



SADS Awareness



Patient and Family Support



Research and Advocacy



Medical Professional Education

**Supporting families. Saving lives.**

## SADS Foundation - Leading the Way to Save More Lives in 2008

*"Before my daughter, Megan 17, was diagnosed in January with LQTS, I was totally unaware that such a thing existed. Your wonderful organization has helped to educate and bring comfort to me during this otherwise very traumatic time. 'Thank You' from the bottom of my heart. Keep up the good work" -Pamela*

The Sudden Arrhythmia Death Syndromes (SADS) Foundation exists 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. Each year over 4,000 children and young adults die unexpectedly due to Long QT and other arrhythmias. If more families knew where to go for information, medical care and support, most of these deaths would not occur. For over 16 years, the SADS Foundation has educated, supported and advocated on behalf of children and their families.

The Foundation is proud of its record of accomplishments, last year addressing the needs of over 800 new families, providing materials to almost 135,000 people via our website and communicating with over 12,000 US households through the SADS News publication. The Foundation is visible in local communities, at national conferences and in the halls of Congress increasing public awareness and calling for research, diagnosis and treatments to save more young lives.

We have made excellent progress, but more needs to be done! The SADS Foundation hears from newly diagnosed families every day. We learn of the untimely deaths of children each month. We worry that thousands of children go undiagnosed and untreated each year.

**New Ways of Looking at Our World:** The Foundation's Board of Directors determined that it was important to focus on all channelopathies, not solely Long QT and that the Foundation should re-frame its materials and activities to reflect the hope that exists for our patients and families to "live and thrive with SADS." Toward this end, we are changing our logo and tagline, revising the look and functionality of our website and developing new physician and patient materials.

**Critical goals for 2008:** The SADS Foundation has established an ambitious agenda that includes goals in each of our four major areas – patient and family support, public awareness, education of health professionals and advocacy for increased research.

**Enhance Patient and Family Support:** Provide information, resources, and support to assist children and their families to make informed medical decisions and to live and thrive with these conditions.

- Initiate a family health history project to enable families to find and inform members who may be at risk of sudden cardiac death;
- Enhance work with genetic counselors, physicians and nurses who assist SADS families to expand their family pedigree;
- Hire a Family Support and Volunteer Director to increase the level of support to families who are newly identified as being at risk and to expand the number of trained volunteers to work at the local level;
- Expand information and resources on the website, including development of individual channelopathy materials, as well as translation to Spanish;
- Create a needs assessment (survey) to identify additional ways in which we can serve patients and their families.



**Increase Awareness of SADS and SADS Warning Signs:** Increase the general public's knowledge of the warning signs of heart rhythm abnormalities that can cause sudden death in the young.

- Expand materials and activities related to SADS Awareness Month and increase media outreach efforts during this time;
- Develop a pilot project focused on identifying and disseminating key messages, outreach to the public and the media and increasing the profile of the SADS Foundation and of cardiac arrhythmias;

**Expand Education to Health Professionals:** Facilitate early diagnosis and treatment of heart rhythm abnormalities by ensuring that healthcare providers have all available current and relevant information.

- Enhance information and tools to assist health professionals (especially focused on primary care) to recognize cardiac arrhythmias, to refer appropriately and to rely on the SADS Foundation for family support; e
- Partner with the Pediatric and Congenital Electrophysiologists Society (PACES) on our newly re-designed website to ensure that materials meet their needs and those of their patients; making SADS the premier online resource, offering accessible, authoritative information about cardiac channelopathies and sudden death in the young, its prevention, management and care
- Propose to PACES that we work together to promote development of a national channelopathy registry;
- Sponsor the lecture at the annual PACES dinner meeting in honor of Katherine Timothy.

**Increase Advocacy for Research, Screening and Medical Treatment:** Encourage increased arrhythmia research, nondiscriminatory treatment and efforts that will improve the quality of life for patients with heart rhythm abnormalities.

- Support funding increases for federal research efforts and help identify unanswered research questions and areas for further exploration related to Long QT, Brugada and other arrhythmia syndromes;
- Support efforts to identify appropriate screening protocols to determine who should be tested, by what means and how often;
- Encourage continued innovation in medical technology and treatments, including ICDs, for children at risk of sudden death;
- Encourage medical emergency plans that include placement of automated external defibrillators (AEDs) in all schools throughout the United States;
- Promote CPR/AED training as a requirement for high school graduation;
- Advocate for nondiscriminatory treatment for people who are diagnosed with arrhythmia conditions;
- Promote access to health insurance coverage and medically-necessary treatments;
- Initiate an annual SADS Young Investigator Award in Cardiac Channelopathies; administered through PACES.

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