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FOR IMMEDIATE RELEASE

The SYNGAP1 Foundation, the world leader in research, advocacy, and education for neuro-divergent SYNGAP1 discoveries, is pleased to announce these new members to the Board.



Matt Toresco is the Founder & Editor-in-Chief of The Advocate: Supporting the Patient Voice. He is also a Partner & Chief Commercial Officer at The Brooks Group. He has nearly 20 years of healthcare experience & is committed to the growth of the patient voice & patient advocacy. He himself is an advocate for patients facing the many struggles of chronic pain and the hurdles chronic pain patients face daily from all angles of today's society.



Liz Sachnoff is a clinical trial professional working for a Contract Research Organization aligned to overseeing rare disease clinical trials. She has 18 years of experience in the pharmaceutical, biotech, and medical device field. The last several years she has been focusing on CNS diseases. She has a project management professional certificate and has an MBA in Data Analytics. She serves on several committees for A Safe Place in Lake County, IL, an organization to help victims of domestic violence and human trafficking.



Rich Elles is a project management professional, fierce patient advocate, and veteran of both the life science and medical technology industries. Rich has a decade of experience of life science industry consulting and led global product development efforts within the Johnson & Johnson family of companies. Rich works as a strategic advisor to Tortus AI based in London and volunteers with both the EveryLife Foundation & the Life Goes On Foundation in Oakland, CA.



Stephanie Lee is a business operation and accounting professional. She has a BA in political science and philosophy from Christopher Newport University and an MS in accounting from Liberty University. She works as the Business Operations Lead at Palo Alto Networks.

She enjoys supporting nonprofits, as giving back is one of her passions. Stephanie enjoys reading a book or binge-watching TV shows in her free time.



Tracy Carroll brings strategic expertise in global enterprise stakeholder relations, specializing in communications and transformative special projects. He is a pioneer in live streaming, digital transformation, and a practitioner of performance improvement programs with senior executive level change management experience ranging from Wall Street, Washington, Health Care, Energy & Academe.



John Groth - Vice President, Pharma at Optima Corporation (Member At Large). John has over a decade of experience in the Health Sciences & Technology sector, specifically in aseptic processing, He also has more than 20 years of commercial finance experience. He recently completed his Master's degree in Law from Northwestern University Law School and has degrees in Business Administration and Finance.



Neil Morris is Senior Director, CIO, leading IT for Maxar Technologies. He led Technology Architecture at ADT Security Services, which provides security, video, and home automation solutions to over 6.5 million residential customers and over 100,000 large corporations and US agencies. Neil has a great depth of experience in digital transformation, user experience, business processes engineering, software development, and infrastructure at scale. Neil holds a Master's in Information Systems Management and a Bachelor's in Business Management.

“We are so very pleased with this new infusion of talent and expertise,” exclaimed Monica Weldon, CEO & Founder of The SYNGAP1 Foundation, “ and we feel we are now better poised than ever for continued growth and improved outcomes in delivering better advocacy on behalf of the many individuals and families currently dealing with SynGAP1 as well broadening awareness and stimulating more clinical research that has already proven to have positive benefits to our expanding global community.”

BACKGROUND

The SYNGAP1 Foundation

Our mission at the SYNGAP1 Foundation is based on three pillars (Advocacy, Education and Research). It is upon these pillars that we as a community are able to bridge gaps and make a positive and meaningful difference in lives on every continent.

Advocacy - We strive to make all SYNGAP1 community members feel valued, empowered, and connected. Our priority of patient advocacy and patient and family participation in ongoing research is already accelerating pathways to better treatments.

Education - Our SYNGAP1 Family Conferences and Clinical Meet-Ups maximize opportunities for SYNGAP1 patients and families to connect with other families and SYNGAP1 clinical and research experts. They provide a comfortable yet engaging setting where SYNGAP1 patients, families, and caregivers can connect and gain knowledge about SYNGAP1-related healthcare, education, research, and community resources, that will help them navigate their journey.

Research - We proudly steward the largest SYNGAP1 patient database in the world. Established in 2016, our data has been used to discover new mechanisms, biomarkers, and endpoints to support clinical trials

The SYNGAP1 (MRD5) Natural History Study and Registry is a pioneering research project that examines SYNGAP1 changes that are associated with intellectual disability, epilepsy, autism, and other overlapping symptomology and neurodevelopmental disorders.

Participants in the study:

- Learn about their family member's diagnosis
- Partner with some of the best minds in science
- Get updates on the latest research findings
- Connect with others who share their diagnosis
- Contribute to advancements that will change the future for families with SYNGAP1 gene changes.
- SYNGAP1(MRD5) Natural History Study and Registry is a research project that aims to study the SYNGAP1 gene changes that are associated with intellectual disability, epilepsy, autism, and other overlapping symptomology and neurodevelopmental disorders.

FOR MORE INFORMATION, please visit: [SYNGAP1Foundation.org](https://www.syngap1foundation.org)

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