

This year, the SCN2A community is focusing on speaking up in a unified VOICE to raise awareness for this rare disease. Because most of our children are non verbal, we need to be twice as loud!



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.



We started the [Annual Campaign](#) in early May and we've already reached the \$20,000 mark! In the next 8 weeks our goal is to raise another \$40,000 toward 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

#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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