

2026-2029 FamilieSCN2A Foundation Strategic Plan



Accelerate Research and Therapeutics

- Establish and execute a standardized process to achieve expert consensus on SCN2A patient-level variant interpretation, and expand the resulting database to support research and clinical decision-making.
- Develop targeted therapeutic roadmaps for each SCN2A functional variant category (Gain-of-function, Loss-of-function, Mixed).
- Launch a venture philanthropy effort focused on advancing new treatments for SCN2A-related disorders by leveraging existing research, partnerships, and funding pathways.
- Complete a high-throughput drug repurposing screen to identify at least five FDA-approved compounds with demonstrated potential in SCN2A-relevant models.
- Accelerate SCN2A therapeutic development by expanding access to critical research tools—including animal models, patient-level data, and validated surveys.
- Ensure the sustainability and impact of our SCN2A research grant programs by diversifying funding sources, strengthening review processes, and tracking return on investment.
- Deepen collaboration between the FamilieSCN2A Foundation and key stakeholders—including researchers, clinicians, and industry partners—to accelerate progress and knowledge sharing.



Improve Access and Quality of Care

- Develop and disseminate evidence-based diagnostic and treatment guidelines to improve accuracy, standardization, and outcomes for individuals with SCN2A-related disorders (SRDs).
- Expand and sustain SCN2A Multidisciplinary Centers (MDCs) to deliver expert care, advance research, and accelerate precision therapies for those affected by SCN2A-related disorders.
- Create and distribute accessible, evidence-based educational materials on SCN2A diagnosis and treatment—tailored to healthcare professionals, researchers, and families.
- Expand provider education initiatives to emphasize the importance of genetic testing for early and accurate SCN2A diagnosis.



Support and Empower Families

- Grow the global SCN2A Awareness Day campaign to increase visibility, understanding, and education about SCN2A-related disorders worldwide.
- Maintain an up-to-date, user-friendly website that hosts the leading source of SCN2A information and resources to provide affected families with the best, reliable information, support services, and tools for navigating SRDs and related challenges..
- Secure official proclamations recognizing SCN2A Awareness Day (February 24th) in all 50 states increasing public and legislative awareness of SCN2A-Related Disorders.
- Launch a Community Support Ambassador Program to strengthen peer-to-peer support, expand outreach, and empower SCN2A families to share resources and connect with others on similar journeys.



Strengthen our Organization

- By Q2 2027, establish a foundational advocacy and lobbying strategy that increases awareness, builds key relationships, and secures initial commitments for state and federal funding to support research, treatment, and resources for SRDs.
- Strengthen organizational capacity and governance by expanding and diversifying the Board of Trustees to better support strategic growth, fundraising, and mission-driven impact.
- Launch a bold and unifying Vision Campaign by Q1 2026 to galvanize long-term support for the FamilieSCN2A Foundation's mission, articulating a clear path toward a cure and improved quality of life for all affected by SCN2A-related disorders.