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Dear Friends,

As we bid farewell to 2023, I am, once again, amazed at the progress the Foundation has made since 2015. The past year has been a whirlwind of accomplishments, setting the stage for what promises to be an even more extraordinary 2024 (see below).

The momentum we've built is extraordinary and reflects the unwavering dedication of our passionate team. Thanks to the [CZI Rare As One](#) grant, we assembled an outstanding science team who charted a course aligned with our strategic plan goals. Investments into our research science programs encompass both drug discovery and repurposing and we are boldly preparing to enter the realm of gene therapy.

I believe the far-reaching impact of the Foundation can be felt in reflections from our most significant event, the summer conference in Boston:

- Families forming profound connections
- Siblings forging bonds destined to endure a lifetime
- Parents leaving armed with actionable insights for their healthcare providers
- A clinical trial participant sharing life-altering outcomes
- Researchers uniting to propel the understanding and treatment of SRDs forward

One memorable conversation stands out—a young researcher shared with me her vow to stay focused in the lab after realizing the profound impact our conference had on her perspective. "Remind me of this moment," she told her colleague, "and I'll get back to work!" Such anecdotes reaffirm the power of shared experiences in fostering deep connections.

As I write this, sitting by my father's bedside in the hospital, I'm reminded of the fragility and value of every human life. Our FamilieSCN2A community serves as a daily testament to this truth, with individuals offering support to one another and celebrating triumphs often measured in 'inchstones.' We are family. We may not have chosen this journey, but together, we uplift one another through both pain and joy.

Looking ahead to 2024, get ready to be part of something special! We'll be extending an invitation for you to join us in a collaborative campaign for International SCN2A Awareness Day on February 24th. And, stay tuned for details on The Dragonfly Study, Multidisciplinary Clinics, and the Family & Professional Conference in Anaheim, CA (7/31-8/4).

On behalf of the Board, I want to express our eternal gratitude and deep honor for the support of families, friends, advisors, volunteers, researchers, scientists, clinicians, and donors. You are the family in FamilieSCN2A.

Wishing you a healthy, happy new year filled with anticipation for the remarkable journey that lies ahead!

~Jenny Burke

Chair, FamilieSCN2A Foundation Board of Trustees

P.S. Did you notice my new title? In 2023, we updated our bylaws in keeping with our evolution as a growing nonprofit organization.

CHARTING THE COURSE

Thanks to your support, we were able to chart the course towards a cure in 2023!

RESEARCH

- ✓ TASC0 (Team for Accelerating Science and Clinical Outcomes) develops a research roadmap
- ✓ Awarded >\$2.7M in grants
- ✓ Submitted 5 publications from Clinical Trial Readiness Study and other projects
- ✓ Clinical trials have begun!

ADVOCACY

- ✓ Doubled # of state proclamations declaring February 24th 'SCN2A Awareness Day'
- ✓ Updated scn2a.org to be more inclusive
- ✓ Planning Patient-Focused Drug Development meeting with FDA in 2024

COMMUNITY

- ✓ Hosted largest SCN2A Family & Professional Conference yet
- ✓ Awarded 5 Patient Assistance Grants, helping provide families with therapies & assistive devices
- ✓ Provided travel scholarships for 10 international families to attend SCN2A/BA Conference in Denmark

LOOKING AHEAD: 2024

- ✓ International SCN2A Awareness Day on February 24th
- ✓ SCN2A Multidisciplinary Clinics
- ✓ DRAGONFLY Study launch
- ✓ Family & Professional Conference Anaheim, CA | July 31-August 4

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is part of our name for a reason

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