SCN2A RELATED AUTISM & EPILEPSY

FAMILIESCN2A FOUNDATION

WWW.SCN2A.ORG

Guess Who's Having A BIRTHDAY!

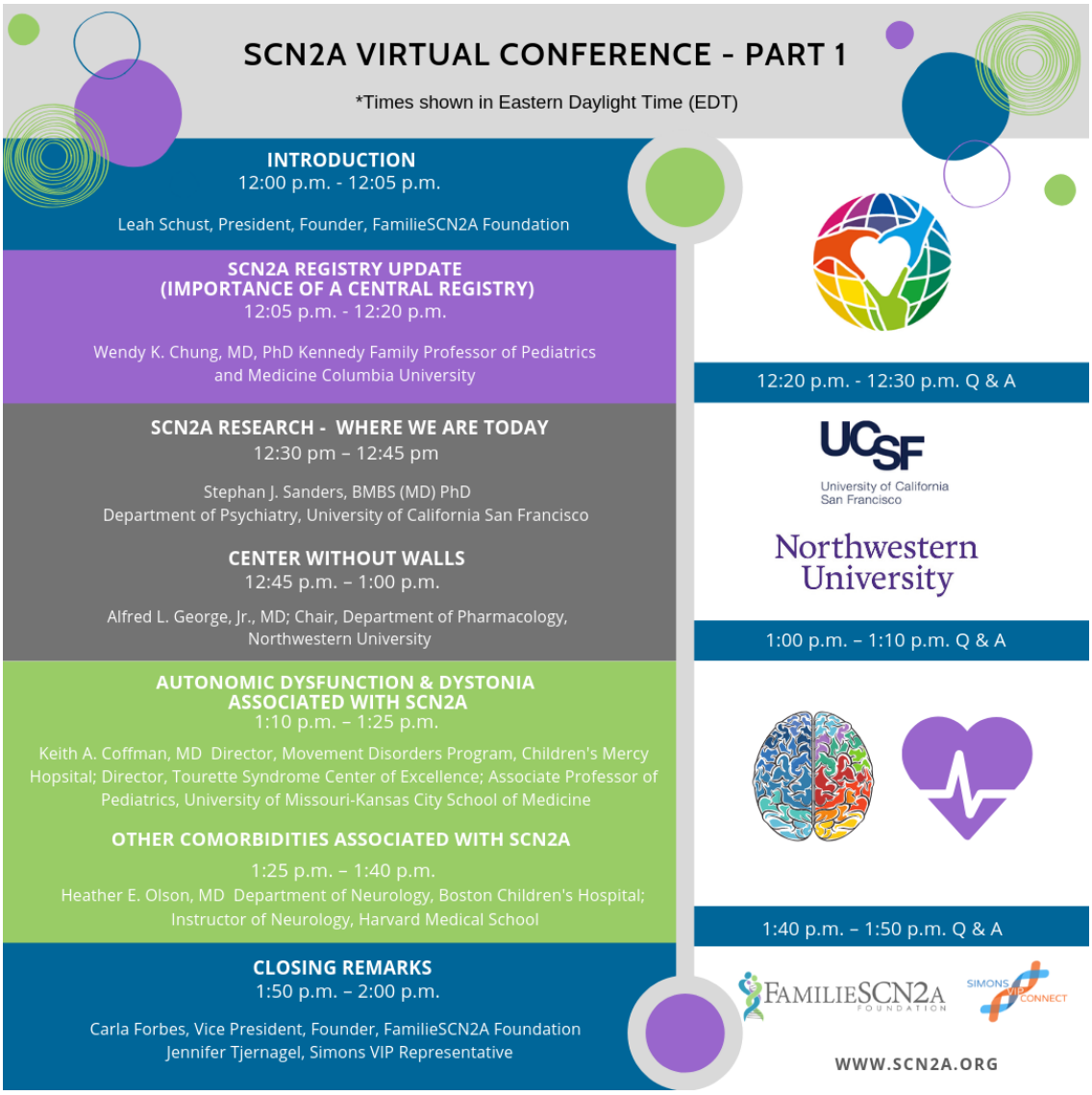
October marks the **THIRD** year the FamilieSCN2A Foundation has been officially incorporated as a nonprofit organization [also known by the IRS designation 501(c)(3)].

To celebrate, throughout the month of October, we will be blasting social media with fundraising and research updates including introducing our Scientific Advisory Board (SAB) members. Be on the lookout for more from us during the entire month of October!

Upcoming SCN2A Events: Saturday October 6, 2018

The SCN2A Virtual Conference is a two part series hosted by the FamilieSCN2A Foundation and Simons VIP Connect. The focus is on educating families, physicians, and other community members on the advancements made in the field. We thank Simons VIP Connect for their partnership and commitment to all genetic research, including SCN2A.

Part One on **October 6, 2018** will spotlight the latest exciting discoveries in basic research, drug development and improvements in clinical treatments. Our presenters include Alfred L. George, Jr., MD; Keith A. Coffman, MD; Stephan J. Sanders, BMBS (MD) PhD; Wendy K. Chung, MD, PhD; and Heather E. Olson, MD.



Register Here

SAVE THE DATE: Wednesday November 7, 2018
SCN2A Virtual Family Meeting: **Part Two**

We Need Your Help: Calling All Families & Friends of Those Affected By SCN2A

Coming in October, we will be providing a new fundraising platform, powered by Classy, which will make it easy for you to help raise money to support our efforts of funding SCN2A specific research. Research is key to better treatments and a faster cure, but it is very expensive.

Our goal is to raise an additional $50,000 by year-end, specifically to sponsor research grants which will be awarded in 2019.

We will provide a template, guidelines, and individual assistance to help you set up your own fundraising page in Classy. Through this platform you will be able to share your child's story to help raise funds in a variety of creative ways through simple crowdfunding, peer-to-peer email, social media campaigns or even for hosting a specific event. The possibilities for fundraising are limited only by your imagination! Some suggestions are to hold an office football pool, host a paint party or a wine tasting, ask for donations in lieu of birthday gifts, set up a link on your business page so customers can donate money to support a good cause and more. In addition, many boutique

businesses and even restaurants have options for hosting fundraising events. We can't wait to see what you come up with!

The season of giving is right around the corner and we want to be fully prepared for all the generosity on Giving Tuesday (in the U.S.), as well as everyone's mad dash to make donations before the end of the tax year. Check your email and social media outlets for updates from us on how you can actively help us reach our goal of $50,000 raised for SCN2A related research. Stay tuned...

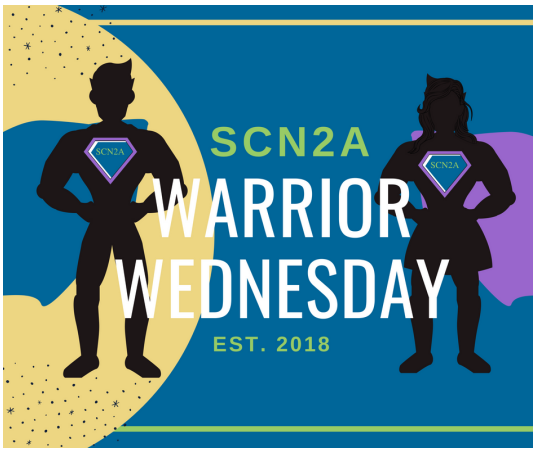
Check out this SCN2A related article: "Analysis of sequences pegs 99 top autism genes"

In the article linked to below, the team at UCSF shows the results of testing 35,000 DNA sequences in people with Autism along with their family members. New genes were discovered from this testing; however, SCN2A continues to be the top single gene known to cause Autism.

At UCSF, Sanders' and Bender's labs are leading the way in discovering genetic causes of Autism as well as treatment options. Their valuable work is cutting edge. The FamilieSCN2A Foundation supports their work by co-funding Joon An, a postdoctoral associate in Sanders' lab. We appreciate their collaboration and willingness to share pre-published work such as this in order to expedite research around the world.

Recently, Leah Schust, President of the FamilieSCN2A Foundation represented the SCN2A community during a visit to the labs. Leah says, “the team at UCSF uses an innovative approach with cutting edge technology and passionate team members. We are lucky to have such committed researchers working around the clock to help find a cure for our children.”

Click to Read Article



Warrior Wednesdays

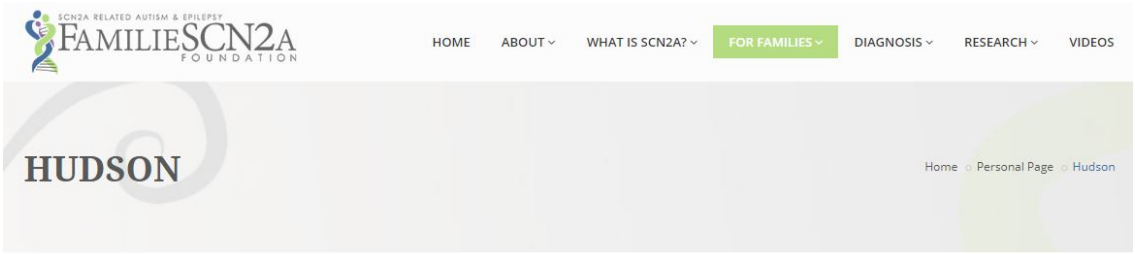
On Warrior Wednesdays, we welcome families to post pictures of their SCN2A Warrior on our PRIVATE Facebook Discussion page. Families can share a story about how they are "Fighting On." These stories help us connect with one another as a community. Each week we also feature a Warrior's story on our public social media pages to help raise awareness. **#SCN2A #CureSCN2A #SCN2AWarriorWednesday**

Building a Community: SCN2A Family Event Grants

The FamilieSCN2A Foundation is proud to introduce to our community the SCN2A Family Event Grant. This 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

NEW: Create A Personal 'Awareness Page' For Your Child!

Raising awareness is a critical step in working toward a cure for SCN2A. Therefore, we have created a way to feature your child AND raise awareness. We are excited to announce this awesome new part of our web site that allows you to share a little about your child's likes, dislikes, personality, or anything you wish. The hope is for you to share your child's story with family, friends or whomever you choose to help raise awareness about SCN2A Related Autism and Epilepsy. To request your child's page creation just fill in the form online. Once submitted, you will receive a link to your child's Personal Page within two weeks of it being processed. Check out Hudson's personal page below to help inspire you!



De Novo Nonsense Mutation

Hi, I'm Hudson.

> *I like riding on my jeep, swinging, bubbles, books, puzzles, singing songs like "Wheels on the Bus", airplanes, anything that spins, and I love to EAT!*

I'm in Pre-School and live at home with Mom and Dad in Texas, United States.

I had a pretty normal first 23 months of life. I was talking, playing, laughing and being a normal toddler. On July 4th, 2016, I had a seizure that was the first of many. I now live with daily seizures (tonic-clonic, myo-clonic that typically present with sleep) and am working very hard to gain back my lost function and abilities. I was diagnosed with a rare form of epilepsy caused by a gene mutation on the SCN2a sodium channel. I have also recently been diagnosed with autism. Currently there is no proven cure or treatment.

I have a diagnosis of Refractory Epilepsy and Autism. As a family we are learning how to cope with epilepsy and autism, and continue to Hope and Pray for a Cure!

$ Make a Donation | Shop With Us on Amazon | Shop With Us on iGive.com

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 a birthday card on their birthday and possibly even a little extra something special too! Also, 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).
So what are you waiting for? Sign up today!

Click Here to sign up!

CONNECT I SUPPORT I RESEARCH

Putting SCN2A on the map!

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