SCN2A-RELATED AUTISM & EPILEPSY

FAMILIESCN2A®

FOUNDATION

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We've been very busy! Please scroll all the way to the end so you don't miss anything!

Friends,

This October, we faced more heartbreaking losses in our SCN2A community. As we step into '*Thankful November*' with heavy hearts, we find strength in remembrance and purpose. We honor these brave Warriors and their families by carrying their names in our hearts, ensuring they are never forgotten. In their memory, we channel our grief into a fierce resolve to push harder for life-saving treatments and cures for all SCN2A-related disorders.

We are deeply grateful for the unwavering support of our incredible community—families, friends, scientists, clinicians, and caregivers. Each day brings us closer to breakthroughs, but we must also remember that another SCN2A warrior may be in crisis. Throughout November, we'll be sharing our gratitude in various ways, and we invite you to join us in celebrating the love, resilience, and HOPE that fuels our mission.

As we enter the season of giving, we want to emphasize how crucial this time is for our fight against

SCN2A-related Disorders. Over the next two months, your contributions will play a vital role in advancing research, supporting affected families, and advocating for treatments that can really change lives.

To make your gift, please visit scn2a.org/donate.html. Every donation, no matter the size, helps us move closer to our goal of finding a cure and providing essential resources for families on this journey. This is a collective effort, and your generosity can make a tangible difference.

We invite you to consider supporting FamilieSCN2A as part of your end-of-year giving. Together, we can honor the memory of those we've lost and uplift the spirits of those still fighting. Let's unite our efforts, spreading hope and creating a brighter future for all SCN2A Warriors and their families.

Thank you for standing with us. Your support means everything.

~ *Leah Myers,* Executive Director

WHAT'S HAPPENING

Celebrating Our Extraordinary WARRIOR CHALLENGE TEAMS! Families raised > $50K!

This year's Warrior Challenge was a profound testament to the strength of our community. With 35 registered teams and hundreds of attendees from around the world, we've woven a network of families united in purpose and driven by hope. Their passion and determination have inspired not only those within our community but everyone who has encountered their stories.

Together, our teams raised over $50,000! **Thank you, families, for being the heart and soul of this initiative to push our mission forward.**

The Power of Participation

DRAGONFLY Study Updates & Insights

by Brad Bryan, Director of Patient Registry Affairs

Every day, our community learns and grows from the experiences of individuals affected by SCN2A variants. The challenges our families face inspire us to keep moving forward. Thank you to all the families who have taken the time to participate in the DRAGONFLY study—from 9 countries so far! Your contributions have a real and lasting impact on our understanding of SCN2A-Related Disorders and the journeys within our community, and they're crucial to helping us find new treatments.

We have learned that individuals with SCN2A variants are typically diagnosed at just over 2 years of age, indicating the critical need for early diagnosis.

Our DRAGONFLY registrants represent over 30 different SCN2A variants, leading to challenges with learning and motor skills, and, in many cases, emotional control, autism-like symptoms, and seizures. While nearly half of the DRAGONFLY registrants do not experience seizures, in those who did, most have seizures daily. The most common anti-seizure medications prescribed include Levetiracetam, Clobazam, and Oxcarbazepine, among many others.

Every new finding reported in the DRAGONFLY Study by our community brings us one step closer to better care and support for SCN2A-Related Disorders everywhere. We encourage everyone who has previously shared their information in these surveys to continue doing so as this is an 'evergreen' study that will help researchers understand the course of the disease. If you haven't contributed yet, please **Register Today**—it benefits not just your loved ones, but also everyone around the world affected by SRDs. And it's open to everyone with a diagnosed SCN2A variant.

Raise Awareness this November!

Join us in spreading the word by changing your social media profile frame for Thankful November or Epilepsy Awareness Month. Wear purple to show your support and tag #CureSCN2A in your posts!

The FamilieSCN2A Foundation collaborates with many epilepsy organizations and is proud to be a member of the American Epilepsy Society's Epilepsy Leadership Council.

Tell your neurologist to stop by our Booth (#N2055) at the AES Annual Meeting in Los Angeles December 6-10.

Attention all Federal Employees and Retirees!

Federal employees and retirees, find us in the **Combined Federal Campaign Charity List!** Our donor designation code is **85766**.

Your support will make a meaningful difference in our community. No matter the size, every donation sends a powerful message of hope to our brave families. Pledging has already begun!

A big thank you to the Williams family for sharing their inspiring story: **Read about Parker's journey here**

The 2025 SCN2A Warrior Calendar is HERE! Order Yours Today!

We're thrilled to announce that our 2025 SCN2A Warrior Calendar is now available for purchase!

This calendar celebrates many of our Warriors throughout the year, making it a perfect addition for your home or a thoughtful gift for a family member, friend, or donor. **Buy your 2025 Warrior Calendar here.**

Conference Recordings are Up!

The 2024 SCN2A Family & Professional Conference video recordings from July's meeting in sunny California are now available for viewing! Catch up on the sessions here:

2024 SCN2A Family & Professional Conference: Day 1

2024 SCN2A Family & Professional Conference: Day 2

SCN2A IN THE NEWS

SCN2A Clinical Trial Readiness Study Publication Now Available!

We are thrilled to announce that the latest SCN2A Clinical Trial Readiness Study (CTRS) publication **is now available to our community!** This is a monumental step forward for individuals and families affected by SCN2A-related disorders.

The CTRS has transformed the landscape for the SCN2A community by providing critical insights into the natural history of SCN2A-Related Disorders and the best practices for clinical trial design. These findings pave the way for more effective therapies and interventions, ultimately improving the lives of those affected.

One of our core beliefs is that research should be accessible to all. That is why we have ensured that the data from this study is freely open-sourced. We encourage everyone to read all the publications and engage with the findings. Your involvement can amplify the impact of this research and support our ongoing advocacy efforts! **Read the publication here.**

Doubling Down on Impact: CZI RARE AS ONE Network

Families attending the SCN2A Family Conference in September 2023 in Bonn, Germany, organized by SCN2A Germany. | Photo by Max Buchholz

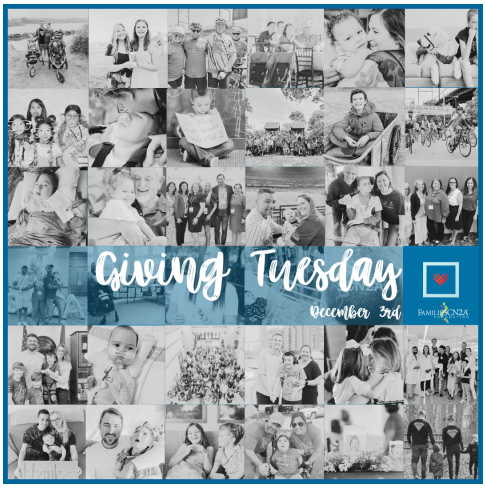
Grant Awarded to SCN2A Italy and SCN2A Germany!

We are thrilled to share that our friends at SCN2A Italy and SCN2A Germany have recently received a CZI Rare As One Project Grant! This award represents a "doubling down" on our collective efforts and will significantly empower both organizations to make a meaningful impact on the lives of individuals affected by SCN2A-Related disorders worldwide. Our own CZI grant comes to an end this year, but we remain in the RAO network to continue our work in this collaborative research environment.

Read more about the SCN2A Italy and SCN2A Germany award!

GET INVOLVED

Let's Make a Real Difference on GIVING TUESDAY - December 3rd!



On December 3, Giving Tuesday offers us the opportunity to turn our collective energy into real change. After the busy shopping days of Black Friday and Small Business Saturday, it's the perfect moment to pause and reflect on what truly matters. This global day of generosity invites us all to contribute in ways that can transform lives. So how will you make an impact?

Reach out to an SCN2A friend—a simple check-in can bring comfort and connection when it's needed most.

Give your time and talents—whether through volunteering or sharing your skills, your help can make a lasting difference.

Share your SCN2A story—your voice can raise awareness and inspire others to take action.

Make a donation—every contribution, big or small, moves us closer to a cure and brighter future.

Whatever you choose, share your generosity on social media using **#CureSCN2A**. Your act of kindness can spark a ripple effect, helping to bring hope to all families affected by SRD's.

MONTHLY RECAP

Our Executive Director, Leah Schust Myers, and Program Manager,

Amanda Gale, represented the FamilieSCN2A Foundation at the NORD Breakthrough Summit in Washington, D.C. in October.

The summit, themed "Equitable Access to Innovation," brought together advocates, researchers, and leaders to tackle the urgent need for advancements in rare disease treatments. With over 7,000 rare diseases identified and fewer than 5% having an FDA-approved treatment, the discussions and connections made at this event were crucial in driving our efforts to advance research for all SCN2A-related disorders.

Joining Leah and Amanda in advocacy were Angie Weaver, Warrior Mom and Bereavement Support Volunteer for FamilieSCN2A, and Jenny Burke, Board Chair of the FamilieSCN2A Foundation.

Leah Myers Elected to the Board of Directors for the American Brain Coalition!

The American Brain Coalition (ABC) is a leading advocacy organization dedicated to supporting individuals affected by brain disorders and advancing research in the field of neurology. Leah's appointment to this prestigious board is a natural extension of her ongoing commitment to supporting and improving the lives of those impacted by rare genetic conditions like SCN2A. We are excited for the opportunity to collaborate with other passionate leaders and advance the shared missions of both the FamilieSCN2A Foundation and ABC.

2024 Society for Neuroscience (SfN) Conference in Chicago

As one of the largest gatherings of neuroscientists worldwide, the SfN conference provided a deep dive into cutting-edge research across a range of areas and served as a valuable opportunity to explore developments directly related to our mission at FamilieSCN2A Foundation.

Leah connected with leading experts, strengthening our collaborative network and gathering fresh ideas to accelerate our impact. The experience reinforced our commitment to finding innovative solutions and advancing treatments for those affected by SCN2A-related disorders, while deepening our dedication to pushing the boundaries of brain science for the benefit of patients and families.

We're feeling inspired by the invaluable insights, connections, and knowledge gained at the recent CZI *Science in Society 2024* meeting.

At the meeting, contributors discussed how advances in large language models, computational tools and more could help shorten the rare disease diagnostic journey for patients and their clinicians.

The meeting also highlighted the critical role of patient-driven research in advancing scientific discovery. Attendees shared how investments in patient-powered data and research infrastructure are driving meaningful progress toward finding cures for rare and complex diseases like those caused by SCN2A mutations.

Our Chief Scientific Officer, Shawn Egan, represented our mighty community at the Epilepsy Pipeline Conference in Atlanta, where he shared his personal and professional journey. During a session titled 'Gene-Based and Cell Therapies,' Shawn spoke passionately about his "why," offering valuable insights as both a parent and a professional in the field of rare disease. His story highlighted the importance of advancing research and therapies for those affected by epilepsy and rare genetic conditions like SCN2A.

"We are incredibly grateful for this SCN2A community. The support and invaluable information we've received here have truly made this journey easier. When Jax was first diagnosed, our group was small, but we're so proud to see how much we've grown—now a global community. This growth helps us expand our knowledge to make more informed choices for our kids. I'm also deeply thankful for the leaders of this foundation and their tireless efforts in search for a cure for all SCN2A-Related Disorders."

- Dimattia Kolb Family

Our mission is to accelerate research, build community, and advocate to improve the lives of those affected by SCN2A-Related Disorders around the world.

Our Contact Information
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