



Building Community



We are proud to report that the SCN2A Summer Seminar was a resounding success! Nearly 300 stakeholders in the SCN2A community came together in Columbus for an exciting and very busy 2 days in July (and another 150 joined virtually). The event kicked off with a Research Roundtable discussing important questions in SCN2A followed by a fun evening for kids of all ages at Legoland. Dads and Moms each got a 'night out,' there were multiple opportunities for families to participate in research and we hosted our first scientific poster session. The seminar itself was jam-packed with family stories, research updates, clinical guidance and practical advice. We began two new traditions: Honoring all of our SCN2A angels by reciting their names and recognizing outstanding SCN2A researchers with our Core Values Awards.



"Nothing can compare to connecting with other families just like ours, as well as researchers studying SCN2A in their labs. The FamilieSCN2A summer seminar helped us all to remember that we are not alone, not by a long shot, and there is real, tangible hope." SCN2A Warrior Mom, Angie

Summer Seminar Video Links

2022 SCN2A Summer Seminar recordings are available here:

Session 1 <https://youtu.be/6MZtvtaA4WU>

Session 2 <https://youtu.be/kOqmGk8dGSA>

Session 3 <https://youtu.be/EztF0QHTvWo>

Session 4 <https://youtu.be/K-JFTkzx7do>

CALLING ALL SCN2A CALENDAR MODELS!

It's time to update the Warrior
Calendar for 2023.

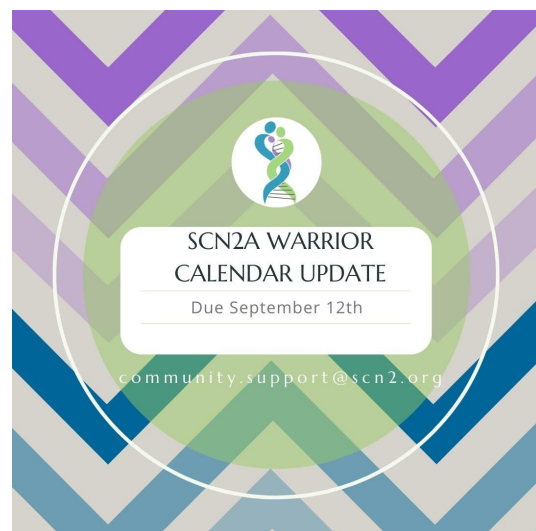
Returning models, check your email
for instructions to update your photo.

New to the calendar? Email

community.support@scn2a.org for

info. **The deadline for sending**

pictures for the 2023 calendar is



Monday, September 12th.

Research Grant Opportunities



the
orphan
disease center

**REMINDER! DEADLINE 9/6
ORPHAN DISEASE CENTER
MPS I PILOT GRANT PROGRAM**

Letter of Interest Due Tuesday, September 6, 2022 by 8 PM EST.

<https://www.orphandiseasecenter.med.upenn.edu/.../mps1gra...>

The SCN2A community helped raise \$61,068 for this research grant by participating in the Million Dollar Bike Ride!

Don't miss this opportunity! Open to international researchers!



AMERICAN EPILEPSY SOCIETY

Now Accepting Applications: AES Early Career Grant Programs

Deadline: 5:00 PM Eastern Time, Thursday, January 12, 2023

As one of the largest non-governmental funders for those starting careers in epilepsy research, AES is committed to developing the next generation of epilepsy investigators. [AES grants](#) are made possible by the generous support

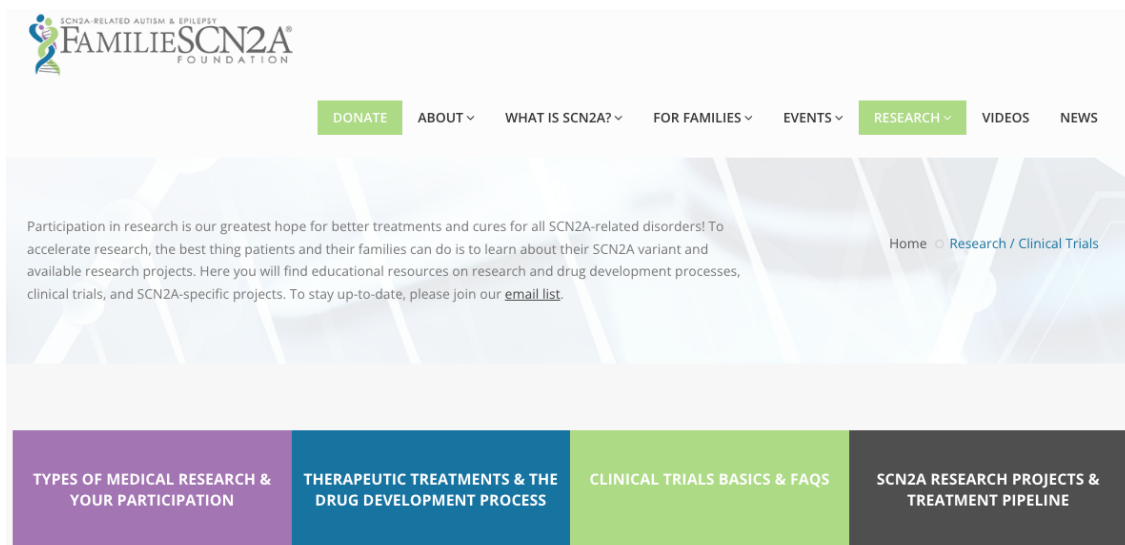
of AES members, funding partners, industry supporters, and other donors. The FamilieSCN2A Foundation partners with AES to fund research that will accelerate the development of therapeutic treatments and disease-modifying advancements for those living with changes in the SCN2A gene.

[Click here for more information](#) and to [APPLY NOW](#)

Building Research

You asked, we delivered! Visit our brand new Research Page for a comprehensive overview of all the exciting research updates and opportunities to participate in clinical trials! <https://scn2a.org/research-scn2a.html>

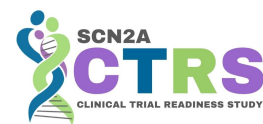
Have fun exploring and learning how to best advocate for patients with SCN2A-related disorders.



Participants are starting to cross the finish line and researchers are already asking for the data! Thank you for your participation in this important study.

Please take the time to keep up with your surveys and interviews by logging into [SCN2ACTRS.study](https://scn2actrs.study). For questions, contact SCN2ACTRS@SCN2A.org.

The SCN2A community is READY for clinical trials!



Research opportunities for the SCN2A community

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.



**Now enrolling: the PACIFIC study for the treatment of adults with developmental and epileptic encephalopathies
[NOW EXPANDED TO INCLUDE THOSE AGE 12 AND UP!]**

To learn more about the PACIFIC study,

visit: www.pacificclinicalstudy.com and scn2a.org/research-projects.html



We're excited to announce a new development related to our planned EMBRAVE study (PRAX-222), known as EMBRAVE, which is specifically designed for **early onset children with gain-of-function SCN2A epilepsy**. EMBRAVE (PRAX-222) is planned to launch later this year, and eligibility for that study may require three months of recent electroencephalogram (EEG) data as well as seizure diaries. Patients residing the United States with early-onset SCN2A-DEE now have an opportunity to participate in a preliminary assessment of their condition called the SCN2A EEG Observational Study, which involves at-home collection of this information that could provide information that may facilitate later enrollment in EMBRAVE (PRAX-222).

To learn more and see if your child may qualify, visit:

<https://scn2a.com/clinical-research-studies/scn2a-eeeg-observational-study/> and scn2a.org/research-projects.html



GOT CRID?

Families: If you've participated in any research, including the CTRS and SimonsSearchlight, please take this simple step...

Create a **Clinical Research ID (CRID)**. This is a **free** service that allows patients to control access to 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). It takes 5 minutes to set up!

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

Building Resources



Ever wonder why we call our children and their families **Warriors**? It's because there is currently no cure for SCN2A-related disorders so we are **fighting** hard to change that. With precision medicine on the horizon, now is the time to charge full speed ahead towards our vision of a CURE.

More research is desperately needed to push treatments forward. Neurodevelopmental disorders like SCN2A receive significantly less research funding than other diseases, which is why we all have to do whatever we can to raise funds and awareness.

We need your help! Please join us for the 3rd annual SCN2A Warrior Challenge during the weekend of October 22-23, 2022.

This event is a great opportunity to engage with your community, friends, and family to spread awareness while raising funds for the FamilieSCN2A Foundation. Being virtual means we provide the event platform and incentives and all you need to do is create your team and plan to run, stroll or walk to show your support. It's that simple!

"Last year was our first year participating in the warrior race and it was held just a few short weeks after we almost lost Emily. My heart was overflowing with love and joy to see so many people from our community coming out to celebrate Emily's life and to walk beside her in faith and love on this journey."
SCN2A Warrior Mom, Jaclyn

To learn more and join the Warrior Challenge go

to: <https://runsignup.com/Race/MA/AnyCityAnyState/SCN2AWarriorRunWalkRollStroll>

Need help? Here are two videos that explain:

1. How to register without joining a team https://youtu.be/4_TiFhpXgYg
2. How to join and create a fundraising team <https://youtu.be/rT8Yy2rjRyY>



**Big thanks to Shawn
and Stephanie Egan
for hosting**

THE 2ND ANNUAL
'GOLF FORE SCN2A'

AUGUST 29th
in BUFFALO, NY!

Great fun was had by all at this sold-out event. Join us next year!



EASY FUNDRAISING: AmazonSmile Renewal

Did you renew your AmazonSmile account?

Check your Amazon app to make sure

AmazonSmile is turned on and set to support the
FamilieSCN2A Foundation. We earned more than
\$500 last quarter!





THANK YOU to all who volunteer to participate in research studies and raise funds for the Foundation. We know it's not always easy but funding and participating in research is the way to change the future for those currently suffering from SCN2A-related disorders and the ones who will come after us. You give us HOPE.

Build Resources, Donate Here

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