



Long QT Syndrome (LQTS)

Any young person who has experienced unexplained fainting should be tested and evaluated by an Inherited Arrhythmia Clinic specialist.

LQTS affects apparently healthy people, but with early diagnosis and proper treatment, they can **live and thrive**.

It is extremely important that **all family members be tested** for LQTS once one family member is identified with LQTS.

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.

What is Long QT Syndrome (LQTS)?

1. LQTS is a disturbance of the heart's electrical system, causing an abnormality of the heartbeat, or rhythm of the heart in apparently healthy people.
2. It is a genetic heart condition that can be passed on in families and affects 1 in 2,000 people.
3. Because of this abnormality, affected people are vulnerable to sudden fainting (syncope) and even death.
4. Unfortunately, many times the cause of the syncope is overlooked and the events are called simple fainting spells or seizures.
5. However, with increased awareness, genetic testing, and effective treatment options, LQTS can be diagnosed early and sudden death prevented.
6. Most often, these events occur during physical exertion, emotional stress or startle (alarm clock). Sometimes they occur during sleep.

What are the symptoms? *A child should be seen by a doctor if she/he has:*

- ♥ Fainting episodes (syncope) during or immediately after exercise
- ♥ Fainting as a result of emotional excitement/distress/startle
- ♥ Family history of unexplained death under the age of 40

How is it Diagnosed?

The diagnosis is made from an ECG that has been read by a cardiac electrophysiologist, not a computer. Exercise (treadmill) testing and a heart monitor will help clarify the diagnosis. Finally, a diagnostic genetic test is the standard of care for anyone with LQTS and their family members. More than 80% of LQTS patients will have a positive genetic test. Genetic testing, along with a thorough evaluation, is the best way to know for sure if you have LQTS, as well as to help guide treatment decisions.

How Is It Treated?

Treatment is very effective in the vast majority of patients. Medications called beta-blockers are very effective in about 90% of patients. In the remaining cases, an implantable cardiac defibrillator (ICD) is used. With proper treatment, you can live and thrive with Long QT Syndrome.



Pediatric Sudden Cardiac Death Risk Assessment Form

Parents - Please answer these questions (or have your child's doctor help complete them) every few years at these times: preschool, before/during middle school, before/during high school and before participating in organized sports.

Patient History Questions:		Yes	No
Has your child fainted or passed out DURING exercise, emotion or startle?			
Has your child fainted or passed out AFTER exercise?			
Has your child had extreme fatigue associated with exercise (different from other children)?			
Has your child ever had unusual or extreme shortness of breath during exercise?			
Has your child ever had discomfort, pain or pressure in his/her chest during exercise?			
Has a doctor ever ordered a test for your child's heart?			
Has your child ever been diagnosed with an unexplained seizure disorder?			
Family History Questions			
Are there any family members who had an unexpected, unexplained death before age 40? (include SIDS, car accident, drowning, others)			
Are there any family members who died of heart problems before age 40?			
Are there any family members who have had unexplained fainting or seizures?			
Are there any relatives with certain conditions such as:			
Hypertrophic cardiomyopathy (HCM)			
Dilated cardiomyopathy (DCM)			
Aortic rupture or Marfan syndrome			
Arrhythmogenic right ventricular cardiomyopathy			
Long QT syndrome (LQTS)			
Short QT syndrome			
Brugada syndrome			
Catecholaminergic ventricular tachycardia			
Pacemaker			
Congenital deafness			
Please explain more about any "yes" answers here:			

If you answer yes to any of these questions, your doctor should check your child's heart.

For more information or if you need a referral to a heart specialist, contact:

StopSADS.org The life you save may be your child's...or your own!

Supporting Families. Saving Lives

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