next couple years of his life that required subsequent hospitalizations, until an effective treatment to better control his seizures was found.

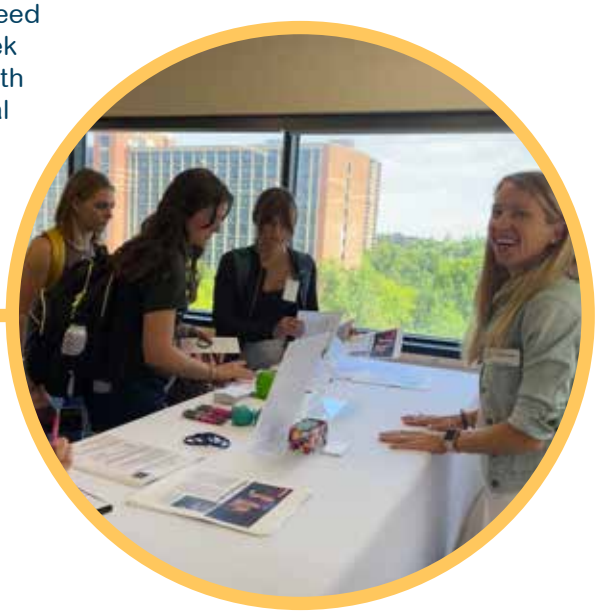
Through medical treatment and therapies, Kyle has made incredible progress. Eric and Kate are thrilled that he has developed eye contact, recognizes people, voices and faces, and smiles far more than he cries. Kyle's entire family, including an older sister and younger brother, are grateful for his presence in their lives and only wish for him to make more developmental progress and find continued happiness.

Kyle requires a wide variety of devices to get him through each day. He is unable to move on his own and needs to be repositioned frequently to be comfortable. While some medical equipment is covered by insurance, there are many needed items that can only be obtained at a high out-of-pocket expense. Without the necessary equipment, Kyle becomes upset, but when comfortably positioned he especially enjoys having his siblings play with him and make him laugh.

Always on the lookout for ways to help Kyle, Kate had noticed that many children with conditions similar to Kyle's were able to be comfortably positioned in a therapeutic seating device called the P Pod, enabling them to more easily interact with family members. However, the P Pod is not covered by insurance and therefore was unattainable for their family at the time. Luckily, a fellow medical mom encouraged Kate to apply for financial assistance from the JJMF. Kate was happily surprised by the simplicity of JJMF's financial assistance application process that made it easy to access the necessary funding. As Kate explained, the JJMF's application is different from others because "they don't ask for tons of referrals or letters from doctors and therapists; they're just here to help families in need, families of children whose needs require a never-ending list of things for their extra care." For the Fitzgerald family, the P Pod turned out to be a great early holiday gift for Kyle, and he loves it just as they had expected!

Respite Care

Since launching a pilot program in 2022 to address the incredible need for respite care solutions for families, the JJMF has continued to seek opportunities to expand this program in order to connect families with quality care providers. When caring for a child with complex medical needs, families often find it difficult to take much-needed breaks to rest and recharge.



In an effort to expand our program connecting healthcare students with families seeking reliable and trustworthy respite care providers, JJMF team members recruited students of Washington University's Doctor of Physical Therapy program. This mutually beneficial program helps families develop relationships with qualified providers, while students gain a greater understanding of the care of children with complex neurological conditions.

Making an Impact: JJMF Youth Board

With the positive energy of our newly established Youth Board, an incredible group of middle and high school students helped make a great impact on JJMF's mission-based work. Led by Youth Board President Trudy Redmond, these highly-motivated teens are always seeking ways to help support children and families, making a genuine difference for the JJMF community. Throughout the year, Youth Board members joined the JJMF team as volunteers at a variety of events, strengthening the important work that is our shared focus.

BRACELETS

Gathered to make 200 beaded bracelets with the word "STRONG" to be included in Month of June care packages

CARE PACKAGE ASSEMBLY

Assisted the JJMF team and volunteers with Month of June care package assembly

FACE PAINTING

Provided face painting at the JJMF's booth during St. Louis Children's Hospital's Tri My Best Adaptive Triathlon

Advancement in Medical Care

By bringing awareness of the unique needs of children with complex neurological conditions to pediatricians, specialists and medical residents, JJMF shares important perspectives on how healthcare professionals can best support families. In turn, families feel better supported by the level of high-quality, compassionate care they receive.

Genny Jessee presented a Washington University interprofessional course on hospice and palliative medicine, sharing her personal experience on caring for a child with a complex neurological condition and the importance of palliative care for this patient population. Students learned about the overall patient and family experience and how healthcare professionals can help relieve the challenges of navigating a complicated healthcare system.

JJMF hosted Blyth Lord, Founder and Executive Director of Courageous Parents Network, for a lectureship at St. Louis Children's Hospital. Blyth provided critical guidance to doctors through her presentation aimed at helping them build positive partnerships with parents and caregivers of their patients.

Youth Board Mission Statement

Raising awareness and gaining support amongst middle and high school teens for children with complex neurological conditions and their families.

Youth Board Officers

Trudy Redmond, *President*
Katie Todorovich, *Vice President*
Meghan Niemeyer, *Secretary*
Gen Baumer, *Treasurer*
Ella Clayton, *Volunteer Coordinator*
Margaux Harris, *Event Coordinator*
Bridget Hoff, *Volunteer Coordinator*
Charlotte Kittner, *Middle School Liaison*
Katie Williams, *Event Coordinator*

EVENT VOLUNTEERS

Volunteered at our "Not-so-haunted house" Halloween Party at The Magic House and our annual fundraiser, An Evening of Joy

TOY DRIVE

Held a sensory and adaptive toy drive to benefit children with complex neurological conditions

HOLIDAY FAMILY EVENT

Planned and facilitated activities for an inaugural Holiday Family Event

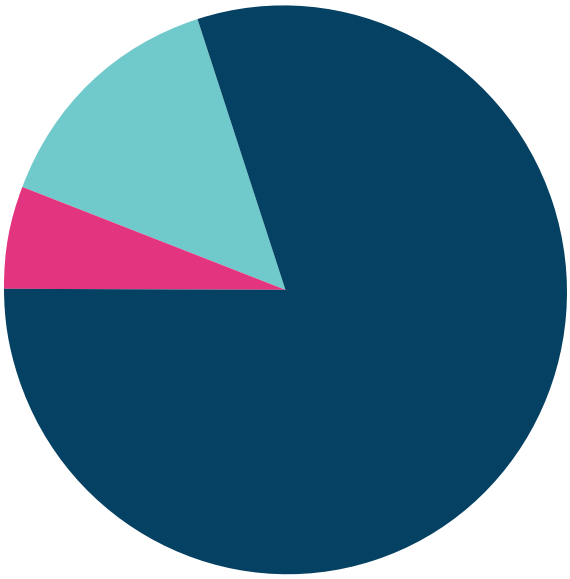
More than $300,000 raised in donations and pledges

Giving Source

80% An Evening of Joy

14% Individuals, Corporations, Foundations & Grants

6% Give STL Day



176
New Donors

379
Total Donors

13%
increase in dollars raised

An Evening of JOY

Our signature annual fundraiser encompasses an evening of delightful food, drinks and merriment, while featuring a high-value auction, raffle and inspiring family stories. With gratitude for our sponsors, supporters, attendees and volunteers, we're proud to share that this year's event resulted in a record amount of funds raised to further JJMF's mission and programs to support children with complex neurological conditions and their families.

"When you attend the event, you gain a greater understanding of the emotional and financial support JJMF families need, and you know you are supporting a great cause!"

– JULIE LINIHAN
AN EVENING OF JOY CO-CHAIR

Save the Date to join us in 2024!

An Evening of Joy
Friday, November 8, 2024
The Reverie - Chesterfield, MO

DONORS

$15,000+

Canepa Family Fund
Tim O'Toole
Poolhouse
Carol and Tim Size

$10,000-$14,999

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