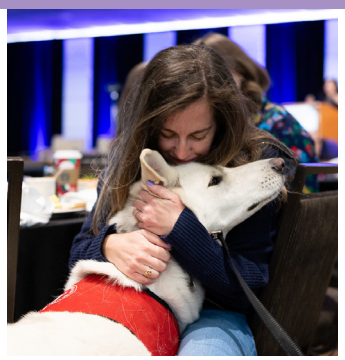
The Cute Syndrome© FOUNDATION
TheCuteSyndrome.com

2024 IMPACT REPORT










Stories of Strength.
Science with Heart.

Celebrating a year of powerful community, courageous progress, and unwavering hope.

Dear friends and supporters,

2024 was a year of connection, courage, and progress. From the hospital rooms to the conference halls, and across every Zoom meeting, support group, and research collaboration—you were with us.

This year, we gathered. We grieved. We celebrated small wins and took bold steps toward bigger ones. With every story shared and every dollar donated, you helped us support families facing SCN8A and rare epilepsies with the compassion, resources, and fierce advocacy they deserve.

We are proud to share this 2024 Impact Report—not just as a summary of what we accomplished, but as a reflection of the community that makes this work possible.

Thank you for being part of this story.

With love and gratitude,



Kacie Craig
Executive Director

16
CONNOR JAMES SMITH PATIENT ASSISTANCE GRANTS
awarded, totalling nearly $40,000.

3
CUTE CONNECTIONS
family meetup events funded.

$25,000
IN DR. MANDY HARRIS TRAVEL GRANTS
awarded for the Annual Gathering.

185
ANNUAL GATHERING
virtual and in-person attendees.

13
conferences, speaking opportunities, and advocacy events attended.

204
PARTICIPANTS
in our global Virtual Race event.

8
FAMILY EDUCATION
webinars produced.

545 FAMILIES
54 COUNTRIES
43 U.S. STATES
represented in our SCN8A family support group.





The Power of Gathering: **Celebrating 10 Years of Connection at the SCN8A Gathering**

In 2024, The Cute Syndrome Foundation marked a powerful milestone: our 10th Annual SCN8A Clinician, Researcher, and Family Gathering. What began as a small meeting of determined families and researchers has grown into a globally recognized event—bringing together families, scientists, clinicians, and industry leaders from around the world.

Held in Los Angeles, this year's Gathering celebrated a decade of collaboration, discovery, and community. It was more than just an event. It was also a reminder of what we've built together, and what we're still building.





SCAN TO VIEW MORE PHOTOS FROM THE EVENT!











Family Day: **Where the Heart of Our Mission Lives**

Thanks to a generous grant from CarVal Investors, we were able to expand our programming for families with our most meaningful Family Day yet.

CLINICAL TRIAL INDUSTRY PANEL

Families heard directly from industry partners leading two SCN8A clinical trials, giving parents the chance to ask questions and better understand clinical trial phases, approval processes, and everything in between.

STORYTELLING TRAINING WITH KARA RYSKA

Families participated in a hands-on workshop to learn how to share their stories with confidence and purpose. These powerful narratives are now fueling our advocacy and awareness efforts online and beyond.

SEIZURE SAFETY & SUDEP AWARENESS WITH ROLAND WAGNER

Bereaved parent Roland Wagner courageously shared the story of his SCN8A angel, Bruno, while educating families on seizure safety, monitoring, and SUDEP. His powerful session provided critical knowledge, fostered connection, and honored Bruno's legacy by helping protect other children.

BREAKOUT SESSIONS WITH REAL IMPACT

Attendees had the opportunity to gather in smaller, tailored support sessions, including:

- A **Dad's Hangout Group** focused on the unique challenges and strengths of fatherhood in rare disease.
- A support group for caregivers with children who are challenged with **difficult-to-manage behaviors**
- The **Calm Toolbox: Strategies for Easing Anxiety** training to better equip caregivers with handling the day-to-day stresses of an SCN8A journey.

> *Being in the presence of this community and having the most knowledgeable resources at our fingertips was invaluable.* ***We left feeling like we have support and connection with those who truly understand and share our journey.*** *We hope to return and stay connected year after year."*
>
> ***—Carlie, SCN8A Warrior Lucie's Mom***



Research and Collaboration **in Real Time.**

The Gathering created a shared space for families, researchers, clinicians, and industry to come together around the science and treatment of SCN8A. During a dedicated evening session, attendees heard one industry presentation and six researcher and clinician talks, allowing families to engage directly with those advancing research and care. This collective experience grounded scientific progress in lived reality and strengthened collaboration across the SCN8A community.

> **For all the parents here...the personal impressions you share give so much fuel for us who are not living your lives. We are doing a pretty boring job, spending long hours every day behind desks or in labs, and just listening to your stories once a year fuels a lot of energy all year. I am really thankful for your sharing."**

Dennis Lal, PhD
Director of the Center for Neurogenetics at UTHealth Houston and 2024 Researcher CUTIE Award Winner

LOOKING BACK—AND FORWARD

The 2024 Gathering reminded us of how far we've come in ten years...and how much further we'll go, together. **With every new family welcomed and every researcher inspired, we move closer to a world where SCN8A is better understood, better treated, and better supported.**

2024 GATHERING BY THE NUMBERS

- **120+ attendees**
- **8 countries represented**
- **1 industry and 6 research presentations**
- **Countless connections made**

Family Stories: **Support in Action.**







Meeting families where they are—in moments that matter most.

Behind every grant, email, and Zoom call is a family doing their best to navigate the complexities of SCN8A. In 2024, The Cute Syndrome Foundation supported dozens of families across the globe—sometimes in moments of crisis, sometimes with a quiet gesture of encouragement, but always with care.

Thanks to our community of donors and partners, we were able to **provide urgent financial assistance**, **help families attend important gatherings**, and **offer comfort and connection** during life's most vulnerable moments.

Connor James Smith Patient Assistance Grant: **A Lifeline for Families.**

The Connor James Smith Patient Assistance Grant was created in honor of a beloved member of our community—and it continues to be a reflection of the compassion, strength, and joy he brought to the world. Through this fund and the support of the Smith Family, The Cute Syndrome Foundation offers **direct financial support** to families navigating the complex and costly realities of SCN8A.

In 2024, this grant helped families pay for:

- **Critical medical expenses** such as medications, therapy co-pays, and medical equipment
- **Travel costs to reach SCN8A specialists** for diagnosis and ongoing care
- **End-of-life support**, including funeral and burial expenses
- **Quality of life enhancements**—whether it was a favorite toy, a sensory swing, or an adaptive stroller that brought comfort and joy to a child



"We genuinely considered discontinuing a medication that was undoubtedly helping my son perform his best in school, secondary to an exorbitant out-of-pocket monthly prescription expense. We explored other options and came up empty-handed. The grant took that stress off completely. We could not be more thankful."

Ann
Wade's Mom

This grant doesn't just ease financial burdens. It reminds families that they are not alone, and that their child's life—*every bit of it*—matters.

Beyond Dollars: **Emotional and Practical Support.**

Sometimes support looks like funding. Other times, it's a late-night message, a resource shared, or a moment of solidarity in a caregiver support group.



In 2024, we:

- **Connected 73 families** to resources and peer support
- **Hosted 23** virtual support events and webinars

A GLOBAL COMMUNITY, ONE FAMILY AT A TIME

SCN8A is rare. But no family should feel isolated. Our goal is to make sure that every parent facing this diagnosis finds a hand to hold, resources to lean on, and a community ready to walk with them.



Cute **Connections.**

In September, **SCN8A Italia** hosted a Cute Connections family meetup at Camping Village I Tre Moschettilleri di Comacchio in Italy for **over 40 SCN8A family members.** The families spent rejuvenating time in nature enjoying music, outdoor activities, and being together as an SCN8A community. This event was funded in part by The Cute Syndrome Foundation's Cute Connections grant, which funds up to $2,000 in costs associated with organizing a regional meet up so SCN8A families can gather for fun and fellowship.

In addition to the Italy meet-up, TCSF funded past Cute Connections meetups in Midland, MI; San Antonio, TX; Nashville, TN; Atlanta, GA; Branson, MO; and Orlando, FL.

> "This year it was great to meet, share smiles and worries, have fun and be together. These rare moments ***help us not feel lonely*** and are ***an important enrichment for our lives.***"
>
> **Cinzia Scarcelli**
> SCN8A Italia Founder and Aron's Mom

Strengthening the SCN8A Voice **in Research and Drug Development.**

In 2024, TCSF ensured the SCN8A community was represented in critical research and treatment-development conversations.

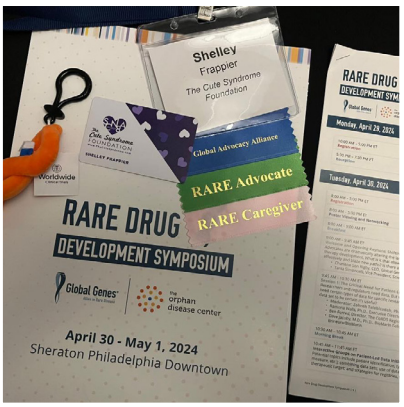
In August, Executive Director Kacie Craig participated in the first **SCN8A Research Roadmap meeting** hosted by the International SCN8A Alliance, helping shape future research priorities alongside global researchers, clinicians, and advocacy leaders.

In September, Kacie shared the family perspective at the Praxis Precision Medicines **DEEP Dive event** and, later that month, joined Board Secretary Marianne Sutcliffe at the Epilepsy Foundation's **Pipeline Conference** to engage with emerging therapies and foster collaboration across the epilepsy community.

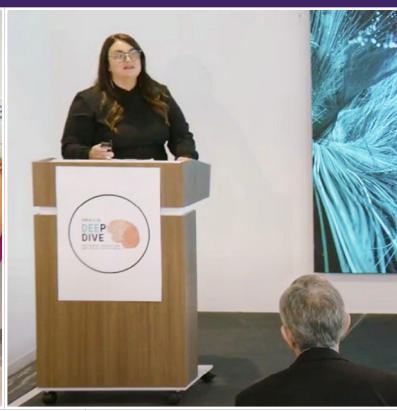
SCIENCE-FOCUSED CONFERENCES ATTENDED:

- **Gatlinburg Conference**
- **Global Genes Rare Drug Development Symposium**
- **SCN8A Alliance's SCN8A Research Roadmap meeting**
- **Praxis Precision Medicines DEEP Dive event**
- **Epilepsy Foundation's Epilepsy Pipeline Conference**
- **Global Genes Week in RARE event**
- **NORD Breakthrough Summit**
- **Partners Against Mortality in Epilepsy Conference**
- **American Epilepsy Society Annual Meeting**



















Raising Awareness. **Shifting Perspectives.**

INTERNATIONAL SCN8A AWARENESS DAY: #IfYouOnlyKnew

On February 9, TCSF marked International SCN8A Awareness Day with the #IfYouOnlyKnew campaign, highlighting the often unseen realities of living with SCN8A-related disorders.

Throughout February, TCSF shared reflections from 34 SCN8A families worldwide, amplifying lived experiences of both challenge and resilience. The campaign's centerpiece—a video produced by TCSF volunteer Dianely Cabrera (Max's mom) and Motive Cinemas—featured caregiver stories and moments from the 9th Annual SCN8A Gathering and reached over 90,000 views on social media.

With strong community engagement, the campaign increased awareness of SCN8A and reinforced the importance of earlier diagnosis, access to resources, and collaboration to improve outcomes.

CONNECTING CAREGIVERS AND CLINICIANS THROUGH STORY

On February 29, Rare Disease Day, Kacie Craig, Executive Director of The Cute Syndrome Foundation, served as the keynote speaker at the Rare Disease Day Symposium at Washington University School of Medicine in St. Louis. **Her keynote, "The Heart of the Journey: SCN8A Diagnosis from a Mother's Perspective," shared lived experience as both a caregiver to her daughter Stella and an advocate for the SCN8A community.** By grounding research and clinical care in real-world family experience, Kacie provided researchers and clinicians with critical insight into the daily realities, challenges, and resilience of families living with SCN8A.

AWARENESS-FOCUSED CONFERENCES ATTENDED:

- Washington University Rare Disease Day Symposium
- Purple Day at Disney World
- Layla: The Festival of Mark Making, Mark II
- Epilepsy Awareness Day at Disneyland











Fueled by **Generosity.**

More than half of The Cute Syndrome Foundation's support comes from individual donors—friends, family, and supporters—who believe in our mission and choose to invest in a better future for the SCN8A community. This collective generosity powers our work every day, showing that progress is made possible by many people coming together to make a difference. Every dollar truly counts, and together, these contributions fuel research, expand support programs, and bring us closer to a future with better outcomes for individuals living with SCN8A-related disorders.

TOTAL REVENUE 2024
$385,958

CORPORATE/SPONSORSHIPS
$155,000
(40% of all revenue)

INDIVIDUAL DONOR CONTRIBUTIONS
$219,748
(57% of all revenue)

GRANTS
$12,110
(3% of all revenue)

Community in Action:
2024 Fundraising Highlights.



VIRTUAL RACE

Our Virtual Race united families, friends, and supporters around the world in a shared commitment to the SCN8A community. Participants formed 15 teams in honor of SCN8A warriors, turning miles into moments of connection, visibility, and hope. **Together, this global effort raised over $26,000 while strengthening community bonds and raising SCN8A awareness.**

"When we lost our SCN8A angel, Mae, on March 25, 2024, we knew we wanted to honor her memory in a way that reflected the joy, fight, and love she embodied. Being approached to support the organization of the 2nd Annual TCSF Virtual Race felt like the perfect opportunity, a chance to channel our grief into purpose and celebrate our Wildflower Mae with the community that had stood beside us through every chapter of her journey with SCN8A.

On a beautiful October day along a nature trail in our hometown of Goshen, New York, over 150 participants gathered to walk, run, and stroll in Mae's honor. For those who couldn't be with us in person, we invited them to lace up wherever they were, and they also showed up in force. The turnout, the outpouring of support, and the overwhelming love we felt for Mae, for our family, and for all SCN8A warriors was something we will carry with us always. Team Miles & Smiles for Wildflower Mae raised over $17,000 for the Cute Syndrome Foundation, a testament not only to Mae's impact, but to the power of a community united by love and a shared commitment to bringing awareness and hope to those living with SCN8A.

Mae may no longer be with us, but her light continues to move people and us, quite literally, forward."

Kelly Johnston
Mae's Mom and TCSF Volunteer



THROW A STRIKE FOR SCN8A

Throw a Strike for SCN8A, hosted by TCSF Board Treasurer Ryan Pitino and his family, brought supporters together for an evening of bowling, connection, and purpose. **The event raised more than $85,000 to support the Cute Syndrome Foundation's work and strengthen efforts to "strike out SCN8A."**



INTERNATIONAL SCN8A AWARENESS DAY

SCN8A Warrior Mia and her family marked International SCN8A Awareness Day by turning their Shake Shoppe ice cream purple, creating a joyful and meaningful way to bring their Florida community together. **Through sweet treats and community connection, they raised more than $800 for the Cute Syndrome Foundation.**

Grants Powering **Our Mission.**

Through the Global Genes RARE Mental Health Impact Grant, TCSF expanded emotional support for families affected by SCN8A-related disorders. The grant helped make one-on-one and group caregiver support programs possible through the Grief Recovery Method, giving families space to process loss, diagnosis, changed expectations, career shifts, and the many ways SCN8A can reshape daily life. By helping cover materials, childcare, and internet access, this funding made support more accessible and helped caregivers feel less alone while building practical tools for grief, healing, and connection.

How to **Stay Involved.**

The SCN8A community is strongest when we come together. There are many ways to support families, raise awareness, and advocate for change.











GIVE

Your donations directly fund programs, grants, and events that make a real difference for SCN8A families.

JOIN & CONNECT

Participate in TCSF events and programs open to all, such as our annual TCSF 5K Run, Walk, Stroll, and upcoming social and emotional programming designed to keep the community connected. SCN8A families can also access specialized support programs, including the Connor James Smith Patient Assistance Grant, Family Travel Grants, and Cute Connection Grants.

SHARE & ADVOCATE

Help increase understanding of SCN8A by following, sharing, and engaging with TCSF on social media: Facebook, Instagram, LinkedIn, and TikTok. Share your story, educate others, and advocate for research, resources, and support.

Every action—giving, connecting, sharing, or advocating—strengthens the SCN8A community and *helps ensure no family faces this journey alone.*



Thank You, **Volunteers.**

The Cute Syndrome Foundation's work depends on all of our volunteers. Thanks to each of you, we are able to advance our mission of raising awareness of SCN8A mutations, funding the dedicated and talented scientists researching SCN8A, and supporting the families around the world who are affected by this disorder.

Executive Committee

DANIELLE HAYWARD
Director of Fundraising

KACIE CRAIG
Executive Director

KAREN VARNER
Family Support Director

LIZ RAMIREZ
Bereavement Support and Grants Advisor

MEGAN VARNER
Marketing Director

SHELLEY FRAPPIER
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