



SCN2A RELATED AUTISM & EPILEPSY

FAMILIES SCN2A

FOUNDATION
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FOUNDATION NEWS

HERE WE GROW AGAIN!



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The FamilieSCN2A Foundation is excited to announce one of our Committee Members, Maura Bragg, is now on the Board of Directors.

Maura is first and primarily a mother to Ashlyn in North Andover, Massachusetts who has SCN2A. There she works as an attorney for a national law firm managing Massachusetts and Maine cases against large banks and financial institutions.

Prior to moving back to Massachusetts from Maine a few years ago, Maura adjudicated business and employment cases for the Department of Labor. Previously, as General Counsel of a drug testing company, Maura minimized the legal risks advising its officers on matters of regulatory compliance.

All FamilieSCN2A Board and Committee Members are unpaid volunteers. Their overall goal is to work together to support the FamilieSCN2A Foundation's mission to find a CURE.



The FamilieSCN2A Foundation is also excited to welcome Amanda Van Schoick as a new Committee Member!

Amanda lives in New York with her husband, Jim, and are parents to Morgan, born in 2012, and their SCN2A warrior, Harrison (Harry for short), born in 2015. Harry was born at 37 weeks after a normal pregnancy and showed no signs of health issues at birth. As Harry grew, he started to show signs of developmental delay and by 9 months old, when he was not yet sitting up independently, Harry started in Early Intervention. By 18 months old, Harry was receiving PT, OT, Speech and Special Education services. In January 2018, at 26 months old, Harry had his first seizure. In the six months that followed Harry's first seizure, Harry was diagnosed with autism, apraxia and an SCN2A mutation. The SCN2A mutation diagnosis provided a lot of answers to the questions that Jim and Amanda had been seeking for Harry, and led them to find comfort in their new "family" through the FamilieSCN2A Foundation.

In addition to juggling the needs and demands of two very active children, including all of Harry's medical and therapy needs, Amanda is an attorney, and serves as real estate and construction in-house counsel for an American multinational corporation that designs, develops, manufactures and sells footwear and apparel worldwide.

Amanda began volunteering with the Foundation in 2019, with the hope of being able to assist with the Foundation's goals - connecting families and supporting research for a cure.

"It is nothing short of amazing what the FamilieSCN2A Foundation has been able to accomplish with only volunteers, all while caring for a disabled child and most working full time jobs. The progress we have made in supporting research has yielded exciting results and now is the time to prepare the community for the next stage - clinical trials! Increasing fundraising efforts and strategic planning for sustainability is now critical. We are thrilled with the potential that the Executive Director position will bring to our organization. Leah Schust Myers, founder and our former president, has a proven track record of moving mountains and now that she will be able to dedicate all of her time to these efforts - watch out!"

- FamilieSCN2A Foundation Board

EVEN MORE EXCITING NEWS FOR THE FOUNDATION!



The FamilieSCN2A Foundation is excited to announce Leah Schust Myers has taken on the role of Executive Director!

Leah has spent her entire career working in health care administration and never imagined she would find a use for her skills in an entirely different way. From medical secretary to hospital manager and everywhere in between, Leah learned how to manage the needs of large populations within a medical setting. When her son, Ben, was diagnosed with an SCN2A Disorder in 2012, it became abundantly clear how to leverage her 20+ years of experience to help not only her family, but hundreds of others.

In July of 2019, Leah transitioned from her volunteer position as President of the Foundation Board, to a full time Executive Director role. The experience she brings with her, especially from her most recent position as Executive Project Manager for a fortune 500 Healthcare company, is giving the Foundation the professional edge to meet the growing needs of the community.

Communication and collaboration being her area of expertise, Leah has been instrumental in forming relationships with clinicians and scientists to advance progress in studying SCN2A and novel treatments. These alliances with researchers and industry leaders have been influential in catapulting SCN2A on to the map of exciting targets to study.

Are you curious who else is behind the scenes at the FamilieSCN2A Foundation?

The FamilieSCN2A Board Members play a key role in the success of working toward our mission *to improve the lives of those affected by SCN2A related disorders through research, public awareness, family support and patient advocacy.*

The FamilieSCN2A Foundation is always seeking volunteers, especially those with skills in the following areas:

- Finance / Accounting
- Board Governance
- Fundraising
- Administrative Skills
- Graphic Design / Marketing

Maybe you have a family member, friend, or co-worker who you think would be a great fit for a position. Send them our way! info@scn2a.org

Please take a minute to check out our amazing Board, Committee and Scientific Advisory Board Members: <https://www.scn2a.org/board.html>



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