Join Our Community

Join the SCN8A Families Support Group

This group has been set up for parents and caregivers to interact with other families via Facebook or to receive current information via email. Email to join:

supportgroup@thecutesyndrome.com

Attend our annual Clinician, Researcher, and Family Gathering

This is an opportunity for our SCN8A families to be empowered with vital information about their children's health; clinicians to learn how to better serve their SCN8A patients; and researchers to establish collaborations inspired by the SCN8A patients and their families.

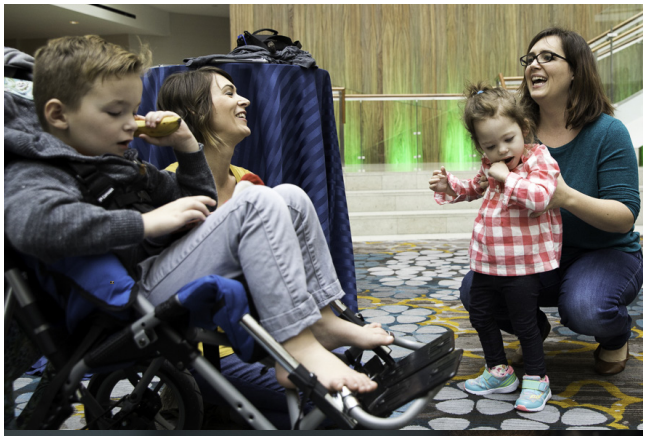
Contact Us

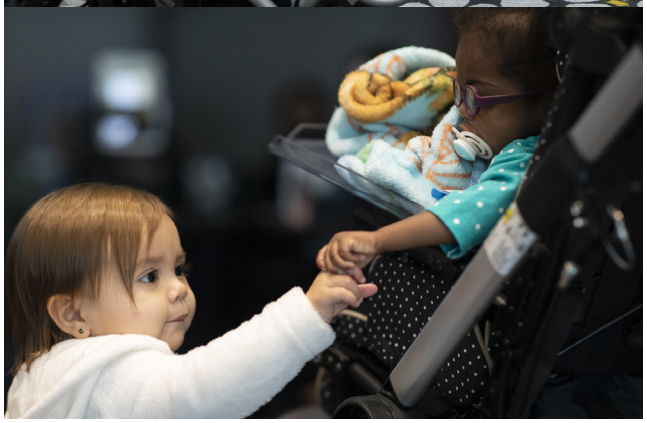
If you are interested in volunteering, organizing fundraisers, or sponsorship opportunities, contact Kacie Craig:

executivedirector@thecutesyndrome.com

Find us on Facebook and Instagram

@thecutesyndrome

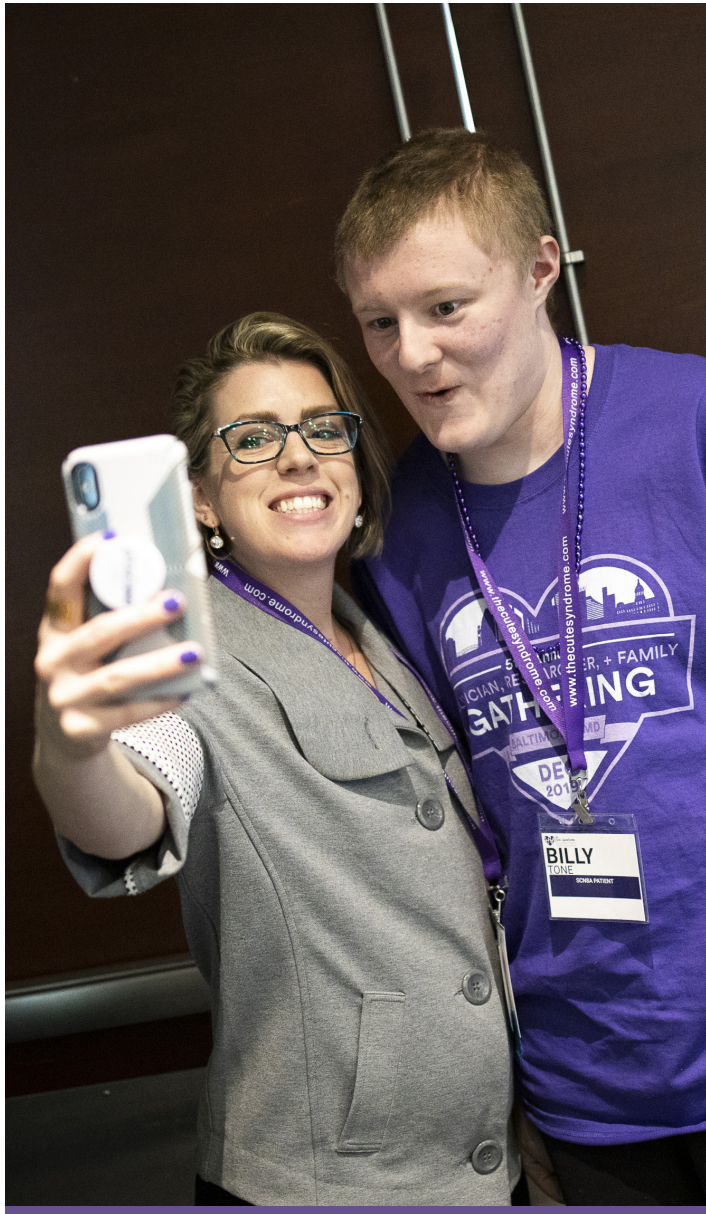




Photos by: Ryan Collerd

The Cute Syndrome© FOUNDATION

www.TheCuteSyndrome.com



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About SCN8A

SCN8A is a gene that affects the way brain cells function. Variations in this gene can disrupt the normal function and lead to struggles ranging from mild behavioral or movement disorders to severe developmental and cognitive delays.

Epilepsy is a hallmark of this disorder, with the majority of patients experiencing seizures early in life. Problematic variants in SCN8A are very rare and most commonly sporadic, not inherited.

SCN8A currently affects less than 1 in 15,000,000 worldwide.

All epilepsy subgroups exhibit better seizure control with ***sodium channel blockers***[1]

The median age of seizure onset is ***4 months***[2]

<5%

of patients with SCN8A variants ***never*** experience seizures[3]

Greater than 3/4 of patients with SCN8A variants experience ***delayed neurodevelopment***[4]

[1] Gardella E, Møller RS. *Phenotypic and genetic spectrum of SCN8A-related disorders, treatment options, and outcomes.* Epilepsia. 2019;60 Suppl 3:S77-S85. doi:10.1111/epi.16319

[2] Schreiber JM, Tochen L, Brown M, et al. *A multi-disciplinary clinic for SCN8A-related epilepsy.* Epilepsy Res. 2020;159:106261. doi:10.1016/j.eplepsyres.2019.106261

[3] Encinas AC, Moore IKM, Watkins JC, Hammer MF. *Influence of age at seizure onset on the acquisition of neurodevelopmental skills in an SCN8A cohort.* Epilepsia. 2019;60(8):1711-1720. doi:10.1111/epi.16288

[4] Encinas AC, Moore IKM, Watkins JC, Hammer MF. *Influence of age at seizure onset on the acquisition of neurodevelopmental skills in an SCN8A cohort.* Epilepsia. 2019;60(8):1711-1720. doi:10.1111/epi.16288

About TCSF

Our Mission

The Cute Syndrome Foundation mission is to raise awareness of SCN8A mutations, fund the dedicated and talented scientists researching SCN8A, and support the families around the world who are affected by this disorder.

Our History

The Cute Syndrome was a term used by the family of Esmé Savoie to describe the suite of symptoms that she had since birth that are now presumed to be caused by as many as four separate genetic mutations. However, the Cute Syndrome has evolved into something more than just Esmé's condition—it is now the name of the foundation created by Esmé's mom, Hillary Savoie, that represents an international community affected by SCN8A developmental and epileptic encephalopathies.

Our Vision

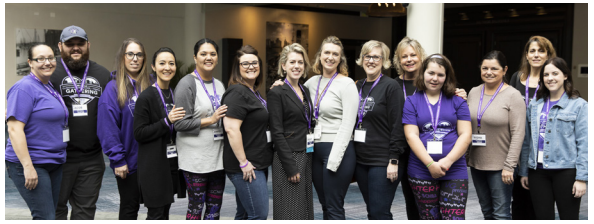
The Cute Syndrome Foundation's goals are to:

- Support families
- Help clinicians standardize treatment
- Expand scientific knowledge of rare genetic mutations
- Increase public knowledge of SCN8A mutations as well as rare genetic mutations and pediatric epilepsies

Get Involved

Volunteer

The Cute Syndrome Foundation is a 100% volunteer organization made up of parents and family members. We are always looking for someone with special skills to help us continue our quest to improve the lives of our community.



Donate

Visit **thecutesyndrome.com/donate** to make a one-time or subscription donation. Your support will help us in our mission to fund research, facilitate treatment, and raise awareness of SCN8A Epilepsy.

Follow us on Social Media

Learn more about our SCN8A Warriors, our Annual Clinician, Researcher, and Family Gathering, as well as our annual SCN8A Awareness Day. Share our posts to spread awareness. Get updated on current research and treatments for our community.

@thecutesyndrome