2019 EPILEPSY PRECISION MEDICINE CONFERENCE SUPPORTED BY A $10,000 SRF GRANT

Palo Alto, California. (September 9th, 2019) – SynGAP Research Fund (“SRF”) is pleased to announce that it has awarded a $10,000 conference support grant to the 2019 Epilepsy Precision Medicine Conference. The event will be held in Washington, DC on September 16th & 17th.

SRF was established in 2018 to improve the quality of life of patients afflicted with SynGAP-1, a rare disorder deriving from a single gene mutation on the SynGAP gene, which typically causes intellectual disability, global developmental delay, epilepsy, autism, and related afflictions.

SRF Managing Director, Mike Graglia, explained the grant, saying, “Parents with a genetic diagnosis are the lucky ones — we know exactly what is causing our children’s symptoms. And we are candidates for precision medicine. But delivering these therapies to our patient population will require considerable advances as well as collaboration among scientists, doctors, regulators, and payers. Prof. Lowenstein has gathered 140 researchers, doctors and other stakeholders to address this challenge, and SRF is thrilled to be able to support this critical work.”

The values of SRF are: Collaboration. Transparency. Urgency. These grants capture all three of these values.

Collaboration

“The involvement of SRF and other patient-led groups is absolutely critical given that our collective success depends on having the voices of all stakeholders at the table, and building the highly functional, inclusive teams needed to achieve these goals,” said Prof. Dan Lowenstein, MD, Vice-Chancellor of UCSF and the organizer of the conference. The other patient-led groups supporting this conference are EF, CURE, LGS Foundation and Dravet Syndrome Foundation; SRF looks to exactly these organizations as models for how to operate and what can be accomplished. Furthermore, through this conference, SRF will seek to expand the network of Syngap-interested researchers, potential collaborators and future grantees.

Transparency

Following the conference, which the two SRF co-founders and 2019 SRF grantees will attend, SRF will report back to the Syngap patient community promptly. The agenda and speakers should give parents hope that real progress is afoot and therapies are coming.
This meeting builds on an earlier convening documented in the December 2015 *Lancet* article ‘A roadmap for precision medicine in the epilepsies’. The summary of that article states:

“Technological advances have paved the way for accelerated genomic discovery and are bringing precision medicine clearly into view. Epilepsy research in particular is well suited to serve as a model for the development and deployment of targeted therapeutics in precision medicine because of the rapidly expanding genetic knowledge base in epilepsy, the availability of good in-vitro and in-vivo model systems to efficiently study the biological consequences of genetic mutations, the ability to turn these models into effective drug-screening platforms, and the establishment of collaborative research groups. Moving forward, it is crucial that these collaborations are strengthened, particularly through integrated research platforms, to provide robust analyses both for accurate personal genome analysis and gene and drug discovery. Similarly, the implementation of clinical trial networks will allow the expansion of patient sample populations with genetically defined epilepsy so that drug discovery can be translated into clinical practice.”

**Urgency**

“The purpose of this meeting is to take a careful look at the current state of knowledge of the science, policies, and clinical issues related to the care of people living with epilepsy, and to define a roadmap that will enable us to achieve effective, personalized treatments, including cures, as rapidly as possible,” said Prof. Lowenstein.

“By convening diverse stakeholders in a focused session with collaborative intent, Dr. Lowenstein is taking an important step forward to develop therapies for genetic epilepsies like Syngap. We are grateful for his leadership and believe that it is collaborations like these that will help our patients, in the timeframe that matters” said Ashley Evans, Chair of the SRF Board.

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**About the Syngap Research Fund**

The mission of the Syngap Research Fund (SRF) is to improve the quality of life of SynGAP1 patients through the research and development of treatments, therapies and support systems. Syngap Research Fund, Incorporated is a nonprofit 501(c)(3) public charity (83-1200789) headquartered in Palo Alto, California. For more information, visit syngapresearchfund.com
Epilepsy Precision Medicine Conference

Epilepsy Precision Medicine
September 16-17, 2019
Washington, D.C.

A multi-disciplinary conference to help accelerate the application of individually tailored diagnostic and therapeutic approaches for patients with epilepsy.

This 2019 meeting is a second chapter to our initial 2014 meeting. We will bring together experts with a vested interest in the development of precision medicine for genetic epilepsies, and map out a strategy for accelerating the pace with which this goal can be achieved.

Scientists, clinicians, and representatives from lay organizations, industry, and government will have the opportunity to exchange ideas about key advances, prospects, and issues from a range of fields, including epilepsy research, clinical care, big data, biotech, and public policy.

The format of the two-day conference will include didactic presentations, open forums, poster sessions, and self-aggregating discussion groups that form around key ideas that emerge from the presentations.

See the agenda and speakers pages for more information.

From the Event registration website.