SCN2A RELATED AUTISM & EPILEPSY
FAMILIESCN2A
FOUNDATION
WWW.SCN2A.ORG

Who or what is the FamilieSCN2A Foundation?

The FamilieSCN2A Foundation is an organization created by parents of children diagnosed with Epilepsy and Autism as a result of a change in the SCN2A gene.

Are you curious who is behind the scenes at the FamilieSCN2A Foundation? The foundation is run entirely by unpaid volunteers. All FamilieSCN2A Board Members are unpaid volunteers each playing a key role in the success of working toward our mission *to improve the lives of those affected by SCN2A related disorders through research, public awareness, family support and patient advocacy*.

Please take a minute to check out our amazing Board, Committee and Scientific Advisory Board Members: https://www.scn2a.org/board.html

REGISTRATION IS NOW OPEN!

Register now for the 3rd SCN2A Family & Professional Conference hosted by the FamilieSCN2A Foundation, Bernier Lab, and the Center on Human Development and Disability at University of Washington.

Who typically attends this conference?

The audience is typically made up of SCN2A family members and professionals who work with or have an interest in SCN2A or sodium ion channels.

Can children attend the conference?

Yes, however, please note children are not permitted in the conference room, and formal childcare is not included. There will be a hospitality room for children with SCN2A and their siblings who are accompanied by a parent or caregiver.

Register Now

Need Financial Help Getting To The SCN2A Family & Professional Conference?

We've got you covered! Scholarships are available for families with a child diagnosed with SCN2A. A copy of their genetic report must be emailed to info@scn2a.org at the time of the application. Scholarships may cover up to 2 nights North American / 3 nights International in the conference hotel, one family registration fee, and/or flight assistance (up to $200 North American / $500 International families.) Application deadline is **April 30, 2019.** You will be notified whether your application has been selected for sponsorship between May 1st - May 8th, 2019.

North America Scholarship Application

International Scholarship Application

Research:

The TIGER Study is an on-going research opportunity at the University of Washington. We have worked with the team to modify the assessments to allow our families to participate in conjunction with the SCN2A Family & Professional Conference. Available days will be August 1st - 5th (either AM or PM.) The researchers are able to schedule **10** families for this and it will be first come, first served, so please consider this opportunity and plan ahead.

A note from the research team:

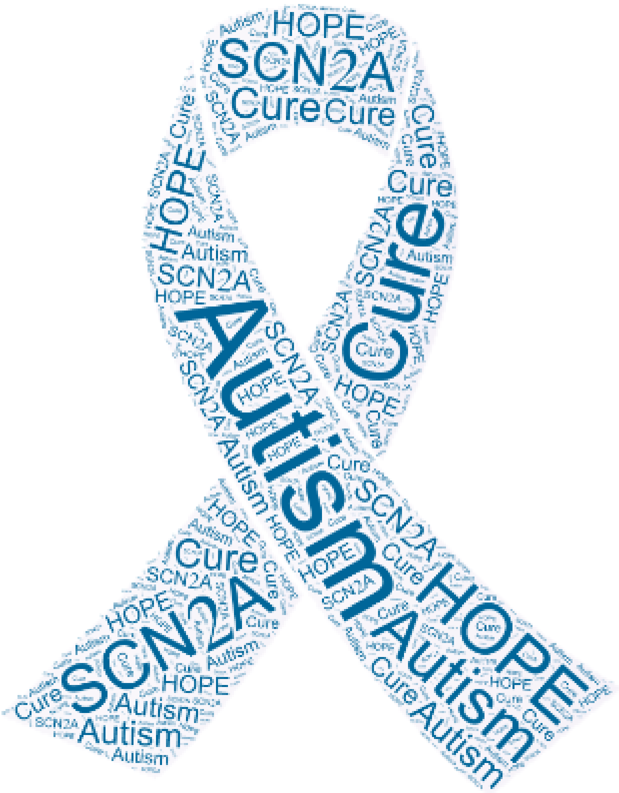
The TIGER Study stands for The Investigation of Genetic Exome Research. The goal of the study is to explore how different genetic events impact behavior and development in individuals **ages 4 and up**. As part of our assessment, we will complete two gold-standard measures to test for Autism Spectrum Disorder. If possible, we would want your child and both biological parents to participate. Since this study will take place around the SCN2A Family & Professional Conference it will involve a reduced battery of tests that will only take half a day.

The study involves:
1) Cognitive testing (IQ, other standardized tests) for your child and both biological parents
2) Additional language skills testing for your child and both biological parents
3) Blood draw for your child and both biological parents
4) EEG for your child , if she/he's able, and both biological parents
5) 2D photos of your child and both biological parents
6) Height, weight, head circumference measurements for your child and both biological parents
7) Questionnaires for you to fill out
8) A few phone interviews before the visit to learn about your child medical history and current abilities

We are able to pay for airfare for both parents and one child, a hotel for two nights, and provide a per diem to cover the expense of your food for the child, as well as give you $100 compensation for your family's participation in the study. We also provide a report after the visit is completed with all of your child's results so you will have that for your records.

Lastly, we also try and keep all of our families as up to date on the current research that is coming out, whether from our lab or other labs also studying these rare genetic events. We send out newsletters from our lab as well as e-blasts with what is going on to keep you in the loop with the current information. We can also connect you to other families that have the same event as well, providing that you're both interested in connecting with each other.

To inquire about registering email: brennab2@uw.edu



Did you know a study in 2017 showed the top autism gene may alter sensory perception.

Q: What is that top autism gene?
A: SCN2A

As stated in an article published in Spectrum News by Jessica Wright, SCN2A codes for a channel that allows sodium ions to traverse neurons. In the past two years, it has emerged as one of the genes mostly strongly linked to autism. Following a study of 10 children with SCN2A, researchers were able to show that mutations that impair the activity of the ion channel lead to autism, whereas those that enhance its activity lead to infantile epilepsy.

To read the full article published by Jessica Wright, April 2018 follow this link: https://www.spectrumnews.org/news/top-autism-gene-may-alter-sensory-perception/

SIMONS VIP CONNECT

Did you know Simons VIP is the official, central SCN2A registry? As a foundation we partnered with Simons VIP years ago to collect longitudinal data that defines the disorder. Simons makes the de-identifiable data available to qualified researchers around the world to expedite finding treatments and a CURE. The more researchers looking at this disorder from multiple angles the better. Is your family included? Start the process today and Simons even rewards you for your time and effort with gift cards!

https://simonsvipconnect.org/

#bepartofthecure #rare #SCN2A #CureSCN2A

For Professionals:

The FamilieSCN2A Foundation, together with Simons VIP, hosts a bi-monthly professionals only collaboration call. These calls have been an invaluable resource to our research and clinician community. Our next call is scheduled for March 20th at 3 pm ET. Any professional with an interest in SCN2A is welcome to join this call. If you would like to be added to the call, please email research@scn2a.org

Did you know we have a page dedicated to Professionals on our web site? Check it out: http://www.scn2a.org/professionals.html

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How You Can Help!

The FamilieSCN2A Foundation goes **MOBILE** to Collect Spare Change from your everyday purchases!

Download the Coin Up App http://bit.ly/GetCoinUpiOS or http://bit.ly/GetCoinUpAndroid to support our mission to improve the lives of those affected by SCN2A related disorders through research, public awareness, family support and patient advocacy.

DONATE YOUR VEHICLE AND MAKE A DIFFERENCE!

Rather than let costly vehicle repairs weigh you down, lighten your load and donate it to the FamilieSCN2A Foundation. The process is easy, the pick-up is free, and your gift is tax-deductible! Donate your car, truck or other vehicle today. Call 1-855-500-RIDE or give online at DONATE.

Here's a super easy way to help us raise money toward finding a cure: shop with AmazonSmile and list The FamilieSCN2A Foundation as the organization you'd like to support.

smile.amazon.com/ch/47-3169795

#AmazonSmile #StartWithaSmile

For Families:

Autism Awareness Day is April 2nd. For so many, Autism, is daily life and not just a single day or month. During April we will be featuring our T**ake 5; Give $5** campaign to share facts about Autism, raise awareness, and raise funds to support research and families in the SCN2A community affected by this diagnosis. Stayed tuned on social media for those informative posts to share with your family and friends!

HELP US SPREAD AWARENESS!
Have you seen our SCN2A apparel? You can now order from our apparel shop year round! The apparel comes is sizes ranging from youth to 3XL depending on the product you order. Apparel ships internationally too! Click on the photo to bring you to our shop. Thank you for supporting the FamilieSCN2A Foundation and helping us get one step closer to effective treatments and a CURE! https://www.bonfire.com/store/scn2a-awareness-apparel/

JOIN OUR BIRTHDAY CLUB!

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

[Click Here to sign up!](#)

Building A Community: SCN2A Family Event Grants

Have you heard about the FamilieSCN2A Foundation Family Event Grant? This grant was created to intentionally bring SCN2A families together to cultivate a stronger community and deepen relationships. It is our intention that this grant program will give ownership to our SCN2A families, allowing them to create and coordinate an SCN2A Family Event of their choosing, paid for by the

FamilieSCN2A Foundation. For more information please contact community.support@scn2a.org

A New Faces of SCN2A Video Project Is Underway!

We are in the process of creating an updated Faces of SCN2A video which will premier at the Family & Professional Conference August 1st – 3rd. We need your help! If you would like to participate in this project please send the following to marketing@scn2a.org no later than **April 30th**:

1. Full size photo of your child(ren) who have been diagnosed with SCN2A
2. A photo of your *favorite* piece of artwork your child has created. It can be any media, just snap a photo of it and send it to us!
3. A current family photo
4. Your child's variant (completely optional)

Please note in your email:
“I, (state your name) give permission to the FamilieSCN2A Foundation to use these photos on their website, social media outlets and in any marketing materials.”

To view the 2017 Faces of SCN2A video scroll down to the grey section of our video page:https://www.scn2a.org/videos.html

Questions? Contact Kristy Kargel at marketing@scn2a.org

CONNECT I SUPPORT I RESEARCH
Putting SCN2A on the map!

Our mailing address is:
P.O. Box 82, East Longmeadow, MA 01028