

2021 VISION MISSION VOICE



EXCITING NEWS!

In a huge win for the FamilieSCN2A Foundation, we were selected from more than 200 applicants to receive a grant from the Chan-Zuckerberg Initiative's [Rare As One Project](#). This three-year, \$600,000 grant and inclusion in the Rare As One Network will enable us to increase our capacity to grow our patient and research community. We are thrilled and honored to receive this boost to propel our mission forward. #CureSCN2A #ThankfulNovember



Rare
As
One



The SCN2A Warrior Challenge was lots of fun and a great success with a final tally of over \$45,000 raised by 26 participating families. Special thanks to Jamie & Mark Tuminello and Amanda Smith & Ryan Beckman for leading this annual tradition.

Join the fun next year: Oct 22-23, 2022

Create a team or join a team for your SCN2A Warrior. Our warriors do things their own way so create your challenge your way. Walk, run, ride or roll around the neighborhood or a local park or do a full 5k - or more! (Click on the image below to visit the 2021 website and see what it's all about.)



RESEARCH



Reminder: If you have registered but not scheduled your initial interview, [click here](#). [The study is now closed for new registrations.] We understand that it looks like a big time commitment, but

you can break it up into small steps, starting with the first interview. Once that is done, log back into [SCN2ACTRS.study](https://scn2actrs.study) to complete your BASELINE measurements and earn your first \$50 gift card!

Your voice matters!

Early Study Results

Do you have your CRID yet?

The FamilieSCN2A Foundation encourages all patients enrolled in research to create a CRID (Clinical Research ID.) This is a free service that allows the patient to take control of 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).



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

Ask your neurology team if they are attending The American Epilepsy Society Annual Meeting in early December. Let them know that the FamilieSCN2A Foundation will be at Booth T-08 and ask them to stop by! We love meeting and educating clinicians working with SCN2A patients. Our team is excited to attend this meeting (in person!) for the 7th year. It's a networking extravaganza where we make things happen for the SCN2A community.

It's time for holiday shopping!

You don't even have to leave the house to order a variety of gifts for family, friends and teachers from our new online store. Calendars can be ordered anytime from [CreatePhotoCalendars](#) and the online store is always open, but if you want delivery by Dec. 25th, **please order no later than Dec. 9th.** Remember, if you ever order from Amazon, please go to [Smile.Amazon.com](#) and choose the FamilieSCN2A Foundation as your charity! We also participate with [iGive.com](#) which makes charitable contributions from many online shops.

**BIG thanks to SCN2A Warrior Moms, Kris Ray and Cassy Stewart,
for volunteering to run the new store!**

Ornaments are [here!](#)

Order NOW, while supplies last and to ensure timely delivery.



FREE SHIPPING CODE: SHIPSCN2A

The new [SCN2A online store](https://shop.scn2a.org) is OPEN all the time!

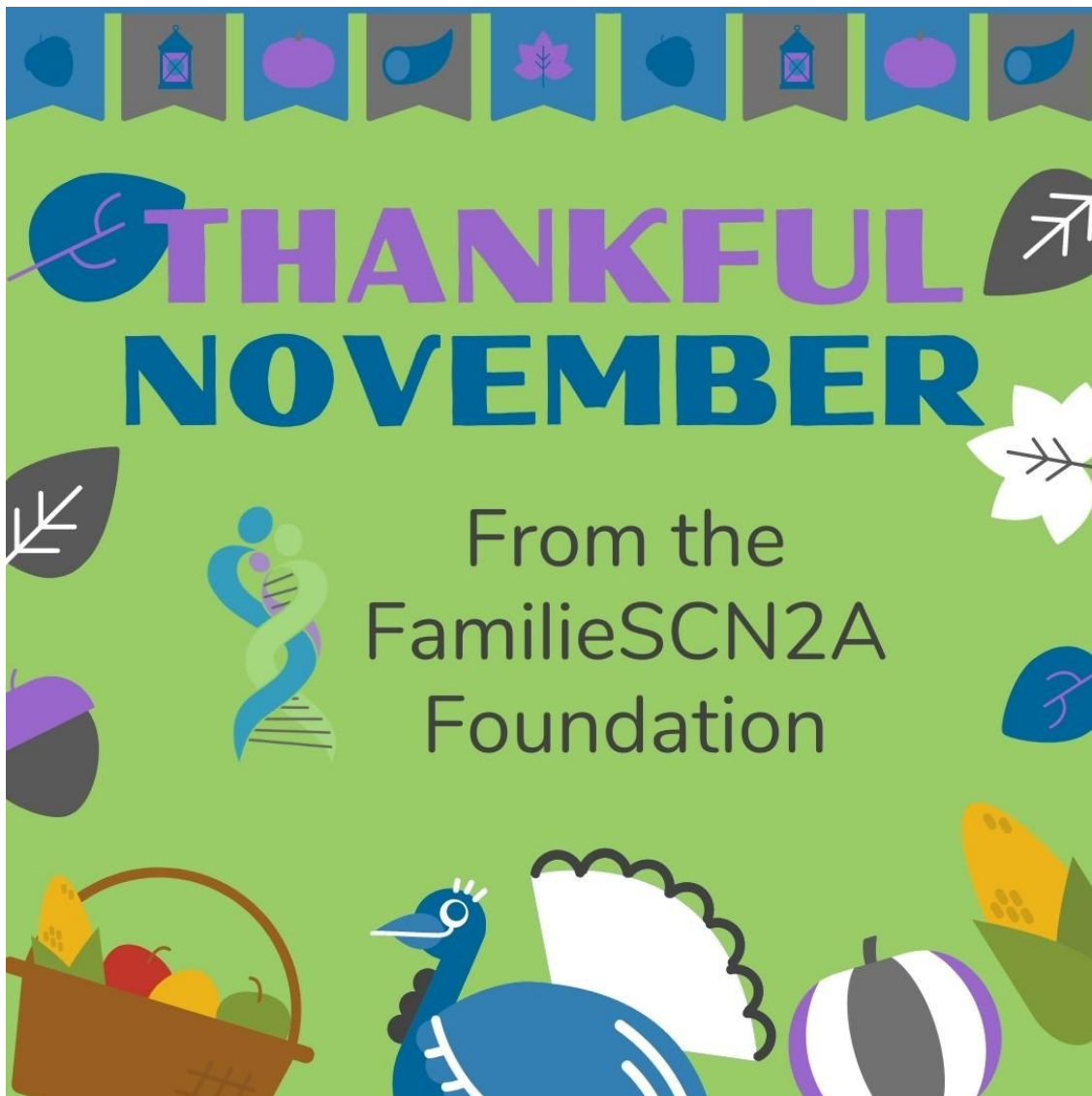
(Order before Dec 9 for Christmas delivery)



[ORDER 2022 CALENDARS HERE!](#)

These popular calendars featuring SCN2A warriors on their birthdays are not available in the FamilieSCN2A online store. (If you'd like to have your warrior included next year, [email us](#).) Big thanks to SCN2A Warrior Moms Amy Leuthner and Amanda Van Schoick for their labor of love on this project!





please give the gift of hope today

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