



*A message from our President...*

*seize*  
YOUR →  
*joy*



Dear Friends and Family,

Last year at this time we were contemplating the promise that a new year brings. I think we can all agree that 2020 fell short of what we had imagined in many ways, but I hope each of you reading this were able to find something good to take away from this year. To help us through the uncertainties that 2020 brought, the Foundation adopted mantras from two of our warrior families: “Seize Your Joy” and “Fight On.”

In honor of Charlotte Umezu, a brave SCN2A Warrior whose family taught us all how to “Seize Your Joy,” we are focusing our energy on the positives! In addition to creating a [Quarantine Joy video](#), here are a few Joys we have accomplished in 2020 thanks to your support:

- Awarded \$375,000 in research support.
- Co-Authored a publication in [Epilepsia](#).
- Added 6 clinicians to our [Medical and Scientific Advisory Board](#) for a total of 13 professionals.
- Shipped 35 Crisis and Bereavement support packages.

- Granted \$35,000 in [direct patient assistance](#).
- Welcomed 75 new members to the [Global Community](#) for a total of 700 from 47 countries.
- Launched [RX: Hope Virtual Series](#), a series of pre-recorded educational SCN2A webinars.
- Hosted 2nd annual [virtual run](#) (5K this time)

At the end of every year we reflect back to the previous ones and are in awe of how far we have come in such a short period of time. Gene modifying clinical trials have started in rare diseases that are similar to SCN2A. Science is moving fast and we need to be ready because our turn is coming. The FamilieSCN2A Foundation is now focusing on preparing our community for clinical trials. One of the ways we will accomplish this is by launching the first ever SCN2A Clinical Trial Readiness Study, a prospective, endpoint measurement study. The data from this project will provide the basis for designing an efficient and robust clinical trial.

We believe that in order to cure SCN2A related disorders, we need a strong, united community of friends and families all striving for the same goal. This is what sets us apart from many other rare disease nonprofits who focus solely on funding research. In 2021, we will continue to support our community, both the patients and the research, as they are equally important.

As you can see, in the face of a global pandemic, we have chosen to Fight On. After all, that is what Amelia Weaver (another strong SCN2A Warrior) and her family have taught us. Amelia fought every day of her life on earth and even now—through tissue donation to science—her fight continues, as her sister Penny reminds us in [this video message](#).

Thank you from the bottom of my heart for helping us to “Seize Your Joy” and “Fight On” together.

*Carla Forbes*

**Happy Holidays!**

**75% of \$100,000 goal!**  
**Help fill our Heart!**

EVERY DONATION FOR THE REMAINDER OF 2020 WILL BE MATCHED, UP TO \$100,000.

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

SCN2A RELATED AUTISM & EPILEPSY  
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