SYNGAP RESEARCH FUND

Collaboration. Transparency. Urgency.

About Mike

When Mike's son was diagnosed with SYNGAP1-Related Disorder in 2018, he founded the SynGAP Research Fund and continues to serve as the CEO, *pro bono*. In the broader Rare Neurological Disease community, Mike serves on the AES Epilepsy Research Benchmarks Stewards, Executive Board of COMBINEDBrain, and is a member of the Leaders Link program by FasterCures of the Milken Foundation.

Mike comes from a career in public policy, international development and strategy. Previous roles have included establishing a new program at the New America think tank, Budget & Planning at both the Gates Foundation & Emerson Collective, healthcare consulting at BCG, serving as a Project Office at the World Bank Group, managing a refugee program for the International Catholic Migration Commission in Zimbabwe, and teaching math in Peace Corps Namibia.

Graglia has an MBA from Columbia where he was a Bronfman Fellow, an MA from Johns Hopkins School of Advanced International Studies where he was a Paul & Daisy Soros Fellow, and a BS in mathematics from Gonzaga University, S.J.

Graglia lives with his wife Ashley & two sons in Marin, California. He is available to connect via LinkedIn, Facebook and X.

About SRF

Michael Graglia's son Tony was diagnosed with SYNGAP1 in 2018 when he was 4 years old. Together with his wife, Ashley Evans, he founded the SynGAP Research Fund, 501(c)(3), to accelerate the science around SYNGAP1 in order to make sure there is a therapy developed in a time frame that matters for his son and children like him. SRF granted over $5M to scientific labs by the end of 2023.

There are over 1,400 cases of SYNGAP1 globally. We are aware of 385+ cases in the USA. SYNGAP1 is a disease that has multiple symptoms. Our children present with epilepsy, autism, intellectual disability, sleep disorder & numerous other symptoms. SynGAP patients are disabled for life, requiring huge investments from society & sacrifices from their families. The patients are often on a range of medications for epilepsy, sleep & other symptoms.

The disease results from spontaneous (not inherited) mutations on the critical neurological gene, SYNGAP1. We all have two copies of every gene, one from each parent. As a result of the mutation causing one of those genes to be unable to make the associated protein, our patients only have 50% of the necessary SynGAP protein. It is this lack of protein that causes this disease and all its symptoms.

SRF has multiple programs to serve patients and their families:

- We have a patient ambassador program to support newly diagnosed families.
- We engage with scientists via grants, conferences and our webinar series.
- We launched a cutting-edge medical records based digital natural history study in September 2020 in partnership with Ciitizen. We currently have over 225 patients enrolled.
- We have a Scientific Advisory Board that includes a number of leading scientists and leaders in the genetic epilepsy space.
- We host a two-day annual conference for scientists, doctors & families to come together.

SRF is governed by a board of fifteen different families of affected individuals.

503 words.

Photos below, please credit all of them to Barbara Kinney

Headshot:

Other photos: