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

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

The JJMF recognizes the significant value of a supportive community of people who understand the unique challenges faced by families caring for children with medically complex, neurological conditions. We aim to grow and strengthen this community by reaching families in a variety of ways to offer support within a welcoming community.

Connecting Through Partner Organizations

Genny Jessee, JJMF Co-Founder and Executive Director, had the honor of speaking about caregiver wellness and overwhelm to a group of families at The Bow Foundation’s GNAO1 Medical Community & Family Conference in St. Louis.

Attending events like St. Louis Children’s Hospital’s Tri My Best Triathlon provides an opportunity for families to learn about JJMF programs directly from our team.

The JJMF presents to partner organizations to share about our programs and resources, helping to reach more families who will benefit from accessing our supportive services.

Digital Reach

Growth in our digital reach enables us to spread the JJMF’s mission to more people, in turn helping more families in need:

- **144,000** Organic Impressions
- **133,000** Organic Post Reach
- **2,823** Fans & Followers

**30% Increase In Email Subscribers**
Mental Health Care

Established in 2019, the JJMF’s mental health care program is a partnership with St. Louis Children’s Hospital and Washington University’s Perinatal Behavioral Health Service and provides free mental health care for parents and caregivers of children with medically complex, neurological conditions.

Funded solely by the JJMF, this program provides for a dedicated licensed professional counselor to serve families whose children are patients of the Neurology Department, Pediatric Advanced Care Team, and Cerebral Palsy Clinic at St. Louis Children’s Hospital. Our dedicated licensed professional counselor provides screenings for anxiety and depression to parents and caregivers whose child is experiencing an inpatient stay, leading to ongoing supportive therapy services to address mental health needs. However, the program is not limited to families of inpatient children; it additionally allows for individuals to reach out for resources and counseling services at any time.

Each year since its inception, this vitally important program has grown incrementally to support families with additional services aimed at reducing heightened levels of anxiety, depression and psychological distress experienced by parents and caregivers. Through JJMF’s commitment to supporting parents’ and caregivers’ mental health, they are able to prioritize their emotional and overall wellness and be best equipped to care for their children.

Therapy attendance remains high at a rate of 90% indicating the important value parents and caregivers place on this much-needed program.

52% of caregivers interviewed in St. Louis Children’s Hospital units report moderate to severe anxiety and/or depression at time of interview.

Advancement in Medical Care

Striving to improve the care of children through education, the JJMF brings awareness of the unique needs of children with medical complexities to pediatricians, specialists and medical residents. By doing so, the JJMF is able to ease the hardships placed on families by raising the quality of medical care they receive.

In 2022, the JJMF hosted a lectureship at St. Louis Children’s Hospital with featured speaker Dr. Bob Macauley, Cambia Health Foundation Endowed Chair in Pediatric Palliative Care at Oregon Health and Science University and Doernbecher Children’s Hospital. Dr. Macauley’s lecture focused on the importance and benefits of palliative care for this special patient population.

“Children with Severe Neurological Impairment (SNI) account for only about 1% of all kids, but represent 14% of all inpatient stays at children’s hospitals and about 50% of all PICU admissions. So, small number, but we see them a lot and it means we have to take good care of them.”

– DR. BOB MACAULEY

Respite Care Pilot Program

The JJMF took one of our first big steps in addressing the challenge of respite care solutions by launching a pilot program to recruit high quality care providers through Washington University School of Medicine, with plans to expand to additional schools and families in the year ahead.

A top goal in 2022 was to address one of the questions JJMF is most often asked by parents of children with medically complex, neurological conditions: “How can we find trustworthy, reliable and affordable respite care for our children?” While solutions aren’t easy to find, respite care is the answer to finding relief to parental burnout, and the JJMF is dedicated to ensuring it is accessible to all parents of medically complex children.

In 2022, we began putting building blocks in place to create respite programming that will set the foundation for future achievements in care for children with medically complex, neurological conditions.

“We connected with Leo, a physical therapy student at Washington University, and he’s since been providing in-home care, building trust with every visit. He’s also assisting with some of Joe’s therapies and is bonding with our older boys by helping to care for and develop relationships with them as well, creating trust and rapport with the whole family.”

– ANNIE AND GEORGE HARPER, JJMF COMMUNITY PARENTS
Family Financial Assistance

Providing critical financial assistance to support the care of children with medically complex, neurological conditions is a cornerstone of the JJMF’s programs. By helping to relieve some stress and worry related to the financial strain of their children’s conditions, parents and caregivers are able to focus more time on what is most important - loving their children.

Ongoing care from multiple primary, specialty, and other healthcare service providers, as well as in-home medical equipment and treatments, therapies, medications and more are necessary costs that add up very quickly. Even families with “good” insurance, Medicaid or higher incomes can become financially overwhelmed and accumulate significant debt with the many out-of-pocket health expenses they acquire to adequately care for their child.

**Grants range**

$250 - $2,200 reflecting the breadth and variety of financial needs

Twelve-year-old Mason Dusenberry has a contagious smile that lights up any room! He loves watching Veggie Tales, playing his piano, going for drives in the van and walks in his wheelchair outside on warm days. With a lovingly tenderhearted personality, he cracks up when others laugh, and he cries when they are sad. Mason thrives with routine and dislikes crowds, sitting still and loud noises. Among his favorite activities is playing shadow games with flashlights in the dark with his little sister (he is the 2nd of 3 children in his family).

Although Mason’s syndrome wasn’t officially diagnosed until he was 9, he has been severely affected since birth with symptoms associated with a Dandy-Walker variant and global developmental delay. With a neurological malformation and multiple eye defects causing very low vision, Mason relies on light perception only. He experiences seizures, and his muscles are impacted by contractures and extreme hand weakness. Due to GERD and feeding difficulties, he requires tube feeding. Weekly antibody infusions and daily antibiotics combat his immune deficiency. Eventually, Mason was diagnosed through a research study, determining that he has the newly-discovered and incredibly rare WDR37 syndrome, with only 10-15 known cases worldwide.

Mason’s family recently received financial assistance in the form of a desperately-needed piece of adaptive equipment - the Special Tomato Catch-Up chair. Mason’s mom, Jennifer Dusenberry, shared how having the chair has been transformative in his daily life.

“This chair has been so helpful for our family because it has simple size adjustability that doesn’t require professional intervention (he’s in the middle of a growth spurt). His wheelchair needed adjustment but was taking months to get parts; additionally, he has a hip problem, so this was a wonderful relief to have a chair that will fit him and give good support for several years. It also has an amazing tray that has allowed us to give him more practice on his occupational therapy and school activities than we could ever do in his wheelchair. It has allowed him to practice self-activating new toys which increases his independence and quality of life. We love seeing his big smile when he plays in this new chair!”

– JENNIFER DUSENBERRY, JJMF COMMUNITY PARENT

Family Spotlight: Meet Mason!
Family Connections and Support

“My family loves ‘music time’ where we sign, sing, dance, and play together. We get all of our instruments (homemade ones too!) and are ready to jam out together. We have loved seeing other families on similar journeys and building a community together.”
– AMANDA MCKEE, JJMF COMMUNITY PARENT

Virtual Music Therapy Sessions

Our monthly virtual music therapy sessions are tailored for children with medically complex, neurological conditions and led by a specially-trained neurological music therapist.

JJMF Connect Facebook Group

Families facing the challenges of their children’s medically complex, neurological conditions have a special bond, and making connections can be deeply powerful. Our private online community enables parents and caregivers to post questions and tips or share concerns and even frustrations, while building relationships within a community that understands.

Trauma-Informed Yoga

Through a combination of virtual live and on-demand sessions, more parents and caregivers are able to access recharging and restorative gentle yoga practice from the comfort of their own home, at a time that works best for them.

Celebrating the Month of June

During the special Month of June, we honored our June’s legacy by sending care packages to over 200 families. Care packages have a nationwide reach and are distributed to families in a variety of ways.

Parent Connection at Katie’s Pizza

Parents of children with medically complex, neurological conditions gathered on a warm summer evening to connect in person, strengthening our positive community of others who understand.

Music Therapy at the Park

As part of our special Month of June festivities, families gathered outside for a memorable group music therapy session followed by a picnic and time to connect.

“I have attended several JJMF parent gatherings, and these events continue to be the best place to make connections. Through JJMF events, I have met and connected with so many new people and grown relationships within this community.”
– LAUREN WALSH, JJMF COMMUNITY PARENT
Our family absolutely loves that there are no limits with the JJMF! This organization is helpful in all aspects of life and always willing to keep pushing for more. We’ve utilized every resource JJMF has offered and we truly feel lucky to have it available in our community.

– AMY SEXAUER, JJMF COMMUNITY PARENT

"One of the coolest parts of the evening was meeting some families in person who we’d only been friends with online. It was great to see so many familiar faces outside of the hospital and therapy setting. We didn’t have to explain ourselves or our children’s condition. We got to be a typical family on a super fun holiday outing.”

– JUSTINE AUBUCHON, JJMF COMMUNITY PARENT

"It is an honor to contribute to the JJMF in memory of June, knowing firsthand just how much this wonderful foundation impacts lives.”

– ANDREW SCOTT, BELL BANK MORTGAGE, JJMF SPONSOR

Over $259,000 total in giving

GIVING SOURCE
- 64% Evening of Joy
- 16% Individuals, Corporations & Organizations
- 14% Give STL Day
- 6% Grants & Foundations

17% increase in JJMF donors

27% increase in dollars raised

Genny Jessee’s interview featuring Licensed Professional Counselor Lauren Gray Weir focuses on the importance of keeping a marriage or partnership strong while caring for a medically complex child.

“Our family absolutely loves that there are no limits with the JJMF! This organization is helpful in all aspects of life and always willing to keep pushing for more. We’ve utilized every resource JJMF has offered and we truly feel lucky to have it available in our community.”

– AMY SEXAUER, JJMF COMMUNITY PARENT
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