



My nephew, Frankie, died at age 13 while running to the school bus one morning. My daughter was then diagnosed with LQTS & has been taking medication for several years.  
—Patti

## Remember...

- 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.
- All children should have the questionnaire completed—and be checked by a doctor if they answer “yes” to any question—before they participate in organized sports programs.

## SADS Foundation

### 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.



**Sudden Arrhythmia Death Syndromes (SADS) Foundation**  
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## Facts About Sudden Cardiac Death in the Young

Your child or a young person you know may be at risk for sudden cardiac death due to an inherited condition. He/she will appear healthy and, in most cases, you will have absolutely no idea that something might be wrong. Once diagnosed, these conditions are treatable!

### About sudden cardiac death in the young:

- Each year in the United States, 356,461 Americans die suddenly and unexpectedly due to cardiac arrhythmias. **These deaths total more than cancer and lung disease combined!** (AHA Heart Disease and Stroke Statistics—2019 Update)
- Approximately 7,000 of those deaths are in children under age 18 (AHA Heart Disease and Stroke Statistics—2019 Update)
- These conditions include LQTS, Hypertrophic Cardiomyopathy (HCM), Brugada Syndrome, CPVT, and ARVC, among others.
- It is estimated a sports-related sudden cardiac death occurs every 3 days, equaling approximately 110 deaths per year. (Br J Sports Med 2013;47:1171-1174)
- Approximately 10-12% of sudden infant death syndrome can be attributable to genetic heart diseases (GHDs). (AHA Heart Disease and Stroke Statistics—2019 Update)

### Other facts:

- Most SCD in children is due to hereditary conditions and, therefore, more than one family member will be at risk. It is extremely important that **all** family members be tested once one family member is diagnosed.
- The symptoms of genetic arrhythmias (like LQTS) are frequently misdiagnosed as vasovagal syncope, asthma or epilepsy without any cardiac evaluation.
- Most cardiac arrhythmias and structural defects that may cause sudden death in the young are treatable. With treatment, people with these conditions often have normal life spans and lifestyles.

### A 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

# Pediatric Sudden Cardiac Death Risk Assessment Form

Parents, 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 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 50? (include SIDS, car accident, drowning, others)		
Are there any family members who died of heart problems before age 50?		
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		
Primary pulmonary hypertension		
Pacemaker		
Congenital deafness		
<b>Please explain more about any “yes” answers here:</b>		

**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:

**Family Support Help Line: 801-948-0654 | [www.StopSADS.org](http://www.StopSADS.org)**

**Supporting Families. Saving Lives**

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