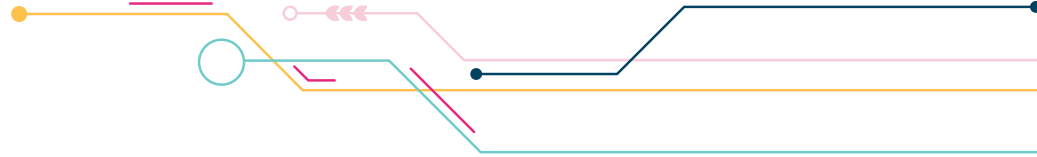


RESILIENCE IN A DIFFICULT YEAR

2020 IMPACT SNAPSHOT



Living with a rare disease or caring for a rare disease patient can be like navigating a minefield with a blindfold because of the uncertainty of symptomatic presentation or associated consequences of disease effects.

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

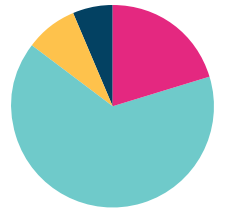
REACH

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

