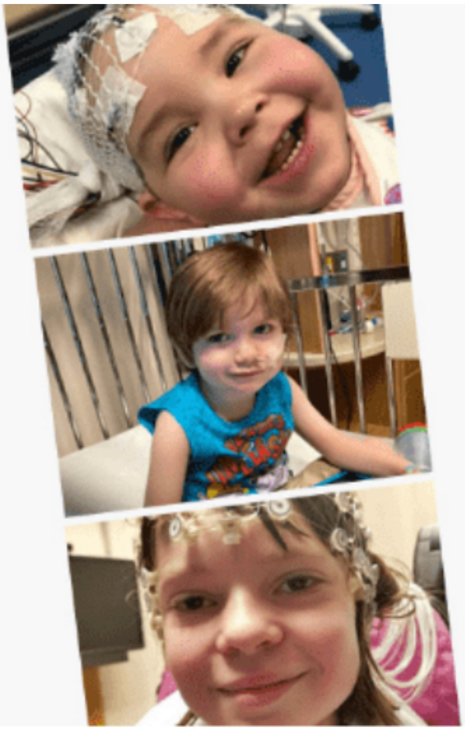


SCN2A RELATED AUTISM & EPILEPSY
FAMILIESCN2A
FOUNDATION

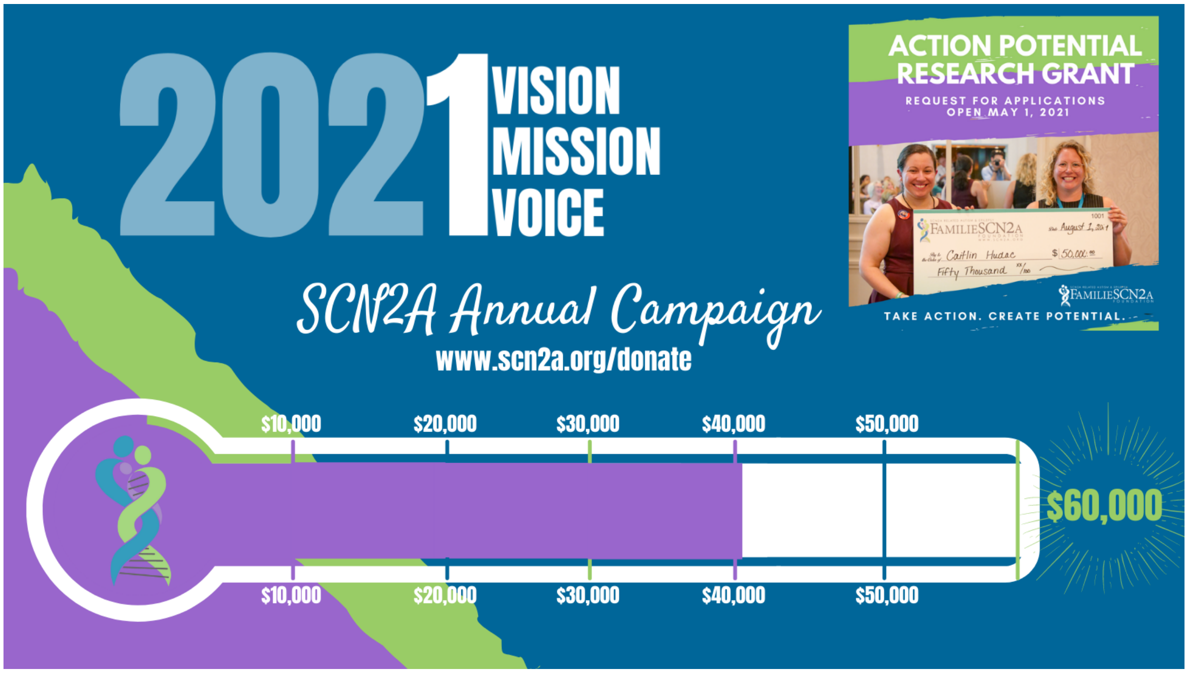
10 REASONS TO GIVE TO THE ANNUAL CAMPAIGN

MAY 1 - AUGUST 31

REASON #10 TO GIVE
OUR STORY NEEDS A HAPPY ENDING

As recently as seven years ago, if you were diagnosed with a variant in the SCN2A gene, you were likely told, “You are the only ONE” and “There is no cure.” Seven years ago, Leah Schust Myers refused to accept those answers and instead harnessed the positive power of social media by starting a Facebook page. Soon the ONE became SOME as families joined the group and were thrilled to find one another. Within a year there were MANY families and the FamilieSCN2A Foundation was established as a nonprofit in order to help ALL of them. The name was chosen to acknowledge that having an SCN2A disorder affects the whole family. We strive every day to give families a foundation of hope with our mission to improve the lives of those affected by SCN2A related disorders through research, public awareness, family support and patient advocacy. **Today, thirteen families from all over the world are in the queue to join our private Facebook group of nearly 1000 members and we have invested close to $1,000,000 into SCN2A research.** But we have a long way to go. The full realization of our vision to find effective treatments and cures for SCN2A related disorders CAN ONLY HAPPEN WITH YOUR HELP. Now that you know how our story began, please help us to achieve a happy ending. **Every $1 matched through 8/31!**

GIVE THE GIFT OF HOPE - DONATE TODAY



REASON #1 TO GIVE
MEET BROOKS

Brooks is almost 2 & 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 Brook's Page on our website and check out the toolkit for information on how to share your story.

REASON #2 TO GIVE
GEARING UP FOR CLINICAL TRIALS PART 1

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. Learn more.

REASON #3 TO GIVE
FINANCIAL SUPPORT FOR FAMILIES

REASON #4 TO GIVE
GEARING UP FOR CLINICAL TRIALS PART 2

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.

At 17 months, Marty had his first seizure & life turned upside down for his family. 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.

REASON #5 TO GIVE SUPPORTING CONVERSATIONS BETWEEN PATIENT FAMILIES & RESEARCH/CLINICIANS

This year Families SCN2A is proud to host a virtual table talk series called RX Hope.

The purpose is to allow families unprecedented access to professional researchers & clinicians working diligently to find a cure for our children.

Families: Click here for the full schedule
& to register for Virtual Table Talks.

REASON #6 TO GIVE IN MEMORY OF SCN2A ANGELS

REASON #7 TO GIVE
MEET MATEO

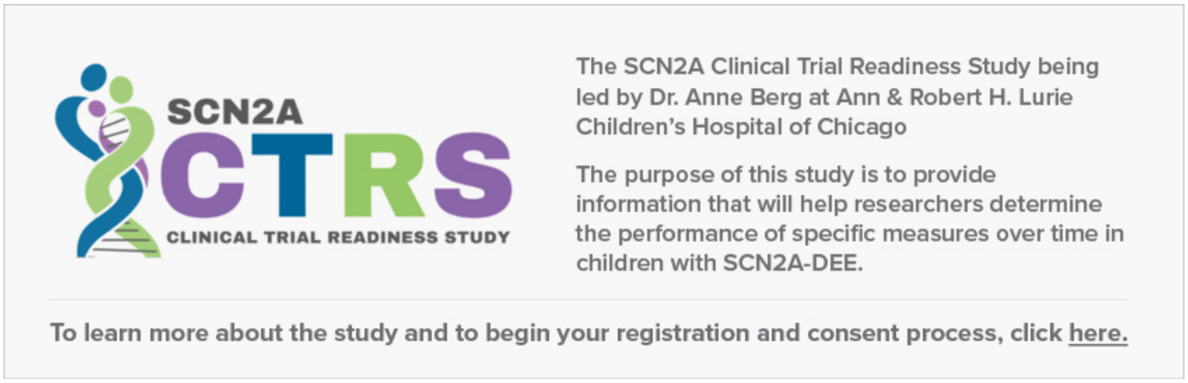
Five-year-old Mateo is still waiting on a cure! Mateo's entire family advocates for SCN2A from the USA to Colombia! Visit Mateo's Page on our website and share your story, too.

REASON #8 TO GIVE
MATCHING DONATIONS

It's not too late! If **we reach $60,000, THE ENTIRE $60K WILL BE MATCHED.** Please help us take advantage of this amazing opportunity!

REASON #9 TO GIVE
WE WILL NEVER STOP FIGHTING FOR A CURE

Three years ago we lost a brave SCN2A warrior. Amelia and her family made the ultimate decision to continue her fight for a cure by donating tissue specimens to science and research for our SCN2A community. Amelia's entire family continues to Fight On for a cure for SCN2A through advocacy, telling Amelia's story and fundraising. Angie Weaver has travelled to every conference, spoken publicly at several fundraisers, and most recently, shared with the FDA what it is like to live with and lose a child to #SCN2A. The Weaver Family inspires us all to FIGHT ON for a cure! **Donations matched through 8/31!**



The SCN2A Clinical Trial Readiness Study being led by Dr. Anne Berg at Ann & Robert H. Lurie Children's Hospital of Chicago

The purpose of this study is to provide information that will help researchers determine the performance of specific measures over time in children with SCN2A-DEE.

To learn more about the study and to begin your registration and consent process, click here.