As you may know, Maddie has been diagnosed with a change in the gene SCN2A which can cause autism and/or epilepsy. The FamilieSCN2A Foundation has been a lifeline to our family where we have been welcomed like family into a community of others battling the same disease. The Foundation is an organization created by parents of children diagnosed with SCN2A Disorders. Their mission is to improve the lives of those affected by SCN2A Disorders through research, public awareness, family support and patient advocacy.

Sadly, not all of the kids with SCN2A Disorders survive childhood. We need a cure now, not only for Maddie, but for all the children currently diagnosed with SCN2A Disorders and those who will be in the future. Please consider making a donation on behalf of Maddie today at www.scn2a.org. Your gift will have a meaningful and lasting impact on so many lives. Thank you!





Dear Friend,

In October of this year, the FamilieSCN2A Foundation has the pleasure of celebrating our five-year anniversary!

What started out as an online support system for parents and caretakers of children with SCN2A Disorders has now grown into an accomplished 501c3 organization that is making great strides in the rare disease community and beyond.

In the past five years, we have dedicated over 80% of the funds we've raised to research to find a cure for SCN2A Disorders.

Changes in the SCN2A gene have recently been recognized as the third most common cause of Autism and fifth most common cause of early onset Epilepsy. Understanding the cause of these devastating disorders has inspired researchers to find new treatments.

There are currently five promising treatments in the pipeline. The Foundation is supporting the work and although all are still in pre-clinical stages of development, we are confident that our children will soon have the opportunity to try these lifesaving treatments. Three of these treatments will aim at correcting the gene, the others are aimed at alleviating the associated symptoms of the disease to improve the quality of life of the patients.

We are hopeful that through our continued dedicated research funding we will not only find a cure for SCN2A Disorders, but also continue our journey to help the larger Autism and Epilepsy communities.

As we look towards the future, we are mindful that research is at the forefront of our mission. However, we know that there are other areas of our community that deserve and are in need of funding.

As a testament to the milestones we have made, we are excited to announce that in honor of our fifth anniversary, we are launching our Patient Assistance Grant program!

Through this program, the foundation will set aside a limited amount of funds each year to offer grants to patients with SCN2A Disorders for necessary medical equipment, therapy devices, and educational aids associated with the condition that are not covered through private insurance or alternative assistance programs.

While there has been great progress to date, it is critical that we continue to grow our dedicated research pipeline and offer the Patient Assistance Grant program to families who desperately need these lifesaving opportunities.



In honor of our five-year anniversary, please consider making a thoughtful donation in support of our foundation as we continue to help children and families with SCN2A Disorders fight through this disease.

Any size donation truly does make an impact. IF you are able to donate \$5, \$50, \$500 or \$5,000 today, you are moving our mission forward through research and directly helping families who struggle daily through this journey. Please <u>click here</u> to make a thoughtful donation.

Gratefully,

Carla Forbes
President, Co-Founder
FamilieSCN2A Foundation

Leah Schust Myers
Executive Director, Co-Founder & Research Chair
FamilieSCN2A Foundation

Tax ID 47-3169795.

P.O.Box 82, East Longmeadow, MA, 01028 | info@scn2a.org

Copyright © 2020 The FamilieSCN2A Foundation, All rights reserved.

For more information, please visit our website at www.scn2a.org

Our mailing address is:

The FamilieSCN2A Foundation PO Box 82 East Longmeadow, MA 01028-0082

Add us to your address book

Want to change how you receive these emails? You can <u>update your preferences</u> or <u>unsubscribe from this list</u>.