

Dear Families and Friends,

The 2024 SCN2A Family and Professional Conference in Anaheim was more than just a gathering; it was a powerful convergence of hope, progress, and community. With nearly 400 participants, including caregivers, people with SCN2A-related disorders (SRD), researchers, clinicians, biotech professionals, and investors, the event marked a pivotal moment in our journey toward treatments and cures for all SRDs.

This year's conference was a clear sign that treatments and cures are within reach. The momentum is undeniable, with six crucial research studies executed and the launch of the DRAGONFLY natural history study. The \$150,000 in new Action Potential grants and the establishment of the first SCN2A Multidisciplinary Center further underscore the progress being made. The science presented was rich and inspiring, with a strong focus on biomarkers, early diagnosis, and the development of targeted therapies. It is clear that the path forward is well-defined and the community's unity of purpose is accelerating our progress.

But the conference was about more than just scientific advancements—it was a deeply emotional experience for many families. For some, this was the first time they had ever met

another person with an SRD. These families, who have often felt isolated in their journey, found a supportive community where they could share their experiences and struggles. The connections made here are lasting and meaningful, providing strength and hope in the face of the challenges that come with this diagnosis.

Hearing from families who bravely shared their journeys was both heartwarming and heartwrenching. The presence of families who have lost loved ones to SCN2A served as a poignant reminder of why urgency is a core value of the FamilieSCN2A Foundation. The parallel program for these families ensured they were supported while honoring the memory of their SCN2A warriors.

For all who attended, the conference was a place of learning, connection, and solidarity. The SCN2A community has grown stronger, more united, and more determined than ever to push toward a future where treatments and cures are a reality. The experience was transformative and the bonds formed here will continue to provide comfort and strength long after the conference has ended.

Thank you to everyone who made this conference a success and to our generous sponsors for their unwavering support. Together, we are not just making progress—we are making a difference.

Take Survey!

We want to hear from YOU! Please take this Post Conference Survey to help us make next year's conference even better!



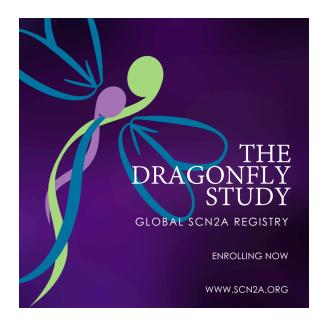












Soar with SCN2A & Join the Registry – Where Dragonflies Inspire HOPE!

Welcome to The DRAGONFLY Study, a registry dedicated to individuals and families impacted by SCN2A-related disorders, serving as a central hub for sharing patient experiences and contributing vital information to drive research forward.

Join us in building a stronger, more informed community and making a lasting impact on the understanding and treatment of SCN2A-related disorders.

For more information about how to register, **click here**.





Buy Raffle Tickets!



Calling all NY friends! If you're in the Buffalo area, come and join us for the 4th Annual Golf Fore SCN2A Tournament!

Don't like to golf? We've got you covered! There will be raffles, swag and a chance to hang out with some of the most fabulous warriors around!

A big shout out to the Eagan family and our Golf Committee who are dedicated to making a difference and putting



together what is shaping up to be a wonderful, family friendly event at the Springville Country Club, NY on August 19th. For those of you who cannot attend, please consider purchasing raffles ticket for your CHANCE TO WIN your very own guitar autographed by TAYLOR SWIFT! Your support is appreciated!



Our Contact Information

- *{{Organization Name}}*
- *{{Organization Address}}*
- *{{Organization Phone}}*
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