University of California, San Francisco, Launches First Consortium on Pediatric MG in partnership with MGFA and MDA

For families with children that have myasthenia gravis, we have some exciting news to share. Thanks to a generous gift from an anonymous donor to the University of California, San Francisco, the first clinical Pediatric Myasthenia Gravis Consortium is now a reality. MGFA was honored to provide a grant to underwrite the costs for the September inaugural meeting of this exciting new project, and to participate on the advisory committee for the Consortium.

Leading the Pediatric MG Consortium is Dr. Jonathan Strober of UCSF Benioff Children's Hospital. Other initial members of the Consortium include: Dr. John Brandsema, Children's Hospital of Philadelphia; Dr. Diana Castro, UT Southwestern; Dr. Emma Ciafaloni, University of Rochester; Dr. Nancy Kuntz, Ann & Robert H. Lurie Children's Hospital of Chicago and Dr. Ricardo Maselli, University of California, Davis. The Advisory Committee is comprised of patients and their families, along with Nancy Law and Dova Levin from the MGFA, staff of the Muscular Dystrophy Association, and representatives from industry- Alexion and Momenta.

A critical goal of this project to develop a pediatric patient database. Unlike the MGFA Patient Registry, where patients self-report through a survey about their health and symptoms, this will be a clinical registry with data direct from patients' medical records. This pool of data will help clinicians to better understand and treat pediatric MG and Congenital Myasthenic Syndrome (CMS).

At this initial meeting, the Consortium made decisions around what data to collect, how to collect data without increasing burden on the healthcare provider, and how to standardize the gathering of data. The Consortium also looked at methods of data collection, database options and possible plans for publication.

All the members of the committee are looking forward to the collection of this highly valuable data in order to enhance research, understanding and management of pediatric MG and CMS for the future.