

A MESSAGE FROM THE FAMILIESCN2A FOUNDER & PRESIDENT:

Thanks to you (our generous supporters and donors) more than 30 children who suffer from a change on the SCN2A gene, received a card and acknowledgement on their birthday to let them know they are celebrated! Many moms and dads felt the love and support of a community when they received a gift card to get a real cup of coffee at the hospital café. If you have ever been bedside to a child in critical condition for days on end, you know how valued a real cup of coffee is!

In addition, we launched a new family support grant program. The purpose of this grant is to fund families affected by SCN2A so they may gather together without the worry of cost. Through the SCN2A Family Event Grant many families (both domestic and international) were able to meet one another and spend time sharing experiences. To be able to share hugs, tears and laughter with others who truly understand their journey is **priceless** and a gift that keeps on giving! On behalf of these amazing warrior families, thank you for these gifts and thank you for all your continued support.

2019 will be the year of **RESEARCH.** There are so many advances being made in science and each advance takes us steps closer to effective treatments and a CURE. Basic science has yielded a very clear understanding of how changes in the SCN2A gene lead to disease and this has enticed multiple drug discovery groups to start investigating therapeutics. Many of these projects are already in the pre-clinical stage and expect to be trialing in patients within the next couple of years. We are proud to say that we have achieved our goal of *putting SCN2A on the map* and are well on our way to finding a cure.

Sadly, this cure will be too late for many of our children. Our small community has suffered great loss this year. The strength and resilience these warrior children show even through their last days will continue to drive me and the other Board members to fight harder. We simply can't do it without you. Your support makes a real, lasting impact in the lives of all of these families.

We are thrilled to report we exceeded our goal for our 2018 Year-end Campaign of raising \$50,000! The funds raised will support funding SCN2A related research in 2019. Help us hit our extended goal of \$75,000 by year-end and know that you are contributing to helping save a child diagnosed with SCN2A related disorders.

Thank you for your continued support and friendship.

With gratitude,



Leah Schust Founding President, FamilieSCN2A Foundation Chair of Research Committee

DONATE NOW!

Parent Testimonial:

"With the Foundation's hard work and the research they support, we were able to finally find an anti-epileptic drug that worked for Joel. This group has a better understanding than even our doctors have here where we live. Everyone works so hard to keep this Foundation going, discovering new things all the time. For the foundation we are truly grateful. Thank you everyone."



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