

sudden cardiac death in the young

- **Each month in the United States, hundreds of young people die suddenly and unexpectedly due to cardiac arrhythmias.**
- **These conditions include Long QT Syndrome (LQTS), Hypertrophic Cardiomyopathy (HCM), Arrhythmogenic Right Ventricular Dysplasia (ARVD), and others.**
- **LQTS is now known to be three times more common in the US than childhood leukemia.**
- **HCM is the most common cause of sudden cardiac death in people younger than 35 years old.**
- **As many as 12 in every 5,000 young people may have one of these conditions that can cause sudden death.**
- **Most sudden cardiac deaths in children are due to hereditary conditions.**
- **Most cardiac arrhythmias and structural defects that may cause sudden death in the young are identifiable and treatable. With treatment, people with these conditions often have normal life spans and lifestyles.**

References for the above facts are available online or at 800-STOP-SAD



BOARD OF TRUSTEES

G. Michael Vincent, M.D., Board Pres., Salt Lake City, UT
 David E. Salisbury, Board VP, Salt Lake City, UT
 Katherine W. Timothy, Board Sec., Salt Lake City, UT
 Michael Ackerman, M.D. Ph.D., Rochester, MN
 Walter Allan, M.D., Scarborough, ME
 Denise Falzon, Orchard Lake, MI
 Ralph W. Hardy, Jr., Washington, DC
 Victoria E. Judd, M.D., Salt Lake City, UT
 Sylvia Priori, M.D., Pavia, Italy
 Peter J. Schwartz, M.D., Milan, Italy

INTERNATIONAL AFFILIATES

Australian SADS, Julie Foley - Victoria, Australia
 The Canadian SADS Foundation, Pam Husband - Ontario, Canada
 SADS UK, Anne & John Jolly - Essex, England

SCIENTIFIC ADVISORS

Peter J. Schwartz, M.D., Chairman, Milan, Italy
 Charles Antzelevitch, Ph.D., Utica, NY
 Robert Campbell, M.D., Atlanta, GA
 Isabelle Denjoy, M.D., Paris, France
 Arthur Garson, Jr., M.D., Houston, TX
 Thomas S. Klitzner, M.D., Los Angeles, CA
 Dan M. Roden, M.D., Nashville, TN
 Jeffrey A. Towbin, M.D., Houston, TX
 Victoria L. Vetter, M.D., Philadelphia, PA
 Samuel Viskin, M.D., Tel Aviv, Israel
 Arthur Wilde, M.D., Amsterdam, Netherlands
 Raymond L. Woosley, M.D., Ph.D., Washington, DC

Sudden Arrhythmia Death Syndromes (SADS) Foundation

508 E. South Temple, Suite 20
 Salt Lake City, UT 84102
 1-800-STOP-SAD www.sads.org

Printed by Lorraine Press, 801-972-5626



Sudden Arrhythmia Death Syndromes (SADS) Foundation

SADS mission

To save the lives and support the families of children & young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

in the beginning

In 1991 a group of scientists headed by Drs. Michael Vincent and Mark Keating at the University of Utah isolated the chromosomal location for the first gene known to cause Long QT Syndrome. This was a landmark discovery in the study of unexplained sudden death in the young. This breakthrough confirmed suspicions that LQTS was more common than once believed. As doctors learned more about prolonged QT intervals, it became clear the syndrome was widely misunderstood, and often, misdiagnosed.

The SADS Foundation was organized to implement widespread educational programs to make people aware of these conditions that can cause sudden death in the young and to provide support to people living with the reality and risks of serious heart rhythm abnormalities.

Your child should be seen by a doctor if she/he has:

- **Family history of unexpected, unexplained sudden death in a young person**
- **Fainting (syncope) or seizure during exercise, excitement or startle**
- **Consistent or unusual chest pain and/or shortness of breath during exercise**

letter from a parent

I want to attest to the critical service that SADS provides internationally to raise awareness of Long QT Syndrome (LQTS) as well as the support it gives to both those afflicted with the genetic disorder and their families at a very critical time.

I vividly remember in May of 2000 when I first heard the term LQT and realized that it was the silent killer that had claimed my mother’s life when I was only seven years old. The local medical community knew that it existed but were still very naive in the area of diagnosis and treatment. Thirsting for answers to the million questions that whirled in my brain I turned to the Internet for information. This was my first exposure to the SADS Foundation and my number one source of information, referrals and, most importantly, comfort during what was an extremely stressful time.

My current involvement with SADS is fueled by multiple stories of people who have benefited from exposure to your organization. I have watched firsthand as you and your team have spread the word internationally. While the passion is unmistakable at SADS, your ability to take it beyond your walls with the network of volunteers that you are setting up around the world is even more impressive. In three short years you have created awareness in the communities of education, medicine and government.

The commitment of the staff and the broad-based expertise of the Board of Directors presents a recipe for future success for all involved. SADS dedication, forward looking vision and the support of volunteers throughout the world will allow LQTS and associated research to become a household word – along the way saving countless lives. There is not a day that goes by that I am not thankful that I came upon sads.org.

KARLA AALAND, FARGO, ND



Karla and Jenna Aaland, Long QT patients and SADS volunteers

how we help

- Provide educational materials annually to more than 25,000 patients, doctors, and families around the world.
- Provide physician and other specialist referrals to more than 100 people each year.
- Recruit, train and support dedicated volunteers working throughout the world to promote awareness and educate their communities.
- Provide media kits to journalists resulting in increased awareness about LQTS and other disorders causing sudden cardiac death—both locally and nationally.
- Distribute hundreds of medical information packets to newly diagnosed patients and family members every month.
- Maintain www.sads.org which receives an average of 5,400 visits a month. Staff responds to an average of 190 phone calls and 400 emails every month.

what we do

Family Support: We provide information, resources, and support to facilitate patients’ and families’ ability to make informed medical decisions about diagnosis, treatment, and living with heart rhythm abnormalities that can cause sudden death.

General Awareness/Prevention: We proactively increase the general public’s knowledge of the warning signs of heart rhythm abnormalities that can cause sudden death.

Education: We facilitate early diagnosis and treatment of heart rhythm abnormalities by ensuring that healthcare providers have all available current and relevant information.

Advocacy/Research: We encourage research, advocate for nondiscriminatory treatment, and support efforts that will improve the quality of life for patients with heart rhythm abnormalities.

Volunteers: We recruit, train and provide support and resources for volunteers across the country who work collaboratively with us to implement SADS’ programs and achieve our goals.

donate SADS relies on donations to support our programs. We hope you can contribute to our life-saving efforts. As a SADS donor, you will join a community of people committed to preventing sudden cardiac deaths in young people.

- I would like to contribute a gift of \$_____.*
- I have enclosed a check payable to the SADS Foundation.*

Charge my: mastercard visa amex

_____ card number exp. date

_____ name on card signature

volunteer SADS relies on volunteers throughout the country for creative initiatives that best spread the word about sudden arrhythmia death syndromes (SADS) and other dangerous arrhythmias. We have many volunteer opportunities. We are always looking for new people and the talents they bring.

- I would like to volunteer.*

find out more SADS provides materials to educate people about the symptoms, diagnosis and treatment of Long QT Syndrome and other dangerous arrhythmias. We have posters, brochures, fact sheets and articles. We also publish a quarterly newsletter.

- I would like more information.*

_____ name

_____ address

_____ city state zip

_____ country home phone work phone

_____ e-mail

Please return this form to: SADS Foundation, 508 E. South Temple, Suite 20, Salt Lake City, UT 84102.