



Chief Scientific Officer (CSO)

FamilieSCN2A Foundation

Location: Remote

Commensurate with experience; this position does not currently include employee healthcare benefits.

Position Summary

The Chief Scientific Officer (CSO) will play a pivotal role in advancing the FamilieSCN2A Foundation's mission to accelerate research and improve outcomes for SCN2A-related disorders. As the Foundation's lead scientific representative, the CSO serves as the primary liaison between the Foundation, the scientific and medical community, industry partners, regulatory bodies, and families.

The CSO is responsible for leading the Foundation's scientific strategy, overseeing implementation of the Foundation's Research Strategic Plan, and managing the Team for Accelerating Science and Clinical Outcomes (TASCO). The CSO will drive scientific priorities from strategy through execution, foster collaborations, manage scientific programs and grants, and ensure that the patient voice remains central to the Foundation's research initiatives. This is a full-time leadership position responsible for the Foundation's scientific strategy and execution across its research and therapeutic development activities.

Empathy for families affected by rare diseases and the ability to translate complex science into accessible language are essential qualities for this role.

Key Responsibilities

Research Strategy & Leadership

- Lead the implementation, ongoing evaluation, and refinement of the Foundation's Research Strategic Plan, ensuring scientific priorities translate into measurable goals, initiatives, and outcomes.
- Manage and provide strategic leadership to TASCO, including setting priorities, developing agendas, leading meetings, coordinating workstreams, and ensuring accountability and follow-through.



- Work with TASCO, the Executive Director, Board of Trustees, staff, and external partners to identify emerging needs and opportunities and keep the Foundation's research strategy responsive to advances in the field.
- Identify, develop, and advance high-impact research and therapeutic opportunities aligned with the Foundation's mission and strategic priorities, including establishing collaborations and partnerships needed to initiate and execute new programs.
- Oversee Foundation-supported scientific initiatives, including study design, project management, progress monitoring, milestones, and deliverables.
- Regularly assess progress against the Research Strategic Plan and communicate priorities, progress, challenges, and opportunities to Foundation leadership and the Board.
- Support manuscript preparation, presentations, and dissemination of findings.

Academic, Industry & Regulatory Engagement

- Build and maintain strategic relationships with academic researchers, industry leaders, and government agencies, including the FDA, EMA, and NIH.
- Represent the Foundation at recurring partner meetings, scientific conferences, and symposia.
- Secure industry funding for research, events, and projects.
- Facilitate collaborations between academia and industry to accelerate therapy development.
- Educate partners on SCN2A-related disorders and provide tools to de-risk drug development.
- Advocate for SCN2A research and therapeutic priorities within regulatory and funding frameworks.

Scientific Advisory & Community Liaison

- Serve as a bridge between families and the professional community, ensuring research priorities reflect patient needs and perspectives.
- Build and sustain relationships across diverse stakeholder communities, including families, researchers, clinicians, industry partners, regulators, funders, and advocacy organizations, fostering alignment across groups.
- Manage the Scientific and Medical Advisory Board, including planning agendas, coordinating quarterly meetings, and soliciting input between calls.
- Organize Research Roundtables and topic-specific working groups.

Research Monitoring, Grants & Communication

- Evaluate and refine the Foundation's funding mechanisms to maximize scientific impact, address critical gaps, stimulate new research, and adapt to the evolving needs of the field.



- Direct the Foundation's grant programs, including RFP development, proposal review, contracting, and progress tracking.
- Maintain comprehensive records of funded projects, publications, and preclinical models.
- Review and summarize SCN2A publications and drug pipelines and communicate updates to both professional and patient audiences.
- Present at professional and community gatherings and submit proposals for workshops, symposia, and conference sessions.
- Provide clear, accessible updates through newsletters, website content, and social media.

Required Qualifications

- PhD and/or MD in biological or medical sciences or a degree in genetic counseling.
- Expertise in genetics, particularly SCN2A and other ion channels, epilepsy, or rare neurological disorders.
- Familiarity with translational research, preclinical models, and clinical study design.
- Excellent written and oral communication skills, including the ability to distill complex scientific information for lay audiences.
- Strong organizational, analytical, and project management skills.
- Proficiency in Google Suite, Microsoft Office, project management tools, and databases.
- Demonstrated initiative, adaptability, problem-solving skills, and collaborative leadership.
- Willingness to travel a minimum of four times per year.
- Deep empathy for individuals and families living with rare diseases.
- Commitment to the Foundation's values of urgency, integrity, collaboration, and inclusion.

Preferred Qualifications

- Knowledge of NIH processes, peer review systems, and regulatory pathways.
- Experience working within rare disease, patient advocacy, nonprofit, academic, biotechnology, or pharmaceutical environments.
- Experience developing and executing scientific or research strategy across multiple stakeholders.

To Apply

Please send your CV to jointheteam@scn2a.org