



Fabry Support & Information Group

The FSIG Mission

Fabry Support & Information Group (FSIG) is a 501(c)(3) nonprofit organization. Our mission is to raise awareness of Fabry disease and its symptoms. The FSIG website provides mutual self-help by linking patients and family members/caregivers. In this way they can support and encourage one another. An increased understanding of Fabry disease and emotional support may alleviate some of the burden associated with this rare disorder.

FSIG's Beginning

FSIG was started in 1996 as a "kitchen table" support group formed by two Fabry patients and a supportive family member with the hope that their particular understanding of this disease, combined with experience at gathering information and working with doctors could benefit others. FSIG is a continually growing and expanding organization constantly looking for new opportunities to assist in improving patient's lives.

Medical Advisors

The contributions of our medical advisors are invaluable and are greatly appreciated. FSIG is very fortunate to have **Christine Eng**, M.D. is Associate Professor, Department of Molecular and Human Genetics at Baylor College of Medicine in Houston Texas, **Edwin Kolodny**, M.D. Professor of Neurology at New York University School of Medicine, New York, NY, **Ravi Ishwar Thadhani**, M.D. M.P.H. Assistant Professor at Harvard Medical School and a Nephrologist at Massachusetts General Hospital, Boston and **William Wilcox**, M.D., PhD is Director of the Metabolic Disorders Clinic in Medical Genetics and Director of the Lysosomal Storage Disease Treatment and Research Center at Cedars-Sinai Medical Center, Los Angeles, CA. They all have many years experience in the treatment and research of Fabry and other related Diseases.

FSIG Services

FSIG's primary goals are to educate and support. Through mutual self help, it is hoped that the emotional support, which is so important to us all, can be obtained. To help facilitate this FSIG maintains a confidential database of Fabry patients to assist in networking. This database also serves as a means of documenting the increasing numbers of diagnosed Fabry cases. FSIG also maintains a library of information about Fabry disease and is continually updating this body of knowledge.

FSIG Membership and Support

FSIG relies on charitable contributions, in kind donations, corporate/industry donations and grants to continue providing services to those affected by Fabry Disease. Contributions may be sent to FSIG, 108 NE 2nd Street, Suite C, P.O. Box 510, Concordia, MO 64020, 660-463-1355.
