

2021 VISION MISSION VOICE



A message from our President...

Dear Friends and Family,

“Audacious Optimism” was not necessarily the way I would have described how I’ve felt in the past year...until December arrived with a renewed sense of purpose and a clear vision to reflect on all of 2021.

The year began with plans continuing to get canceled and the world figuring out how to manage 'life with covid' for a second year. The Foundation chose to focus on the important work of amplifying the voices of SCN2A patients with:

- The first SCN2A [Clinical Trial Readiness Study](#), a major investment that will position us to get new treatments for SCN2A-related disorders approved by the FDA, enrolled over 100 patients and has already yielded [fascinating results](#).
- A virtual FDA 'Listening Session' where several families shared what it's really like to live with SCN2A-related disorders with those who determine the approval of new treatments and cures.
- Our reimagined summer conference—zoom sessions where researchers and families could have direct, live conversations called [Virtual Table Talks](#)
- Continuing [financial assistance](#) for SCN2A families in need

In the broader ion channel, rare disease, autism and epilepsy communities, collaborations were fostered and expanded. Some positive results of covid restrictions included the pre-publication of research, the availability of telehealth, and a level of comfort with 'virtual/hybrid meetings' that made the world seem a little smaller.

In SCN2A alone there were multiple ground-breaking developments, publications and tools created this year: the [SCN Portal](#), an interactive website dedicated to understanding sodium channel disorders; a new [video explanation](#) of SCN2A, the first ever massive digitization of [SCN2A variants](#); and a cross-country road trip that brought [mobile research](#) to the homes of many SCN2A families.

The future of those suffering from SCN2A-related disorders is getting brighter as more and more researchers and industry groups take an interest in this potentially "not so rare" disease. New, transformative therapies are close to hitting the clinics including gene therapies, small molecule drugs and compounds.

This year also brought home a personal reminder that we need a cure NOW. In June, my son's seizures returned after a 7-year absence, turning my world upside down—again. He's bouncing back and so will I, energized by some of these 2021 numbers:

- 110 new families joined our Global Support Network on Facebook
- 52 countries are represented in our group
- We are 1 of 20 new participants in the [CZI Rare as One Project!](#)

Dr. Priscilla Chan opened our first Chan-Zuckerberg Initiative Community Meeting on Dec 8th with the moving story of her Chinese grandparents' heart-wrenching decision to separate their children onto different boats out of war-torn Vietnam to increase their odds of surviving. She believes this power of 'audacious optimism and belief in what's possible,' is in all of us who strive to cure rare diseases.

I believe it too! Over the next three years, we will receive \$600,000 in funding and access to a network of CZI resources to strengthen our organizational capacity, build our community and advance international

collaborative research toward shared priorities. However, one thing we can't fund with the grant is research—and research is critical.

The need has never been so urgent as we have lost 5 children this year alone. With so much hope on the horizon, the foundation is doing all we can to speed up the process to save lives. The only barrier is funding.

The Foundation's dedication to the SCN2A community has inspired our Board of Directors to fund a year end matching opportunity. Until December 31, every dollar raised up to \$50,700 will be matched! We are 75% of the way to that goal and boldly hope you can put us over the top.

Wishing you all an audaciously optimistic 2022!

Carla Forbes

Happy Holidays!

75%
of \$50,700 goal!
Help fill our Heart!

EVERY DONATION FOR THE REMAINDER OF 2021 WILL BE MATCHED, UP TO \$50,700.

THIS END-OF-YEAR CAMPAIGN MATCH WILL GO DIRECTLY TO FUNDING RESEARCH.

\$50,700
\$38,000
\$25,000
\$12,700

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