



Growing Together: Then and Now

Dear Friends,

The FamilieSCN2A Foundation was founded by parents of children suffering from a change in the SCN2A gene. When their children were diagnosed in 2012, there was no group, no support, no useful information to be found online and no cure in sight. What began as an effort to create a safe place for families and caregivers of children with SCN2A Disorders to connect, quickly led to something much bigger and more impactful than even they imagined. Tired of being “the only ones” and being told SCN2A was too rare to study, we knew that supporting research in addition to the families was critical. As families joined the group from all over the globe, their first goal was quickly achieved: Get SCN2A on the map.

I am proud to be one of the founding members, to serve the community and to have had the privilege to witness the many amazing accomplishments our community has achieved over the last 4 years. Our small but fierce global family support group has grown to over 700 members. Through our programs (the birthday club, family meet-up grants, and educational conferences and webinars), we have shown the community that they are not alone and that there is real hope for our children’s future. Through letters of support, seed grants, and collaboration, we have made a huge impact on growing the scientific field from basic research to SCN2A specific therapeutics.

There is still much work to be done, but the moral of the story is that together we are stronger. Together we can accomplish even more. Nothing is done alone. It takes a community, a family. The fact that

Families is incorporated into our Foundation's name is a constant reminder that this disease affects more than the patient, it affects everyone involved and it will take everyone to cure it. Our family consists of anyone who has ever hosted or donated to a fundraiser, attended or sponsored an event, shared a social media post, or reached a hand out to a struggling parent. It includes our patient community, clinicians, researchers, industry partners and our colleagues in other rare disease nonprofit organizations. Each family member plays an essential role in working towards our vision to find effective treatments and a cure for SCN2A Disorders.

Thank you for being part of our family this year!

Carla Forbes

President, FamilieSCN2A Foundation

Donate for a Cure

GROWING TOGETHER



Exciting things are ahead in 2020!
To stay informed, [subscribe to our newsletter](#)

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 update your preferences or unsubscribe from this list.