



✉ Donations can be mailed to: FamilieSCN2A Foundation, PO Box 4260, Gettysburg, PA 17325

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How will you celebrate International SCN2A Awareness Day?

- share your stories on social media; what is it like to live with SRDs every day?
- wear your SCN2A gear ([order some new gear!](#)) for all the world to see
- tell your friends and family about SRDs; point them to scn2a.org to learn more
- [put a frame around your profile picture](#)
- wear and give out awareness bracelets at school, work, the gym, the doctor's office
- update your contact information to make sure you're counted (see below)
- plan a fundraiser and [let us know about it, we can help!](#)
- volunteer for the Foundation, there is always something to do
- call, text or meet up with another SCN2A family or get to know a new one
- [make a donation](#) to kick off our [Annual Campaign!](#)

Let's light up social media with SCN2A awareness day posts from around the world!

Use # hashtags: #CureSCN2A #SCN2A #SCN2AAwarenessDay (and maybe you'll be in the next newsletter)

 BUILDING COMMUNITY



BIG thanks to the Dedon Family who advocated for Louisiana to become the 4th state to officially proclaim February 24 SCN2A Awareness Day!

Arkansas just came in as state #5 with Missouri and Maryland right behind! (CA, PA and MA started the ball rolling last year.) We truly appreciate all the hard work of the Dedon, Beasley, Lewis and Auldridge families! What about YOUR state? [Email us for info on how to advocate in your state.](#)



Complete the contact form today

ATTENTION FAMILIES: As we chart the course for the future of SRD treatments and cures, the most important waypoint is YOU, the patients! It is critical to be able to reach you individually, by email. Count yourself in by [updating your contact information](#) today!

The 2023 Patient Assistance Grant (PAG) program is open!

This program is open to all those affected by SRDs worldwide.

The grant seeks to help with uncovered costs for necessary medical equipment, therapy devices, and educational aids.

Sponsored by:



[Learn more about the conference](#)



BUILDING RESEARCH



The grant cycle opens February 24!

We are very excited to announce the creation of the Team for Advancing Science and Clinical Outcomes (TASCO)

Shawn M. Egan, PhD, the new Chief Scientific Officer of the FamilieSCN2A Foundation will lead a team including Brad Bryan, PhD, MBA; Christina SanInocencio PhD, CPH, CNP; and Karen S. Ho, PhD. [Learn more about them here](#). This team will be an integral liaison between Academia, Biotech, and Pharma, and of course our SCN2A Community as we implement our [Strategic Plan](#). The TASCO will work to fulfill the Foundation mission to accelerate research, build community, and advocate to improve the lives of those affected by SCN2A-related disorders (SRDs) around the world. The primary goal of the team is to propel us toward the vision of a world with effective treatments and cures for all SRDs while encompassing our values of urgency, integrity, collaboration, and inclusion. We are grateful to the [CZI Rare as One Project](#) for the support required to plan boldly, leading us to assemble the TASCO!



We are thrilled to announce the successful completion of the SCN2A-CTRS! Our team is now working on analyzing the results and preparing them for presentation in multiple settings. Thank you, SCN2A Families, for your active participation!! Because of you, we are closer to a cure.

[Click here](#) to read about the Vineland results.

(Individual reports will be available for download in mid-March.) A webinar is in the works which will provide an overview of the findings and a more in-depth discussion of the interpretation of the Vineland. Stay tuned!

CLINICAL TRIAL UPDATES

1) Pre-screening for PRAX-562 Embold study now open!

Emboldstudy.com is live, allowing the opportunity for caregivers of those diagnosed with SCN2A and SCN8A DEE to see the inclusion and exclusion criteria and schedule a pre-screening call with a nurse navigator. [Learn More](#)

2) Pre-screening for PRAX-222 Embrave study now open!

If you think your child may qualify for the PRAX-222 EMBRAVE study and would like to speak to a Nurse Patient Navigator to learn more, please schedule a pre-screening appointment here: [Learn More](#)

Development of novel gene therapy strategies for the treatment of ALL SCN2A Disorders

On February 1st, Samuel Young from the University of Iowa was awarded \$61,068 raised by our intrepid riders in the Orphan Disease Center's 'Million Dollar Bike Ride' last summer!

Here is a summary of this exciting research proposal: *SCN2A disorders comprise a complex landscape of both missense and protein-truncating variants, resulting in a diversity of phenotypes that include epilepsy and intellectual disability. Currently, there is no cure for SCN2A Disorders, nor are there methods in development that would provide therapeutic intervention for all forms of SCN2A Disorders. Here, our team proposes proof-of-principle studies that could be beneficial for both missense and protein-truncation cases, providing a single method to treat the entire diversity of SCN2A Disorders.*



BUILDING RESOURCES

Join us! We're doing it again!



It's only February, not too late to order the sweetest calendar to ever hang on your wall!



2023
little warrior calendar



FAMILIESCN2A
SCN2A-RELATED AUTISM & EPILEPSY

HOW CAN YOU GET INVOLVED?



SPREAD THE WORD

Share all things FamilieSCN2A with your network of friends & family. Talk about our mission. Spread the word about SRDs!

#SCN2A
#CureSCN2A



@FamilieSCN2AFoundation



familiescn2afoundation



@FamilieSCN2A

Finding effective treatments and cures is very expensive!
Direct donation is the single action with the biggest impact.
Every donation matters, every dollar counts.

DONATE NOW

Donate at: www.scn2a.org



START FUNDRAISING

Families, caregivers and friends of those affected by SRDs are in the best position to raise funds for better treatments & cures. Let us help you plan an event, big or small!



Get started today! Email us at: info@scn2a.org

The FamilieSCN2A Foundation always needs volunteers to serve the needs of our growing community. Join us and make a difference!

GET INVOLVED

To join our team, email us at: info@scn2a.org



RARE DISEASE DAY
28 FEBRUARY 2023
#RAREDISEASEDAY RAREDISEASEDAY.ORG



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