Building Towards A Cure: 2022

With *International SCN2A Awareness Day* fast approaching, we reflect on how far we've come since being told 'you're the only one with SCN2A.' With your support since 2015, we have steadily constructed a strong foundation that is anchored by our dedication to: COMMUNITY, ADVOCACY and RESEARCH. In 2022, our focus is on BUILDING. The CZI: Rare As One Grant Network has energized us to be bold as we take the leap forward to expand our infrastructure (see staff and Board changes below). This capacity building will ultimately allow us to fulfill our mission even more quickly. In the next 3 years, we are poised to make the most of the $600K grant and access to the impressive network of CZI resources to strengthen our organizational capacity, grow our community, and advance international collaborative research toward shared priorities. **Together, we are building towards a cure!**

Building Awareness

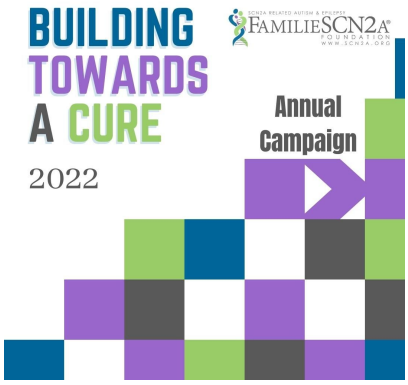
How will you raise awareness and celebrate on 2/24? Click here for great IDEAS. **Pease share whatever you do on Social Media:** Your FB page, our public FB page; our private FB page; and these hashtags: #CureSCN2A #SCN2AAwareness #SCN2A #RareDiseaseDay #RareAsOne

Awareness Day shopping? Visit the SCN2A Store!

Building Resources

February kicks off our Annual Campaign!

Thanks to you, every year we've met our goal, steadily building towards a cure. In our 7th year the goal is **$70,000** in the next 3 months (Feb to April). While we increase our capacity with the *CZI Rare As One* grant and resources, we need to raise money for research. Your donations will be put to work right away as we open the next round of Action Potential Research Grants on International SCN2A Awareness Day, 2/24. Why wait? Give Today



The FamilieSCN2A Foundation and the University of Pennsylvania Orphan Disease Center invite you to participate in the Million Dollar Bike Ride! We are thrilled to be included in this year's annual festival that brings together rare disease families, friends and supporters to raise awareness and funds for rare disease research. Come ride with us in Philadelphia, PA on Saturday, June 11th or ride virtually if you are unable to make the trip. REGISTER EARLY (by 4/1) to get your free jersey, MDBR t-shirt, and discounted registration. **Our goal is to raise the full $30,000 that will be doubled to $60,000 by the Orphan Disease Center—AMAZING!!**

Our SCN2A Warrior Team is required to have at least 15 in-person riders and/or volunteers at the event (plus as many virtual riders as we want). Riders at the event must be 16+ years and volunteers must be 18+. If you have any friends or family in the Philadelphia area who like to cycle, please reach out to see if they would be interested in riding for our SCN2A Warrior Team. **For more info** click here **and to register from there, select RIDE WITH US in top right corner.**

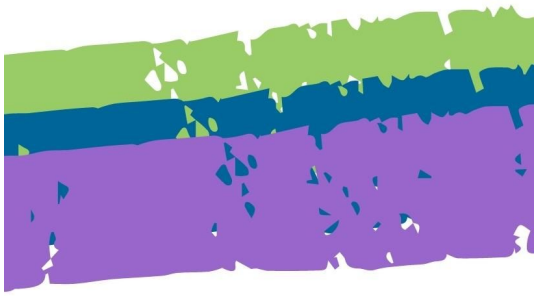
Building Research

Great news! The SCN2A Clinical Trials Readiness study has moved! The FamilieSCN2A Foundation is partnering with COMBINEDBrain.org in an effort to ensure your data will have the maximum value and impact for our community and other DEE communities. You can now expect to receive emails from the research team with an @scn2a.org email address. For questions, contact SCN2ACTRS@SCN2A.org. Please take the time to keep up with your surveys and interviews by logging into SCN2ACTRS.study. Thank you for your participation in this important study. **The SCN2A community is READY for clinical trials!**

Early Study Results

SCN2A RELATED AUTISM & EPILEPSY
FAMILIESCN2A®
FOUNDATION
WWW.SCN2A.ORG

2022 ACTION POTENTIAL GRANT



RESEARCHERS: The 2022 Action Potential Grant Cycle starts on **Feb 24** when the application goes live on our website. We look forward to seeing how you will help us build towards a cure!

Key Dates and Deadlines:
Request for Application: Feb 24
Letter of Intent Deadline: April 1
Full Application Deadline: May 1
Award Announcement: July 1
Project Start Date: Fall 2022 (Flexible)

Families: Got CRID?

The FamilieSCN2A Foundation encourages all patients enrolled in research to create a CRID (Clinical Research ID.) This is a free service that allows the patient to take control of their own data. By sharing your CRID, researchers can then reuse, merge and share your research data without using your PII (Personal Identifiable Information) or PHI (Personal Health Information).

For more info and to create your CRID today: https://thecrid.org/

Building Community

It has been (almost) 3 long years since our last in-person conference and we miss you! This will be a family-focused gathering where we come together to learn about SCN2A-related topics, hear the latest developments in treatment, participate in research and spend time with others who share our experiences. Conference registration is OPEN NOW. Agenda & hotel registration coming soon. Scholarships will be available. #SCN2A #SCN2ASummerSession2022

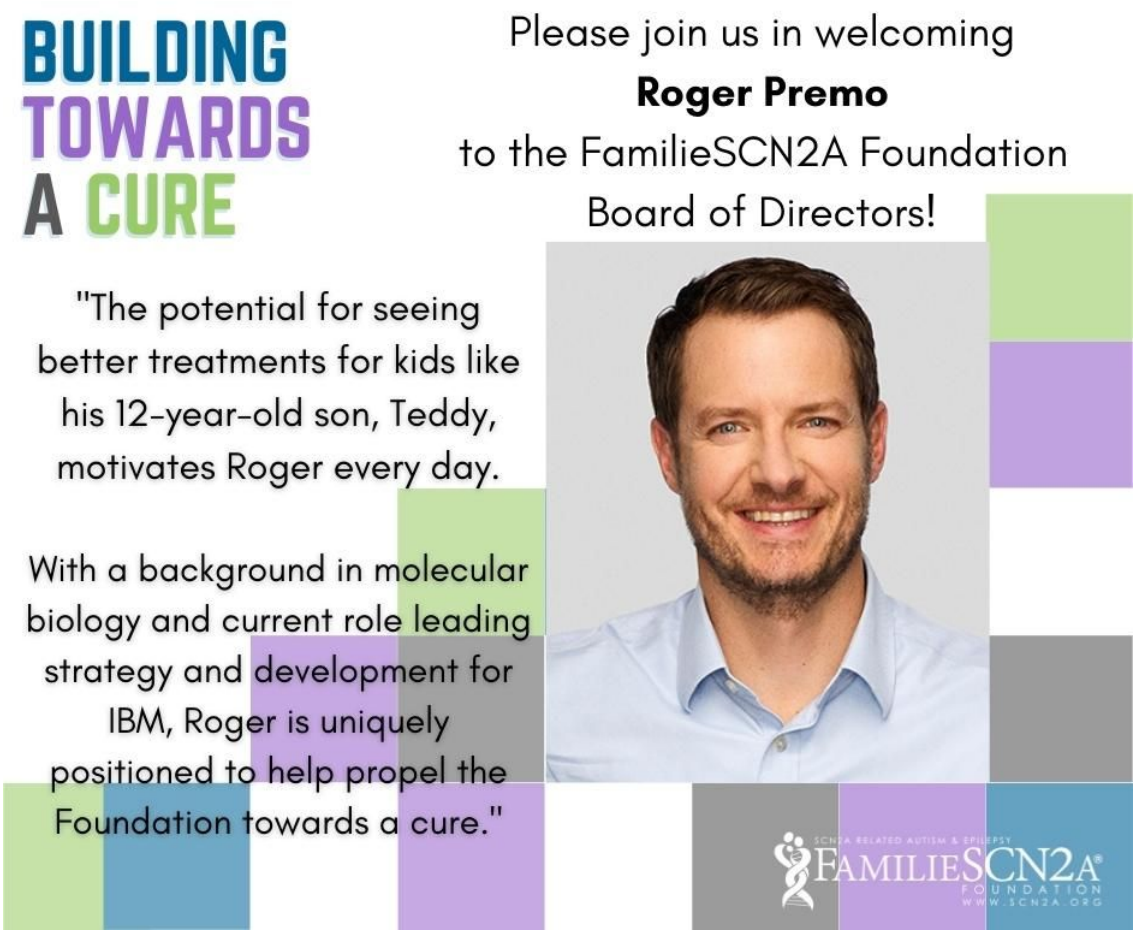
'Mission Moment' Why we're here...

"We are from Venezuela and 2 months ago we moved from Chile to the US . During the initial days we learned that the system to get access to a doctor that provides us an order for medication was totally different and we are running out of all medication for epilepsy treatment we were able to bring with us from Chile. Last week I was desperate even thinking about traveling back to Chile because after going to the pediatrician we were referred to a neurologist that the next appointment was in April next year and we only have medication for one month more. I called the Foundation and in less than one week was resolved (in two days). We got an appointment with an amazing team in CHOP and we are up to continue the treatment that has controlled the seizures of my daughter. Sometimes it is lucky, but this was 90% support from the FamilieSCN2A Global Support Network and the beautiful people on it. One of

the parents even offers us her appointment she has for her beautiful daughter to us...this is amazing and I can't find a bigger word in English to say THANK YOU to this team. I said to my wife that we need to change and cooperate more because I somehow feel that this happening to us is the worst.. but at least if we are in the same problem we need to help our community. The Foundation helped us to resolve a problem but also gave us energy and hope." - a grateful SCN2A father, Dec. 2021

Building Capacity

Here we grow again!



Growth often means change: At the most recent Board of Directors meeting, the FamilieSCN2A Foundation voted unanimously on recommended position changes on the Executive Committee and to create a part-time Administrative Manager position on staff.

Please join us in thanking and congratulating **Carla Forbes** for her 7+ years of dedicated service to the FamilieSCN2A Foundation on the Board of Directors. Carla's positive attitude and fearlessness in the face of the unknown helped to catapult a small facebook group into a major force in the genetic epilepsy and autism world. We are thrilled to announce that Carla is stepping into the new staff position. This strategic move is an initial step in 'building towards a cure' for #SCN2A, made possible by the CZI Rare As One grant.

In addition, **Jennifer Burke** was voted in as the new President for the FamilieSCN2A Foundation; **Mery Oman** accepted the position of Vice President; and **Michelle Lewis** stepped into the role of Secretary. **Michael Vasey** will retain the position of Treasurer. **Leah Myers** rounds out the Executive Committee as Executive Director of the Foundation.

Learn more about our team

Around the world there are 300 million people living with a rare disease. Check out how to 'Share Your Colours' for Rare Disease Day 2022.

Build Resources, Donate Here

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