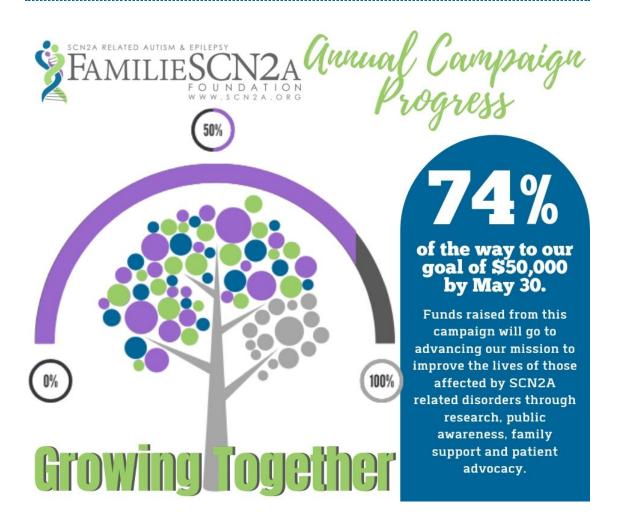


Welcome to our 1st Quarter Newsletter!
Check out what we have been up to...



The Annual Campaign started off with a bang! We know that this is a crazy time around the world but we need YOUR help to reach the goal. Please take a minute to share our <u>Annual Campaign Letter</u> with friends and family. The need for assistance is greater than ever for our community right now. Read on for other ways we are working to help...



Supporting the global SCN2A community is a key part of our mission, so we have created this new emergency program for families in great need. Round 1 is open and will close on Monday, April 20, 2020. Based on financial resources, and the course of the COVID-19 pandemic, the Foundation will potentially award additional relief grants. <u>Apply here</u>. We greatly appreciate our many donors who make this aid possible!



Thanks to the early success of our Annual Campaign, we are pleased to report that the Patient Assistance Grant is fully funded and the application process is open!

In an effort to help connect our community we will be hosting a series of virtual "Community Chats" via Zoom. Families affected by SCN2A are invited to join for informal conversation with others who understand. These calls are not intended to provide medical advice. The next Chat is scheduled for Friday, March 27 9:00 am EDT with Call Leader Catalina Betancur. Please check social media posts or email community.support@scn2a.org for the Zoom link and future Chats.





This 2-day seminar will be a familyfocused gathering, where SCN2A
families can come together to learn
about SCN2A-related topics, participate
in multiple research opportunities, and
spend some time with others who
share your experiences.

[A decision on postponing will be announced by June 1.

We ask that you please register anyway so that we can gauge interest. Families: email info@scn2a.org to request a code to waive fee]

## Register

In case you missed our previous email, here is The FamilieSCN2A Foundation Response to COVID-19.

In addition, here's a link to an informative webinar <u>"Protecting Medically Complex and/or Immune-Suppressed Children with Epilepsy from COVID-19"</u> brought to you courtesy of our partnership in <u>DEE-P Connections</u> along with the <u>International Foundation for CDKL5 Research</u> (IFCR) and <u>The Epilepsy</u> Foundation of America.



Families are welcome to join our private Facebook groups

RESEARCH

in the news

Watch FamilieSCN2A Board Member, Amy Kozsuch, raise SCN2A awareness on her local TV news for Rare Disease Day!

"Seeing Through a Forest of SCN2A Gene Variation" (Michele Solis, Simons <u>SFARI</u>, Feb. 19, 2020)

"Alternative Splicing Potentiates Dysfunction of Early-Onset Epileptic Encephalopathy SCN2A Variants"

(Thompson, Ben-Shalom, Bender & George,

Journal of General Physiology, Jan. 29, 2020)



## **HELP US SPREAD AWARENESS!**

The SCN2A apparel shop year is open year round (click on the photo). Sizes range from youth to 3XL depending on the product you order. Apparel ships internationally too. Remember to post a photo in your awesome new shirt!





To our scientific and medical community, to all the families who celebrated International SCN2A Awareness Day, to those who have sent Annual Campaign emails, and to our wonderful donors: We want you to know that we are grateful for every kindness and every action that enables us to further our vision of effective treatments and a cure for SCN2A Related Disorders.

- The FamilieSCN2A Board of Directors

## Our mailing address is:

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

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