



Incredible Conference!

"Huge thanks to the FamilieSCN2A Foundation for making this trip possible and connecting us with other families from all over the globe who get exactly what we're going through! We are thrilled that there are so many brilliant doctors and researchers committed to finding ways to improve the lives of our SCN2A warriors!" -Sadie's Mom



In July, the FamilieSCN2A Foundation hosted its fifth Family & Professional Conference in Boston. In total, we welcomed 320 people in person with dozens more attending

sessions virtually. In total, there were 56 SCN2A families in attendance from all across the world!

The first day was dedicated to a Research Roundtable, led by CSO, Shawn Egan, PhD. A hundred professionals, including researchers, clinicians, and industry representatives sat together and brainstormed how to accelerate the science on the road to #CureSCN2A. In addition, 13 young investigators shared posters highlighting their current work on SRDs.

The next day, families participated in multiple learning sessions with topics ranging from understanding a genetic report to assessing clinical trial participation. Everyone was transported to the New England Aquarium where we hosted our Family Impact Awards Dinner and honored those we have lost. On the final day, while parents attended more sessions, the Foundation hosted two Super Sibling Events for our incredible SCN2A siblings to meet and bond with one another. Festivities concluded with the inaugural SCN2A Warrior Dance Party. Over the course of the event, families had the opportunity to take family portraits and participate in seven different research projects.

If you attended, please check your email for the link to the conference survey and presentation recordings (sent last week). The recordings will be posted publicly on the website on September 1st. If you would like early access, [register for a link here](#).

The conference was such a success that everyone is asking "where are we going next year?" Normally, the next one would be in 2025, but we HEAR YOU! Holding a conference is a huge undertaking, so as we try to determine the feasibility of hosting one in 2024, fundraising will be critical. In rare diseases, like SRDs, it falls on us to spread awareness and raise funds. **We can't do it without your help.**

Ways to get involved:



- Create your team for the virtual [Warrior Challenge](#)

- Follow the Foundation's public social media pages! Please help us continue to spread SCN2A awareness by liking and following our pages and inviting your friends to follow us as well. *See links at the bottom of this email.*
- Host a [Facebook](#) or [other type of fundraiser](#) for your or your child's birthday
- Celebrate [FamilieSCN2A Foundation's](#) birthday on October 13th
- [Share your experiences](#) with your friends and family and [ask for their support](#) !



JOIN US at the **3rd Annual Golf Fore SCN2A Tournament**. Please join us on Monday, August 21st at Springville Country Club in Springville, NY. **Even if you don't golf**, it's a fun place to socialize with other SCN2A families and the golfers love to meet the people they are supporting!



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