

Dear SCN2A Families,

If you are looking for ways, big or small, to get involved with and support the FamilieSCN2A Foundation's efforts, read on! From the Warrior Challenge to participating in research to joining the Birthday Club there are multiple opportunities to interact with us and support our mission to improve the lives of those affected by SCN2A related disorders through research, public awareness, family support and patient advocacy. If you're interested in volunteering or have any questions, please email us at info@scn2a.org. Thank you!

The FamilieSCN2A Foundation Board of Directors



In a year so full of challenges, who needs another one? You do! And this is one you can feel good about: the **SCN2A Warrior Challenge.**

Join us (virtually) the weekend of **November 7-8** for the inaugural SCN2A Warrior Challenge, where you can run, walk, roll or stroll to support the FamilieSCN2A Foundation.

Since this is a virtual race, you can design the course however you want to challenge yourself: is it 100 meters, a mile, a 5K? Are you looking for a good reason to take on a 10K or something longer? Whatever the distance and location, you'll run, walk, roll in a wheelchair or push a stroller to complete the SCN2A Warrior Challenge for a great cause.

This is a fantastic and fun way to spread SCN2A awareness! Invite your friends, family and neighbors to participate and learn how your warrior fights every day and how everyone deserves a cure for SCN2A related disorders.

The Warrior Challenge is off to a great start with 100 registrants, 17 teams and over \$5,000 raised so far!!

We have made the registration VERY easy! The full package is \$30 and includes an athletic t-shirt, medal, bracelets and a cape! OR you can register for \$10 and opt out of all the products. OR you can add on shirts, medals, bracelets and capes to make sure your family is fully decked out without having to register every single person...it's up to you! Click here for help with registration.

Need help creating your Team Page? Please email carla.forbes@scn2a.org





WARRIOR CHALLENGE Registration



The RX: Hope Virtual Series has launched!

If you registered for this event, check your email for a link to watch the talks! It's not too late to register and the videos will be available through October.

Additional videos will be added as they are completed.

Any issues or questions, please email Leah.schust@scn2a.org.

Happy viewing!

Rx: Hope Virtual Series Free Registration

Research Opportunity!!

The FamilieSCN2A Foundation together with The University of Pennsylvania and Children's Hospital of Philadelphia researchers recognize a need for proper diagnosis and treatment of symptoms associated with neurodevelopmental disorders. Many times, the research is solely focused on the seizures. Caregivers and patients want the other symptoms that too often go hand in hand with a neurodevelopmental

diagnosis such as SCN2A Disorder to be studied with the same vigor. These symptoms can have a huge impact on patient quality-of-life.

Please complete this 20 minute questionnaire.



CALLING ALL SCN2A MODELS!

Deadline to submit photos is OCTOBER 1ST

Please help us raise awareness and funds by adding a photo of your beautiful SCN2A warrior to the 2021 FamilieSCN2A calendar.

First time participants: Email a high quality photo, your child's birth day and month (not year) and that you give permission to publish it to community.support@scn2a.org. If you have already sent a photo for the birthday.club, please indicate that in your email.

Previous calendar models: Let us know if you would like your child to be on the 2021 calendar. If you would like to send a new photo, please do! Calendars will be ready to order in time for holiday gift giving.

You asked, we're delivering!

SCN2A ornaments will be available for the holidays.

Email <u>Carla Forbes</u> for details and to place your order.





Join our Birthday Club!

It's so much fun as a kid getting mail addressed just to you! Sign up today for our Birthday Club and your child will receive a birthday card on their birthday and possibly even a little extra something special too! With your permission we will do a special shout out posting on social media for their birthday (this part is not required to to join the Birthday Club). Sign up today!





We are hosting a series of virtual "Chats" via Zoom to provide a forum for community connection.

Families affected by SCN2A are invited to join for informal conversation with others who understand. These calls are not intended to provide medical advice. "Chats" have been popular so we plan to hold them on the first Friday of every month 2:00-3:00 pm ET! Please check social media posts or email community.support@scn2a.org for the Zoom link.



Other ways to help:

- Have a party! There are many direct sales vendors who would be happy to host a fundraiser for you. Let us know and we'll share it on social media.
- To learn more about Planned Giving, Stock Donations, Used Car Donations, Amazon Smiles, iGive and other ways to donate, please visit www.scn2a.org/donate
- Share your ideas with us! Email info@scn2a.org

We can now receive donations via text! Text "CURESCN2A" to 443-21

We are grateful for your support and involvement in the SCN2A community. Every facebook comment helps another family; every social media 'share' raises awareness; every dollar donated moves us closer to a cure for SCN2A disorders.



Our mailing address is:

P.O. Box 82, East Longmeadow, MA 01028

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