

10 REASONS TO GIVE
#4: Meet Marty



At 17 months, Marty had his first seizure and life turned upside down for his family. Once diagnosed, they were referred to the FamilieSCN2A Foundation and were warmly welcomed into a supportive community with information, access to experts and inspiration to help find a cure. Since then, they have hosted 5K runs, volunteered at conferences and even chaired the 2020 Warrior Challenger virtual fundraiser! Marty's Mom, Dad and big sister work hard every day to ensure Marty's VOICE is heard, most recently by participating in the SCN2A Clinical Trial Readiness Study. [Visit Marty's page](#) on our website and check out the [toolkit](#) for more information on how to share your story.

Marty turned 5 in March and is waiting for a cure!

10 REASONS TO GIVE

#3: Family Support

The world is reopening after Covid quarantine!

After being stuck at home for over a year during the pandemic, most of us need to get out and do something fun. Maybe take a vacation or a nice long weekend at the beach.

When you have a child with SCN2A related disorders, it is not simple or easy to go on vacation. Most of our kids are either too young or too unstable to be vaccinated, so their families are still working hard to protect them. Even if they could travel, many struggle with the financial burden of raising a medically complex child and vacations are very low on the budget priority list.

As you book your travel for your getaway, consider [donating](#) to our direct patient assistance programs. We help families access the proper equipment, therapy, or assistance they need to live their best lives. [Read](#) about how families have been impacted by this support.

We all deserve a break!

PATIENT ASSISTANCE GRANT

RAISING A CHILD IS EXPENSIVE, BUT RAISING A CHILD WITH SPECIAL MEDICAL NEEDS IS VERY EXPENSIVE—AND WE WOULD LIKE TO HELP.



SCN2A RELATED AUTISM & EPILEPSY
FAMILIESCN2A
FOUNDATION

SCN2A

VOICES

Annual Campaign

\$15,000

\$30,000

\$45,000

\$60,000



33%
to
goal

SCN2A RELATED AUTISM & EPILEPSY
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We quickly reached the \$20,000 mark in our [Annual Campaign](#) but giving has slowed and we still need to raise another \$40,000 in the next 6 weeks for life-changing research and support for families affected by SCN2A disorders. Funding for rare diseases is hard fought and we raise much of ours in small increments through grassroots donors. If you'd like to add your voice to the effort, please check out our new [Social Media Toolkit](#) that simplifies fundraising by helping you share your story through social media and email (or even snail mail).



10 REASONS TO GIVE #2: VOICES

The FamilieSCN2A Foundation has created multiple opportunities for SCN2A families to use their VOICES. One we would like to highlight is a research study called the [Clinical Trial Readiness Study \(CTRS\)](#).

Over the last 2 years, we have worked hard to fill the gaps in the process of getting to clinical trials. The FDA put out critical guidance on the very specific data they need to make decisions to approve new drugs and the biggest part, that we will answer with the CTRS, is how to define and demonstrate meaningful improvement.

Our Executive Director explains further, “This may seem easy, like if my kid is having seizures and then stops, that is improvement, right? Seizure reduction

will definitely be among the primary endpoint measurements but as parents, I am sure you can relate, we want more. We want our children to thrive and live the highest quality of life possible. To many of us, these 'secondary' endpoint measurements are just as important, if not more.”

The CTRS was designed to use tools that can quantify even the smallest improvements, like eye contact and head control. We built the CTRS using the most appropriate parts of already validated (meaning the FDA will recognize them) measurements specific to our children's abilities.

10 REASONS TO GIVE

#1 Meet Brooks

Brooks is almost 2 and is still waiting on a cure! Last year, his family gave back in a big way, hosting the top fundraiser during the Annual Campaign by sharing their SCN2A journey. [Visit his page](#) on our website and check out the [toolkit](#) for information on how to share your story.



give the gift of hope today

Hope

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