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

International SCN2A Awareness Day is fast approaching!

Donate

Although we're already into February, the excitement surrounding our milestone year is just beginning to build! As we approach **SCN2A Awareness Day**, the FamilieSCN2A Foundation invites you to continue being part of a growing movement that is raising awareness and support for families around the globe affected by SCN2A-related disorders.

As we celebrate our 10th anniversary, we are determined to **Seize the Moment**—because now is the time to act. Families facing SCN2A-related disorders can't wait any longer for the care they need. In the coming weeks, we'll share more about how we're stepping up to address these urgent challenges and why your support is more critical than ever. Every action—whether it's sharing, donating, or participating—helps create a future filled with hope for our SCN2A community.

How You Can Get Involved:

- **Share Your Story** - Start a Personal Fundraising Page
- **Help Support our Mission** - Kick start our Annual Campaign
- **Spread Awareness** - Update your Social Media Frame & Share!
- **Show Your Support** - Buy some SCN2A Apparel

Shop for International SCN2A Awareness Day

February 24th is International SCN2A Awareness Day! Want to help raise awareness for SCN2A-related disorders and look stylish while you do it?

Visit our Awareness Day Shop today to shop our exclusive SCN2A Awarenss Day apparel... Availablie for a limited time only!

We have options for everyone - Our SCN2A Warriors, parents, and all of your family and friends! Proceeds help fund our mission to improve the lives of individuals impacted by SRDs.

Shop Now!

WHAT'S HAPPENING

State Proclamation Shoutouts!

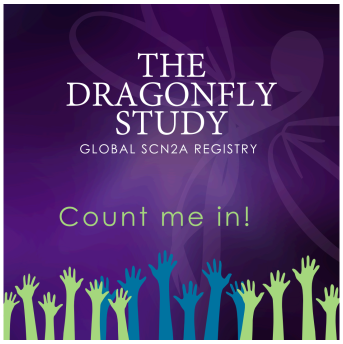
Since Fall 2024, Victoria Opthof-Cordaro has been working with families to secure SCN2A Awareness Day in all 50 states. As we approach the 2025 Family & Professional Conference in Colorado, we're excited to announce that, with the help of Jessica Williams, **Colorado will become the 14th state to recognize SCN2A Awareness Day on February 24th!**

Thanks to Jessica's efforts and collaboration with State Representative Brandi Bradley, the proclamation will be presented at the State Capitol. Congratulations to the Williams family and all Colorado SCN2A families!

We also thank Rachel Dickel for her work in West Virginia, where SCN2A Awareness Day will be recognized again in 2025.

A huge thank you to Victoria for her continued commitment to expanding recognition of SCN2A Awareness Day. Want to get involved in your state's proclamation process? Email us!

Email Us



Dragonfly Study: Sneak Peak!

We're excited to report on the progress of the **DRAGONFLY Study**, a crucial natural history study for SCN2A-related research. If you've started the surveys and need assistance, we're here to help every step of the way. If you haven't signed up, it's not too late! **Sign up today!**

Our DRAGONFLY Study currently has 123 registrants worldwide, whose challenges include learning difficulties, motor issues, emotional control problems, autism-like symptoms, and seizures. This ongoing study is crucial for tracking the progression of these conditions.

Want to see what we've learned so far?
Watch our latest webinar for a sneak peek at the data we've gathered and its impact on SCN2A research! Together, we are making a difference!

Watch Now

Upcoming Caregiver Support Group

Introducing ***Caregivers Connection***!! We're starting a new **virtual** support group on Zoom to empower caregivers of those impacted by SCN2A. This initiative offers a safe, supportive space for parents to connect, share experiences, receive emotional support, and build a community with others who truly understand.

Join us to share both challenges and triumphs, celebrate inchstones and milestones, and prioritize self-care as we navigate the many roles of caring for a loved one with SRD's together.

Learn More

SCN2A Family Event Grant: Bringing Families Together

Want to meet up? The FamilieSCN2A Foundation is proud to continue offering the SCN2A Family Event Grant, designed to bring SCN2A families together, strengthen our community, and build lasting connections. This grant allows families to organize and host events of their choice—whether it's a local gathering, a retreat, or another type of meet-up—with all expenses covered by the Foundation.

Learn More

SCN2A Patient Assistance Grant Program

Did you know FamilieSCN2A Foundation provides financial assistance to those impacted by SCN2A-related disorders?

The FamilieSCN2A Foundation's Patient Assistance Grant Program can provide much needed assistance help improve the quality of life for your family.

Learn More

Exciting Opportunity: We're Hiring!

We are pleased to announce that we are looking for a **Philanthropy and Development Director** to join our team and help drive the exponential growth of the SCN2A community!

This key role will lead our fundraising strategy, setting and achieving annual philanthropy goals to advance our mission. Working closely with the Executive Director, Board of Trustees, and staff, the Philanthropy and Development Director will develop and execute comprehensive development strategies, build strong relationships with donors, and oversee donor engagement initiatives. Interested in joining our team? We want to hear from you!

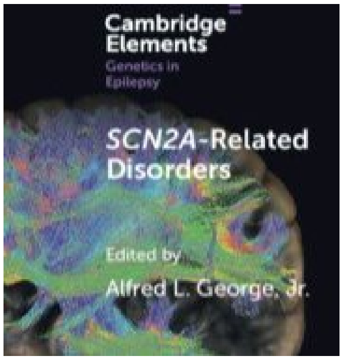
Email us!

SCN2A Related Disorders: An AI-Podcast by Denis Lal, PhD

Take a moment to listen to this 15-minute podcast created by our long-standing Scientific Advisory Board member, Dennis Lal, PhD, using AI technology. In this insightful episode, Dr. Lal dives into SCN2A, the disorders caused by changes in this gene, and the evolving therapeutic landscape. We hope you find this resource informative and engaging!

Listen Now!

SCN2A IN THE NEWS



Cambridge Elements
Genetics in Epilepsy
SCN2A-Related Disorders
Edited by
Alfred L. George, Jr.

Open Access to New Publication Available!

We're thrilled to announce that the newly released ***SCN2A-Related Disorders*** publication is now **available at no cost** to our entire community! This important resource offers in-depth insights into SCN2A-related conditions, featuring the latest research and family perspectives that highlight the experiences of those affected.

We encourage you to explore this valuable publication and share it widely with your **clinical team**, family and friends. Together, we can raise awareness, support research, and improve the lives of those impacted by SCN2A-related disorders.

Read it FREE!

MILLION DOLLAR BIKE RIDE
RAISING MONEY FOR RARE DISEASE RESEARCH

New SCN2A Research Grant Awarded!

Jennifer Kearney from **Northwestern University** is one of 41 researchers awarded a grant as part of the 2024 **Million Dollar Bike Ride.** Her project, focused on *Excitation-Transcription Coupling in SCN2A-Related Disorders*, received a grant of **$62,492** to fund research from February 2025 to January 2026.

This project will investigate how SCN2A mutations disrupt excitation-transcription coupling, a key process that connects brain activity to changes in neuronal connections and is vital for learning and adaptation. Over $2.6 million was awarded to research across 34 rare diseases through the event.

We look forward to the impact of Dr. Kearney's work in advancing our understanding of SCN2A-related disorders.

Read More

Important Update on Longboard Pharmaceuticals

We have significant news to share with our community: **Longboard Pharmaceuticals** has been acquired by Lundbeck A/S. This acquisition brings exciting developments for those of us following the progress of Bexicaserin, Longboard's promising drug candidate for developmental and epileptic encephalopathies (DEEs).

Longboard has already made strides in this area, notably by enrolling patients with SCN2A variants into their clinical trials and recently kicking off a pivotal Phase 3 study (named DEEp Ocean) targeting various DEEs, including those with SCN2A.

What does this mean for our community? Lundbeck is expected to carry on with this crucial study. If you or someone you know is interested in learning more about eligibility and how to participate, please visit the official study website.

Learn More

DISCLAIMER: *Any information related to clinical trials is for informational and educational purposes only, and to raise awareness of such trials to the SCN2A community. The above content does not endorse any specific clinical trial and/or company or institution conducting said trial. Talk with your healthcare provider to determine if any clinical trial is right for you or a loved one.*

FAMILIES is part of our name for a reason

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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Donate Today