As a family with a child that has a neurologically complex condition, there’s not much consistency in our everyday life. And so this Foundation has provided that steady hand, that has helped guide us and support us.

Richard Sexauer, parent

Inspired by the bravery of June Jessee, a young girl who fearlessly faced chronic, life-limiting conditions with no specific diagnosis, the JJMF is the only U.S. nonprofit organization solely dedicated to assisting children with these undiagnosed, neurological conditions and their families.

**FACTS**
- Approximately 75% of rare disease caregivers characterize their care burden as ‘high’ and sacrifice much
  - 1 in 10 Americans is living with a rare disease
  - 50% of known rare diseases affect children
  - 30% of children with rare diseases die before the age of 5 years
  - 28% of neonatal intensive care deaths are caused by a rare disease
  - 65% of rare diseases are associated with a reduced lifespan
  - 3-10% of all hospitalization (regardless of age) is related to a rare disease

**PROGRAMMING**
1 in 3 caregivers in the Neurology unit experience a clinical level of anxiety and/or depression symptoms
- Funded mental health therapy sessions for 258 parents and caregivers including 18 new neurology therapy referrals
- Expanded COVID-19 relief through financial assistance
- Newly-launched Navigating Neurological Conditions webinar
- Nearly 200 “June care packages” delivered to families including those on the neuro and PICU floors
- Fun and interactive group virtual music therapy sessions
- Healing trauma-informed yoga sessions for parents/caregivers
- Private online Facebook community

**REACH**
73% increase in follower engagement over the past year
- Continued partnership with St. Louis Children’s Hospital to reach patients in need
- Guest speaker at the Disability Awareness Convention hosted by Arya Foundation
- Town & Style Magazine: Spring for A Cause spotlight feature and cover
- 2020 Missouri Athletic Club Woman of Distinction Award
- WEGO Health Awards Best Kept Secret finalist plus nominee for Best in Show: Community; Patient Leader Hero; Advocating for Another; Instagram
- Child Neurology Foundation Rising Tides Award

**FUNDRAISING**
Over $120,000 total in giving
- 65% Comfort + JOY Virtual auction and end-of-year giving campaign
- 20% Give STL Day Ranked #6 for total funds raised among 450 similar sized non-profit organizations
- 8% Grants Funded virtual programs and financial assistance to support families’ needs during the pandemic
- 7% Small fundraisers and other donations Social media giving, individual donations and small fundraisers including $4,100 raised in 1 day by Katie’s Pizza and Pasta

Sources: Global Genes and the Child Neurology Foundation, Guiding Principles of Rare Disease Care and Patient Access SEPTEMBER 2020; Rare Diseases International. Rare Diseases: Leaving no one behind in universal health coverage; Position Paper. June 2020; Katherine Aravamudan, LPC, Perinatal Behavioral Health Service, Department of Psychiatry, Washington University School of Medicine