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SADS Foundation History

The mission of the SADS Foundation is to save the lives and support the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

In 1991 a group of scientists at the University of Utah discovered the chromosomal location of genes causing a prolonged QT interval in the heart rhythm responsible for many sudden arrhythmia-related deaths. With these findings, it became apparent that Long QT Syndrome (LQTS) was much more common than generally recognized and was often misdiagnosed. It also became apparent that there was a real possibility to save lives of those with LQTS and other genetic precursors of cardiac arrhythmia, such as brugada and cardiomyopathies, through public awareness and education. The Sudden Arrhythmia Death Syndromes Foundation, or SADS Foundation, was established as a nonprofit, 501(c)3 organization, headquartered in Salt Lake City, Utah in 1992.

In the eleven years since its inception, more than 30,000 individuals have received educational materials and support. The SADS Foundation has compiled a database of more than 27,000 Americans living with, or concerned about LQTS and cardiac arrhythmias.

Each year Foundation staff responds to more than 650 requests for information, medical referrals, and support resources. More than half these inquiries are from newly diagnosed individuals. A nationwide network of volunteers responds to hundreds more inquiries annually. The website www.sads.org receives more than 150 visits daily from people seeking additional information about long QT syndrome and the SADS Foundation.

Chapters of the SADS Foundation were established in Canada (1998), Great Britain (1999), and Australia (2000). These organizations promote awareness events in their own countries through conferences, events and volunteer networks established with the assistance of the US-based SADS Foundation.

The SADS Foundation operates four programs:

- The Awareness Program informs the public about the symptoms and risks of cardiac arrhythmias.
- The Patient and Family Support Services increase individuals' ability to make informed decisions about the diagnosis and treatment of hereditary life-threatening arrhythmias.
- The Medical Education Program brings information and training opportunities to health care professionals.
- Advocacy and Research Program assist to translate research to practice, encourage participation in research and advocate for families rights and quality care.

In 1999 the SADS Foundation produced an educational video documenting diagnosis and treatment of Long QT Syndrome and including family stories. It has been distributed it to volunteers across the country for use in presentations, to show on their local cable stations, and to use in other ways. The SADS Foundation held its first international conference in London in October 2002. This event attracted 40 physicians and 160 individuals from families at risk for sudden death from around the world. A second conference will take place in Atlanta Georgia in October 2003.

By increasing awareness in the general population about sudden cardiac death and its symptoms, more children will be correctly screened after a fainting incident. Physician and patient education improves the chances that relatives of patients will be screened and treated if necessary.

To learn more about educational presentations, activities, events, and programs available in your area, or to receive materials that could potentially save the lives of young people you care about, contact the SADS Foundation at 1-800-STOP-SAD.