2025

ANNUAL REPORT

10 years of progress.
A year of momentum.

SCN2A-RELATED AUTISM & EPILEPSY
FAMILIESCN2A®
FOUNDATION
WWW.SCN2A.ORG

Our Team

Staff

Leah Myers
Co-founder | Executive Director

Angie Weaver
Director of Philanthropy & Development

Amanda Gale
Director of Programs & Operations

Jeff Cotrell
Interim Chief Scientific Officer

Melody Kisor
Director of Advocacy & Education

Board of Trustees

Platinum
Transparency
2025
Candid.

GREATNONPROFITS
2025 TOP-RATED
NONPROFIT

Charity Navigator
FOUR-STAR

Charity Ratings and Recognition

The FamilieSCN2A Foundation is recognized as a top charity for transparency and impact by leading nonprofit evaluators, including GreatNonprofits, Charity Navigator, and Candid (GuideStar). These ratings reflect our deep commitment to accountability, responsible financial stewardship, and making a tangible difference for families affected by SCN2A-related disorders.

To continue this important work, we rely on the generosity of donors like you. Your support accelerates research, advocacy, patient assistance, and family programs that change lives. Please consider making a donation today to help accelerate progress and ensure critical resources reach the SCN2A community.

Donate now at scn2a.org/donate

Letter from the Executive Director

Dear FamilieSCN2A Community,

Progress happens because this community shows up.
Because of your support, the FamilieSCN2A Foundation continues to grow our impact—strengthening families, advancing research, and building a global community determined to change the future of SCN2A-related disorders.

In 2025, we expanded the ways families receive support and connection. This year marked the launch of our Parent Navigator Program, connecting newly diagnosed families with trained parent leaders who understand this journey firsthand. We also introduced a new volunteer platform, creating meaningful ways for families, advocates, and supporters to get involved in our mission and increasing our volunteer community by more than 20%.
At the same time, research remains at the heart of our work. In 2025, the Foundation funded over $1.1 million in research and awarded 7 research grants, supporting scientists dedicated to advancing understanding of SCN2A-related disorders and moving the field closer to effective treatments and cures.

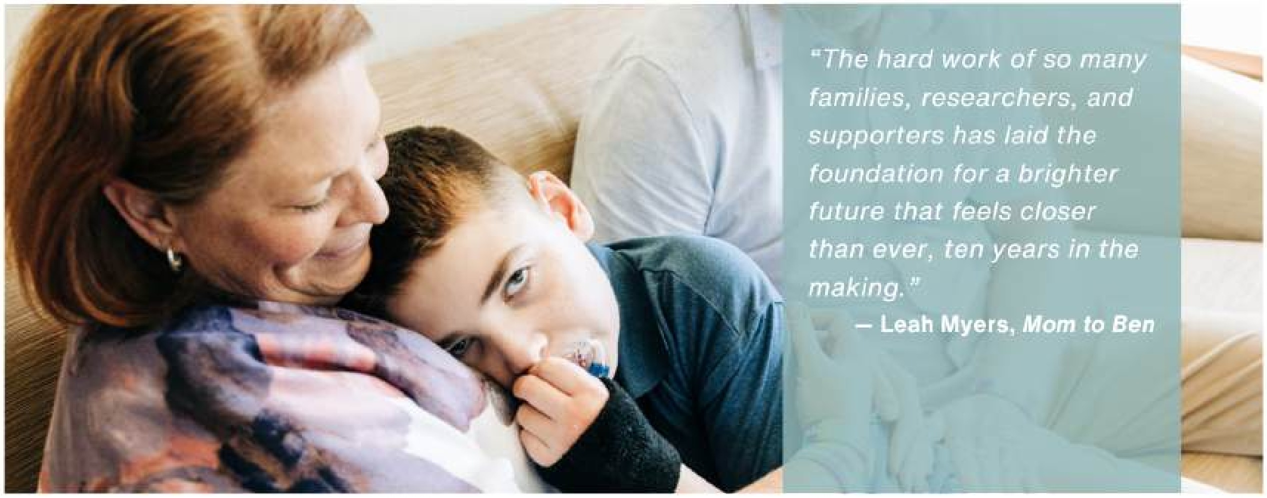
The strength of this community is also reflected in its generosity. In 2025, families, donors, partners, and supporters came together in a record-breaking year of fundraising, raising more than $2 million to advance research, support family programs, and strengthen advocacy efforts.

While we celebrate the progress made this year, we know there is still much work ahead. Together, we will continue building momentum, supporting families today while advancing the research that will change the future of SCN2A-related disorders.

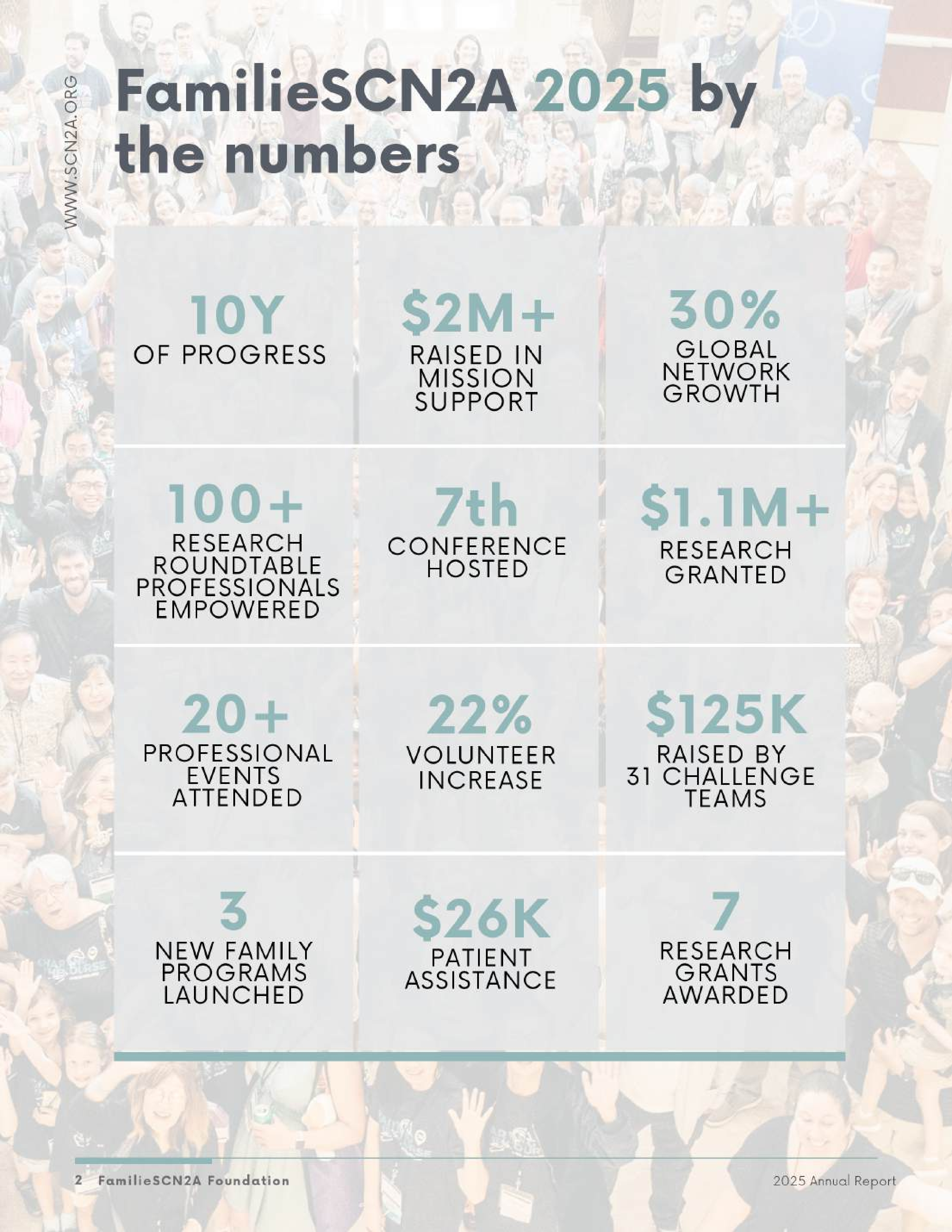
With gratitude,

Leah A. Myers

Leah Myers
Co-founder | Executive Director
FamilieSCN2A Foundation



> *"The hard work of so many families, researchers, and supporters has laid the foundation for a brighter future that feels closer than ever, ten years in the making."*
> **— Leah Myers, *Mom to Ben***



FamilieSCN2A 2025 by the numbers

10Y
OF PROGRESS

$2M+
RAISED IN MISSION SUPPORT

30%
GLOBAL NETWORK GROWTH

100+
RESEARCH ROUNDTABLE PROFESSIONALS EMPOWERED

7th
CONFERENCE HOSTED

$1.1M+
RESEARCH GRANTED

20+
PROFESSIONAL EVENTS ATTENDED

22%
VOLUNTEER INCREASE

$125K
RAISED BY 31 CHALLENGE TEAMS

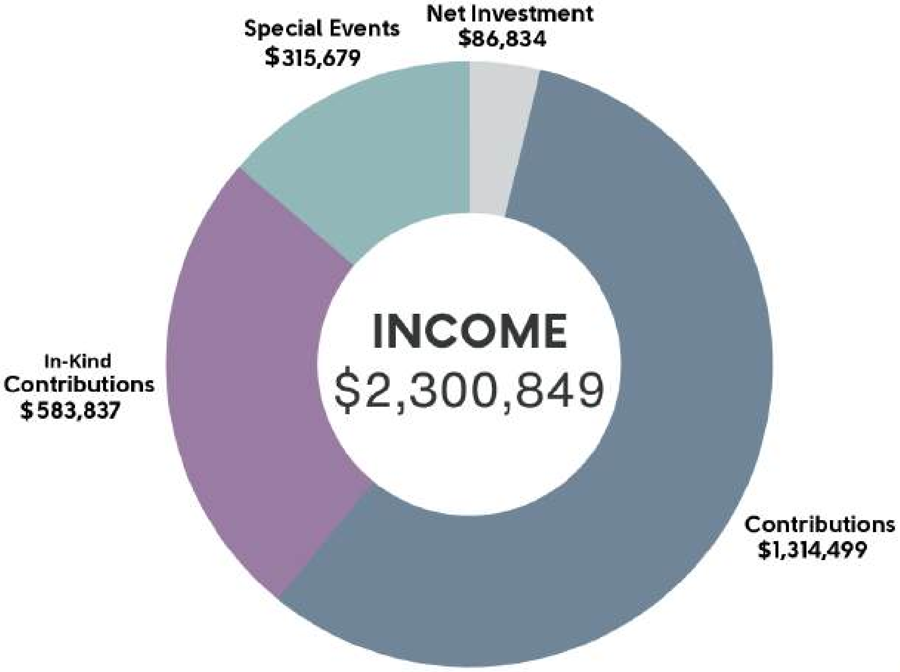
3
NEW FAMILY PROGRAMS LAUNCHED

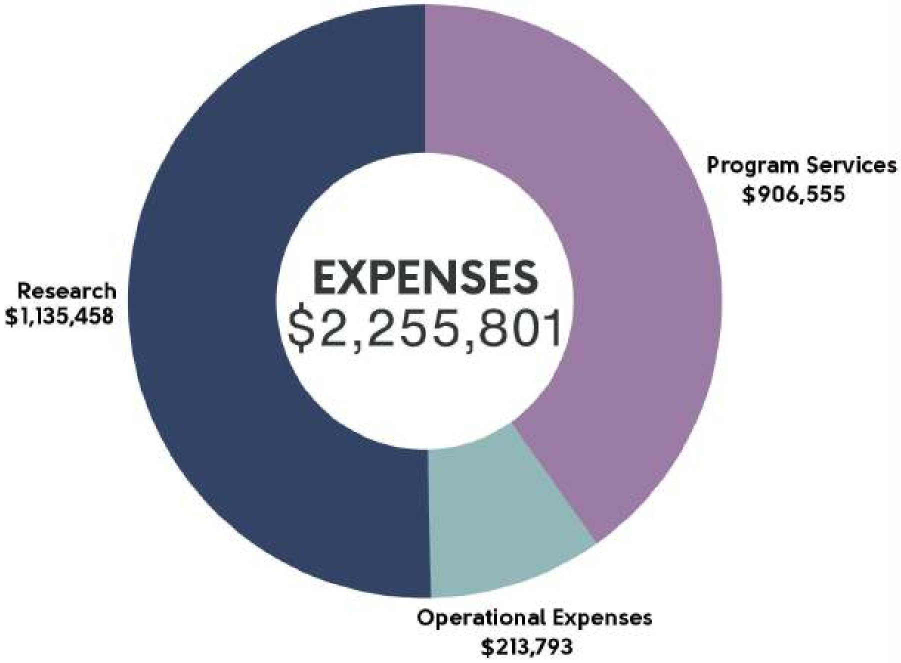
$26K
PATIENT ASSISTANCE

7
RESEARCH GRANTS AWARDED

90% of every donor dollar

contributed in 2025 went directly toward patient and research-focused programs and services





Our commitment to financial transparency and accountability guides everything we do. Our tax filings, independently audited financial statements, and IRS 501(c)(3) determination letter are publicly available on our website.

2500+

families supported worldwide

"...the FamilieSCN2A Foundation has been an essential anchor and support system for our journey with our child..."
— Crasta Family

Family & Professional Conference

Family & Professional Conference

In 2025, the FamilieSCN2A Foundation welcomed 450 attendees to our Family & Professional Conference, with families, clinicians, researchers, and partners joining in person and virtually from around the world. The conference brought together 40 families, including both first-time participants and returning attendees, creating an inspiring space for learning, connection, and collaboration.

Expert speakers led sessions across multiple educational tracks, addressing clinical care, emerging research, and practical supports for families navigating life with SCN2A-related disorders. The program also included a dedicated Bereavement Track, providing space for families navigating loss to connect with others who understand their experience.

Beyond educational sessions, families had opportunities to engage directly with researchers, participate in ongoing research initiatives, and contribute to important data efforts that help move the field forward.

> "Receiving a travel scholarship made it possible for our family to attend the conference when we otherwise may not have been able to. Connecting with other families who just "get it", and hearing about the progress being made in research, gives us so much hope."
> — **Bolin Family,**
> ***Family Travel Scholarship Recipients***

The conference also created time for families to connect with one another, strengthening relationships and building a sense of community that continues long after the event ends.

> *"My lab and I love attending the SCN2A conference every year. Being in a room with SCN2A Warriors and their families is incredibly inspiring. It reinforces that our work is not only about advancing scientific knowledge, but also about the hope families place in us to one day find a cure."*
> — **Yang Yang, PhD, Purdue University**

Gatherings like this remain one of the most powerful ways we bring the global SCN2A community together—advancing research while ensuring families feel supported and connected along the way. **'Families' is in our name for a reason.**

Denver, Colorado 2025

Research Roundtable

One day. 100+ professionals.
Collaborating to accelerate the path from scientific discovery to real treatments for families.

Research Roundtable

In 2025, the FamilieSCN2A Foundation and the International SCN8A Alliance co-hosted a Professional SCN2A & SCN8A Research Roundtable at the Foundation's Annual Family and Professional Conference in Denver, Colorado, bringing together more than 100 researchers, clinicians, industry partners, and caregivers for a structured drug development workshop.

Participants worked in multi-stakeholder breakout groups to collaboratively build therapeutic roadmaps with a focus on three modalities: antisense oligonucleotides (ASOs), gene editing, and small molecules.

Caregiver voices were central to the day's work, reshaping discussions around treatment burden, acceptable risk, and what meaningful improvement actually looks like for families.

The roundtable produced a concrete set of recommendations and established a replicable roadmapping model that can be adapted for other rare epilepsies and neurodevelopmental disorders.

A proceedings paper from the workshop was submitted and is currently under review in the Journal of Clinical and Translational Science.

> *"Partnerships between scientists and patient organizations are essential to accelerating discoveries that can ultimately benefit families affected by SCN2A-related disorders."*
> **— Morgan Robinson, PhD**

FUNDED

$8M+

IN RESEARCH SINCE OUR FOUNDING in 2015

Research Grants

Advancing Discovery & Therapeutic Development

2025 Research Investment

In 2025, the FamilieSCN2A Foundation invested in innovative research to deepen understanding of SCN2A-related disorders and accelerate therapeutic development. Together, these grants reflect the Foundation's commitment to advancing both early scientific discovery and industry-led innovation—moving promising ideas closer to meaningful progress and treatments for families living with SCN2A-related disorders.

2 Competitive Grants Awarded

Action Potential Award

Morgan Robinson, PhD - Purdue University

Research Focus

Gene editing approaches to correct disease-causing variants in the SCN2A gene using CRISPR technology.

Why It Matters

This project focuses on identifying and validating ASO candidates that may one day become targeted therapies for individuals with SCN2A-related disorders.

Accelerator Award

Mahzi Therapeutics

Research Focus

Development of allele-specific antisense oligonucleotide (ASO) therapies targeting disease-causing SCN2A variants.

Why It Matters

This project focuses on identifying and validating ASO candidates that may one day become targeted therapies for individuals with SCN2A-related disorders.

Park Family Grant

This grant was renamed in honor of the Park Family, whose early and visionary support made this funding opportunity possible. They were the first family to invest in this grant, setting in motion a commitment to advancing SCN2A research that now continues to grow with the support of other committed donors. **We are deeply grateful to all donors who choose to support this critical research grant.**

Emily Park,
Trustee Affairs Commitee Chair

> *"We are honored to partner with the FamilieSCN2A Foundation to advance therapeutic development for SCN2A-related disorders. Collaborations like this are critical to translating scientific innovation into real progress for patients."*
> **— Yael Weiss, MD, PhD**
> **CEO, Mahzi Therapeutics**

Strategic Plan
2022-2025

Over the past four years, the FamilieSCN2A Foundation followed a strategic roadmap designed to accelerate research, strengthen community support, and increase advocacy for individuals and families affected by SCN2A-related disorders.

WWW.SCN2A.ORG

View our 2026-2029 Strategic Plan Here

1

RESEARCH

We worked to accelerate scientific discovery and therapeutic development by supporting investigator-led research, advancing clinical trial readiness efforts, and strengthening partnerships with academic institutions and industry leaders

2

COMMUNITY

We expanded programs that provide emotional, educational, and financial support to families, including resources for newly diagnosed families, patient assistance programs, global support networks, and family gatherings.

3

ADVOCACY

We increased awareness of SCN2A-related disorders through global campaigns, educational initiatives, and outreach to healthcare providers and policymakers.

HOW WE GOT THERE

Progress across these priorities was made possible through intentional investment in:

- Strong partnerships with researchers and clinicians worldwide
- Strategic communications and awareness efforts
- Community engagement and development initiatives
- An ongoing commitment to our values of urgency, integrity, collaboration, and inclusion

Community in Action

2025 was a landmark year for our organization. As we celebrated our 10th anniversary, we showed what is possible when bold goals are matched with strong execution. More than 2,000 donors helped move our mission forward, and we are grateful to the individuals, families, and partners whose generosity turned urgency into action.

Through our **Patient Assistance Grant** program, 11-year-old Ben received an adaptive trike that allows him to safely ride alongside his family — sitting on the back while they pedal, enjoying the simple joy of being outside together.

Because caregivers need support too.
In 2025, we launched **Caregivers Connection**, a monthly virtual gathering where parents connect, share experiences, and are reminded that no caregiver has to walk this journey alone.

Every child remains part of this community. Through remembrance and connection throughout the year, we honor their lives and hold their families close.

"Being a sibling of someone with an SCN2A-related disorder can be hard sometimes, but SuperSibs Club reminds me I'm not alone. I love our SibShop meetups and Sibs Camp at the conference where I get to meet other kids who understand. It makes me proud to be a SuperSib and part of this really special community."

— Cora, *SuperSib, age 11*

"During a difficult hospital stay, receiving this gift brightened our stay and reminded us we weren't alone."

— Dan and Alysha Brown

"Sometimes the most powerful support comes from another parent who simply understands. I'm honored to be there for families as they navigate those first steps."

— Sarah Haas, *Parent Navigator*

In 2025, Board Chair Jenny Burke and her husband Mike hosted the **Hope Takes Flight Gala**, raising more than $125,000 to advance the mission of the FamilieSCN2A Foundation.

Through their **Fall Dance for a Cure**, SuperSibs Ethan and Jackson rallied friends and community members to support the FamilieSCN2A Foundation, showing the incredible impact siblings can have.

The **Warrior Challenge** raised a record-breaking $125,000 in 2025. One special team, *Emily's Entourage*, highlights the heart of our community—longtime supporters of the Warrior Challenge and deeply loved members of the SCN2A community whose leadership and generosity inspire us all.

Each year on February 24, families around the globe recognize **SCN2A Awareness Day**. Thanks to advocacy from our community, 15 U.S. states have officially recognized the day through state proclamations.

*"FamilieSCN2A is one of those extraordinary groups that is able to **both** move science and clinical care forward through tireless advocacy **and** form a deeply supportive space where the SCN2A community can come together to share resources and stories. I joined the Board because I want to help advance this multi-pronged mission of science, clinical care, and community."*

— **Dr. Eloise Austin, *Trustee***

Hosted annually in Maine by an SCN2A family, the **Songs of Hope** concert is a powerful example of the community coming together through music to support families and advance the Foundation's mission.

Our **VISION** is a world with effective treatments and cures for all SCN2A-related disorders.

Our **MISSION** is to accelerate research, build community and advocate to improve the lives of those affected by SCN2A-related disorders around the world.

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Support the FamilieSCN2A Foundation in 2026 by scanning the QR code or by visiting our website.