

## Where to Start

Welcome to the SADS Foundation. We hope this page will help you find the information you need about SADS conditions.

### Our Mission

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. We provide education and support to families and the medical community who are dealing with these disorders.

The SADS Foundation is dedicated to providing information, assistance, and hope.

### Facts about these Genetic Conditions:

- Each year 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), Brugada Syndrome, etc.
- LQTS is now known to be 3 times more common in the US than childhood leukemia.
- HCM is the most common cause of sudden cardiac death in people under 35.
- Most cardiac problems that may cause sudden death in the young can be diagnosed and treated.
- With treatment, people with these conditions can have normal, productive lives.
- Most sudden cardiac deaths in children are due to hereditary conditions—so every family member should be tested.

### What You Can Do:

All children should have the Risk Assessment Form (PDF) completed—and be checked by a doctor if they answer “yes” to any question.

- You or your child’s doctor should fill out the Risk Assessment Form (PDF). If you answer yes to any of the questions, your doctor should check your child’s heart.
- If your child has any of the following signs see your doctor.

### Warning Signs:

- Family history of unexpected, unexplained sudden death in a young person (under 40), including sudden drowning and single car accidents

- Fainting (syncope) or seizures during exercise (or right after exercise), excitement or being startled
  - Consistent or unusual chest pain and/or shortness of breath during exercise
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- Ask your school or child's sports association to make this questionnaire a mandatory for all kids before they participate in any active sport.

For More Information:

- LQT\_Facts\_Sheet a simple explanation of LQTS, including the diagnosis of LQTS
- Long\_QT\_Brochure a pdf document with a detailed explanation of LQTS
- Brugada Syndrome Brochure a pdf document with a detailed explanation of Brugada Syndrome
- Kid's Guide to SADS a pdf document with information for kids on LQTS and the SADS Foundation
- Mayo Clinic LQTS information
- Complete list of SADS Informational Materials

Physician Referrals:

These professional groups have information about physician specialists around the country:

- Pediatric Electrophysiology Society: [www.pediatricesociety.org](http://www.pediatricesociety.org)
- Heart Rhythm Society: [http://www.hrsonline.org/PatientInfo/specialist\\_locator.cfm](http://www.hrsonline.org/PatientInfo/specialist_locator.cfm)

#### SADS

has a list of physicians that specialize in the electrical part of the heart and have experience with Long QT Syndrome. These are mostly pediatric electrophysiologists. We don't have physicians from all parts of the country on our list.

We would be happy to answer any questions, send you materials or help direct you to the proper information. Just complete the Family Registration Form and we will get back to you as soon as possible.