SCN2A-RELATED AUTISM & EPILEPSY

FAMILIESCN2A®

FOUNDATION

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

Registration is Now Open for the 2025 FamilieSCN2A Foundation Family and Professional Conference!

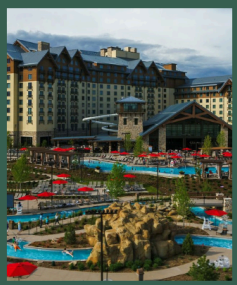
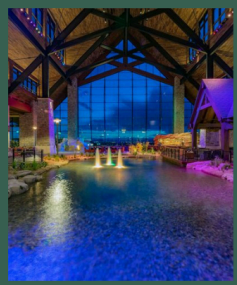
Taking place **July 31 - August 2, 2025** at the **Gaylord Rockies Resort & Convention Center** in **Denver, Colorado**, the **FamilieSCN2A Family and Professional Conference** brings together families, clinicians, researchers, and advocates from around the world to connect, learn, and collaborate in support of those affected by SCN2A. Whether you're a parent, caregiver, scientist, educator, or healthcare provider, this conference has something for you!

Conference Highlights:

- ✓ Latest advancements in SCN2A research
- ✓ Sessions tailored for families and professionals
- ✓ Clinical insights and expert panel discussions
- ✓ Networking opportunities across the SCN2A community
- ✓ Resources for caregiving, clinical care, and research
- ✓ Inspiration, collaboration, and lasting connections

To Register and Reserve Your Room, Click here →



Spring Has Sprung at FamilieSCN2A — and We Are Growing!

Spring brings new beginnings, and we are honored to announce that **Angie Weaver** will be joining us as our new **Director of Philanthropy and Development**! Angie brings over two decades of nonprofit and rare disease experience, having previously served as Executive Director at two organizations. She led successful fundraising strategies, secured major gifts, and built lasting relationships to support mission-driven work.

Angie's commitment to philanthropy is deeply personal. Her daughter **Amelia** was born with an SCN2A-related disorder, and Angie has been an advocate for families, sharing her story to grow grassroots fundraising efforts, support research, and influence policy change. She also continues to serve on the **Bereavement Support Committee** in Amelia's memory.

With her extensive experience, heart, and passion, Angie will help further our mission and bring new energy to our development efforts. We are thrilled to have her on board!

We're also delighted to introduce **Melody Kisor, MS**, to our **TASCO Team**! Melody is a bioethicist and health advocate specializing in maternal/child health and rare neurological disorders. She is dedicated to amplifying the patient and caregiver voice, and has worked on initiatives ranging from FDA advocacy to the creation of patient-centered resources and events. Her insight and compassion will be a valuable asset to the SCN2A community.

In addition, we're proud to share that **Professor Andreas Brunklaus, MD, MRCPCH**, has joined our **Medical/Scientific Advisory Board (M/SAB)**. A leading international expert in SCN-related epilepsies, Professor Brunklaus brings a wealth of knowledge in epilepsy genetics and clinical care. His leadership in global research collaborations and commitment to advancing diagnostic tools will help guide our efforts to improve outcomes for those affected by SCN2A.

If you're new here, we invite you to **meet the rest of our incredible team**—the passionate individuals working behind the scenes every day to support families, drive research, and grow our impact.

Our Second SCN2A Multidisciplinary Center is NOW OPEN!

This milestone marks another major step forward in our mission to ensure families have access to expert, coordinated care for SCN2A-related disorders. We're building momentum— and the impact is growing, thanks to the generous support of our donors and **Dr. Megan Abbott** and her dedicated team at **Children's Hospital Colorado.**

To share more about this exciting development, join us for a special **webinar on May 20th at 8PM ET** in collaboration with the **International SCN8A Alliance**. We'll explore what makes these centers unique, how they're already changing lives, and what's ahead for multidisciplinary care in the SCN space.

Click here to Register for the webinar→

Have questions or want to make an appointment? *Email: sCN2a-8a@childrenscolorado.org*

Where have we been lately?

Our **Chief Scientific Officer, Shawn Egan, PhD**, recently presented on ***"The Status of Clusters: Untangling Status Epilepticus from Clustered Seizures in DEE Across the Lifespan"*** at the **2025 American Clinical Neurophysiology Society (ACNS) Conference** in **Baltimore**.
Being part of such a prestigious conference highlights the importance of our advocacy efforts in advancing research and care for SCN2A-related disorders. Connecting with experts and sharing insights underscores the growing recognition of our mission and its role in advocating for better treatment options and shaping the future of care for SCN2A families.

Recently, our **Program Manager, Amanda Gale**, traveled to Orlando to attend **GiveCon** — a conference focused on empowering nonprofits through connection, storytelling, and innovation. While there, Amanda explored new ideas for engaging volunteers and strengthening our outreach efforts. She also had the opportunity to share the mission of FamilieSCN2A and connect with other passionate leaders (pictured here with Warrior Mom, Angie Weaver!). We're excited to bring these insights back to our community as we continue building programs that support and uplift SCN2A families.

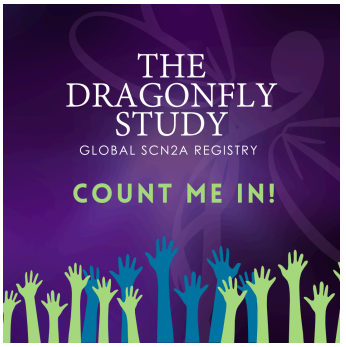
On Rare Disease Day, our **Executive Director, Leah Myers**, and our **Board Chair, Jenny Burke** traveled to Washington, D.C. to attend the ***Rally for Rare*** — a powerful event that brings together advocates, families, and organizations to elevate the voices of the rare disease community. Leah met with other *rare* leaders, shared the stories of our SCN2A warriors, and advocated for policies that support research, access to care, and meaningful change. We're proud to have had FamilieSCN2A represented on Capitol Hill, standing strong for our community and pushing for a better, brighter future for all those living with rare diseases.

M/SAB Member, Eloise Austin and our **CSO, Shawn Egan,** recently attended the **Rare Advocate Development (RAD) Conference** and are excited to share its immense value with our patient community.

This CNS-focused event equipped them with critical insights into the drug development process—ranging from early preclinical research to collecting regulator-approved natural history data, and navigating contracts in this space. They also gained specialized knowledge in gene therapy manufacturing, high-throughput assays, and emerging science.

Attending RAD has empowered them to advocate more effectively for our community.

Be Counted in SCN2A History — Complete the DRAGONFLY Study by June 1st!



The ***DRAGONFLY STUDY*** is the official SCN2A Registry — built *by* our community, *for* our community. It's our most powerful tool for helping scientists, industry and policy makers understand the full impact of SCN2A-related disorders.

We're excited to share that the **first publication from the DRAGONFLY Study** will be unveiled at the **2025 SCN2A Family & Professional Conference** — and families who contribute their data **before July 1** will be included!

This is your chance to directly impact research and **help shape the future of care and treatment.** Your participation matters. Your story matters.

Click here to get started or log in to continue your surveys→

Core Value Award: Nominate a Professional Making a Difference

Do you know a professional who is **moving mountains** for the SCN2A community? Someone whose work is **changing the landscape** of SCN2A research or making a significant impact in the lives of

families affected by SCN2A?

We need your help! Nominate a professional for a **Core Value Award**, to be presented at the **2025 SCN2A Family & Professional Conference**. We will honor four individuals whose extraordinary efforts align with the **FamilieSCN2A Foundation's Core Values** and our shared commitment to improving the future for SCN2A families.

Our Core Values:

- **Urgency** – We race against the clock every day to save lives and improve futures for children affected by SCN2A-related disorders.
- **Integrity** – We say what we believe, and we do what we say. Trust is built on honesty and uncompromising truthfulness.
- **Collaboration** – We are stronger together. By listening and evolving, we unite for a collective goal.
- **Inclusion** – We value the talents, perspectives, and skills of every teammate and family we serve.

If you know someone who exemplifies these values, **nominate them today**! **Click here for the nomination form →**

Two Clinical Trials Currently Enrolling

The DEEp Ocean clinical trial now has a website with key information, including an overview of the study, answers to commonly asked questions, a map of the planned U.S. sites, and a screener for interested families. The studies are also posted on ClinicalTrials.gov(ID NCT06719141). Once the first international site opens, global websites will be launched to support international families as well.
Click here to learn more about The DEEp Ocean Study →

The next phase of the **EMBOLD study** is enrolling early to investigate a potential new seizure treatment for children with early-onset **SCN2A** and **SCN8A** DEEs.
Click here to learn more about Praxis Embold →

***Any specific company, products, processes, or services by trade name, trademark, manufacturer, or otherwise on the website or social media platforms does not constitute or imply the FamilieSCN2A endorsement, recommendation, or favoring by the Foundation. We encourage any interested participants to research, consult with your doctor, ask questions, and get input from multiple, unbiased resources. https://www.scn2a.org/research-scn2a.html*

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
FamilieSCN2A Foundation
PO Box 4260
Gettysburg, PA 17325
301-252-8070
https://www.scn2a.org/

Support our Mission Today