

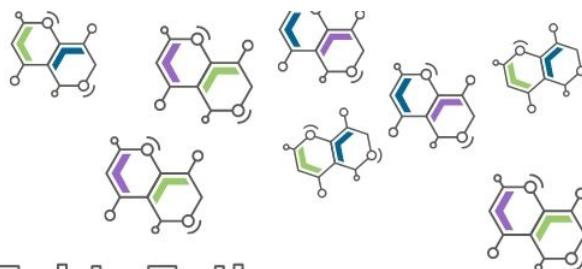


**Please, donate today and help us give our kids a VOICE.
Read on to learn more about the impact of your donation...**

10 REASONS TO GIVE

#5: Connecting Families & Professionals

R_X: Hope



Virtual Table Talks

Format

The Virtual Table Talks Series will allot 15-20 minutes for the featured speakers to give their presentations, with the remainder of the session dedicated to open discussion between the audience and speakers.

Purpose

The goal of the Virtual Table Talks is to allow families unprecedented access to professional researchers and clinicians working diligently to find a cure for our children.

Brought to you by:



One of the best parts of our Family and Professional Conferences are the personal conversations between patient families and researchers/clinicians. To replicate these invaluable interactions, we are now hosting Virtual Table Talks with a variety of SCN2A professionals. Families are invited to join these zoom calls for brief presentations on multiple key topics followed by the opportunity to ask question directly to presenters.

'Table Talks' off to a great start!

More than 20 participants from around the world joined in, learned a lot and had some great conversations with Dr. Demarest and Dr. Press on Tuesday. The subject was *Treating Seizures in the NICU and Beyond*. Doctors have difficult decisions to make in balancing the art and science of medicine when it comes to treating seizures and it was helpful to hear their perspectives. They both agreed that input from the families is a valuable part of the process.



Recordings of each session will be available on our website.

Families living with SCN2A related disorders tell us how critical it is that we empower them with access to information and education. We rely on your [DONATIONS](#) to provide this vital part of our mission.

Families: Click [HERE](#) for the full schedule and to register for Virtual Table Talks.

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.



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



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