SCN2A-RELATED AUTISM & EPILEPSY

FAMILIESCN2A®

FOUNDATION

WWW.SCN2A.ORG

WHAT'S HAPPENING

We've been busy! Please read, or at least scroll, all the way to the end so you don't miss anything!

Join us virtually at the 2024 SCN2A Family & Professional Conference

The conference is SOLD OUT for in-person attendance! This incredible response highlights the life-changing impact of our annual event bringing the SCN2A community together. But don't worry, you can still 'get tickets' to join us virtually on August 1st and 2nd! Check out the Agenda and start planning your conference experience today!

Virtual Registration

The 2024 Million Dollar Bike Ride was a HUGE success, raising over $60K for FamilieSCN2A research

We are so proud of our riders who cycled together through beautiful Philadelphia on June 8th. We are thankful for virtual participants and volunteers who joined the MDBR from afar, raising both funds and awareness! $30K of donations for this ride were **doubled** by Penn's Orphan Disease Center for a grand total of **~$62,000** to drive SCN2A research forward. **Researchers: Look for the grant RFA from ODC later this summer!**

Meet the Newest Additions to our FamilieSCN2A Foundation Team!

Please join us in welcoming Amanda Gale as she joins the FamilieSCN2A Foundation's team as **Program Manager**.

Amanda brings a diverse and accomplished background in the nonprofit sector, with a specialization in community engagement, collaborative partnership building, and innovative approaches to driving impactful initiatives. Her connection to the Foundation is deeply personal, stemming from her middle son Henry, who has SCN2A-related disorders. This connection has ignited a profound passion in Amanda to advocate for and support families like hers. Learn more about Amanda HERE!

We are also pleased to welcome Vanessa Bender, PhD, and Jeffrey Cottrell, PhD, as **Scientific Advisors** to our Team for Advancing Science and Clinical Outcomes (**TASCO**)!

Vanessa is a neuroscientist with a decade of experience in grant writing and editing. Jeffrey is a neuroscientist with twenty years of experience in neurodevelopmental and psychiatric disease research and drug discovery. Learn more here.

SCN2A IN THE NEWS

SCN2A-focused care at UTHealth Houston

We are excited to share updates from the first-ever SCN2A Multidisciplinary Clinic. To streamline the process of getting an appointment, please find the necessary information below:
Appointment Request: Complete the form here. Do not call. Have your genetic report ready to upload for eligibility determination.
Eligibility and Review: After receiving your information, the genetics team will review your eligibility. This may take time due to clinician workload. Once confirmed, your request will go to the treating clinician (Dr. Von Allmen for pediatrics or Dr. Lhatoo for adults) to determine the specifics of your first visit, which may include an EEG and/or a neuropsych evaluation. Additional medical records may be requested; please use email or a portal for uploads.
Insurance Considerations: For out-of-state patients, insurance can be complicated. Obtain a quote on the estimated out-of-pocket costs before your appointment to ensure feasibility.
For more information, click here.

Please note, as this is the first SCN2A MDC, we are still refining our processes and appreciate any feedback.

Longboard Pharmaceuticals receives Breakthrough Therapy designation from the FDA for its investigational drug bexicaserin (LP 352) for the treatment of seizures associated with DEEs for patients 2 and older. Longboard plans to initiate global Phase 3 trials later this year. This designation follows the release of positive interim results from the PACIFIC Study, a clinical trial whose innovative design enabled people with SCN2A to participate.

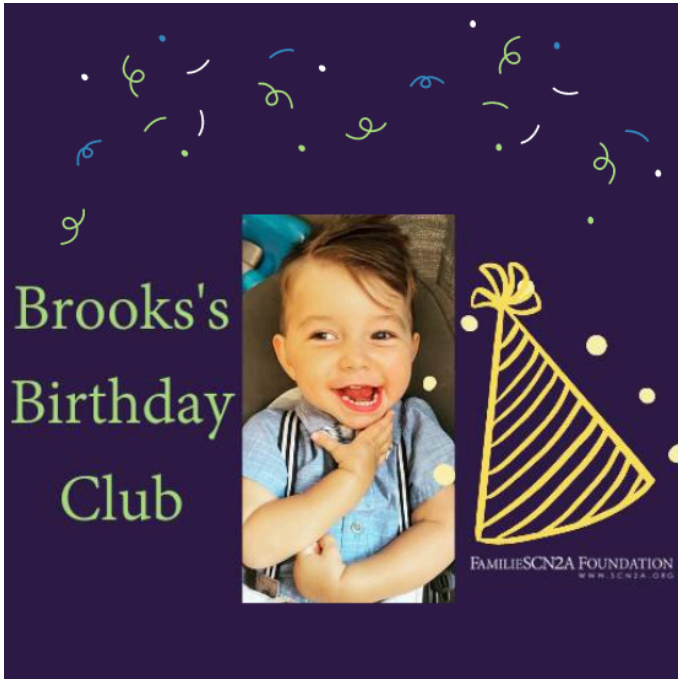
We are pleased to announce that we have officially joined forces with AMERICAN BRAIN COALITION (ABC). ABC is a nonprofit organization comprised of the United States' leading professional neurological, psychological, and psychiatric associations and patient organizations. Together, we seek to advance the understanding of the functions of the brain, and to reduce the burden of brain disorders through public education and advocacy. Through this collaboration, we will raise awareness among policymakers about the causes, impacts, and consequences of neurologic and psychiatric illness including SCN2A-Related Disorders!

GET INVOLVED

Dragonfly Study LAUNCHING Soon!

The Dragonfly Study is an international patient-centered registry for SCN2A-related disorders crafted by researchers, medical experts, and caregivers. It is designed to capture the most relevant information essential for advancing research and sharing the impactful narratives of our community. Your involvement in the Dragonfly Study will play a vital role in shaping the future of research into SCN2A-related disorders.

Learn more about the Dragonfly Study HERE!



Join Brooks's Birthday Club!

Brooks's Birthday Club is in memory of Brooks Thomas Richter who gained his angel wings on his 3rd Birthday. Brooks was a true warrior who loved birthdays although he only was on earth for three. He loved being surrounded by his family and friends; and we loved celebrating what an amazing, strong, and resilient boy he was. Our hope is to provide a smile to the warrior receiving the birthday surprise and to know that they are loved fiercely by so many. - *The Richter Family*

Thank you to Brooks's family and fan club for supporting this wonderful program!

Your child will receive a birthday card on their birthday and possibly a little something extra! With your permission, we will do a happy birthday shout-out on social media. Sign up today!

We always need volunteers...want to give back?

Volunteers are an essential part of our organization, helping us fulfill our mission. We welcome volunteers to assist with various initiatives including fundraising events, community outreach, social media campaigns, advocacy, and more. If you have a desire to contribute in any capacity, or would like to learn more about volunteering and available opportunities, please contact Program Manager, Amanda Gale.

ADVOCACY

Pictured l to r: Ilene Penn Miller, Rep Brian Fitzpatrick (PA), Leah Myers, Laura Lubbers, Pat S.

Advocating for the SCN2A community

Advocacy is an important pillar in the FamilieSCN2A Foundation's Strategic Plan. It means ensuring that the voices of those living with SCN2A every day are heard in all arenas of impact: From the doctor's office to the lab to Capitol Hill and everywhere in between.

So far in 2024, we have attended Rare Disease Day at NIH, NINDS Genetic Strategies to Cure the Epilepsies, NINDS Nonprofit Forum, and more (read on).

Last week, Executive Director, Leah Myers, took a short break from conference prep to meet with lawmakers in Washington, DC. The Foundation has joined a coalition led by the Epilepsies Action Network to campaign for a National Plan for the Epilepsies.

Neurodevelopmental Disorders Collaborate for Progress

It was an honor for the FamilieSCN2A Foundation to be invited to the 4th annual International Angelman Syndrome Research Council (INSYNC) meeting in New York City June 4-5. Organized jointly by the Simons Foundation and the Foundation for Angelman Syndrome Therapeutics (FAST), this event brought together Simons Foundation Autism Research Initiative (SFARI) and other researchers, industry sponsors, regulatory experts, clinicians, and representatives from other rare monogenic neurodevelopmental disorder groups. It was a fascinating event highlighting the need for fostering communication, collaboration and de-siloing of research in order to speed progress toward life-changing treatments.

On May 8th, our Executive Director, Leah Schust Myers, presented at the 27th Annual American Society of Gene & Cell Therapy Meeting in Baltimore, Maryland. Leah discussed the "Four Pillars of Research Readiness," shedding light on crucial aspects of advancing research in rare diseases.

Thank you for representing the FamilieSCN2A Foundation at ASGCT 2024, Leah! Your leadership is driving us closer to better treatments and cures.

Pictured (left to right): Michael Boland (STXBP1), Joni Rutter (NCATS), Leah Myers (FamilieSCN2A Foundation), Richard Finkel (St. Jude)

COMING UP

4th Annual Golf Fore SCN2A Event

Mark your calendars! The **4th Annual Golf Fore SCN2A Tournament** is coming up on August 19th, 2024 at Springville Country Club, NY. Join us on the green as we raise funds for vital research and support for SCN2A-related disorders.

We are grateful to Golf Committee members and the Egan family for hosting this wonderful event! It is the dedicated commitment of families and their networks of friends, colleagues and companies that drives progress in funding research to cure all SRDs while improving the lives of all who are affected.

Can't make it? Please consider a tax-deductible donation to our organization. Your support is vital to our mission.

Donate

Free Caregiver Course Offering From the Child Neurology Foundation

From Surviving to Thriving: Building a Community to Support Mental Well-Being

Intended to provide support for families with: children with complex healthcare needs. Families will learn strategies to successfully manage the challenges of parenting a child with a neurologic condition so they can protect the mental well-being of themselves and members of their family. 100% virtual. **Course opens August 5th and runs through September 6th. LEARN MORE**

FAMILIE SCN2A FOUNDATION

2024 SUMMER CONFERENCE

Our Contact Information
{{Organization Name}}
{{Organization Address}}
{{Organization Phone}}
{{Organization Website}}

{{Unsubscribe}}

Your donation funds our vision of a world with effective treatments and cures for all SCN2A-related disorders