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.
- Most sudden cardiac deaths in children are due to hereditary conditions—so every family member should be tested.
- 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.
- Current training in CPR and use of the AED is very important, especially if you are with active students after school and in different locations.

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.

COACHES: You could save a LIFE!!

A child on your team may be at risk for sudden cardiac death due to an inherited condition. These children usually appear healthy and, in most cases, the young person and her/his parents 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, 350,000 Americans die suddenly and unexpectedly due to cardiac arrhythmias. Almost 4,000 of them are young people under age 35 (CDC 2002).
- 10-12% of SIDS is due to Long QT Syndrome.
- 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.
- 1 in 200,000 high school athletes in the US will die suddenly, most without any prior symptoms—*JAMA 1996; 276.*
- According to the CDC, deaths from SCA increased 10% (from 2,719 in 1989 to 3,000 in 1996) in people between the ages of 15 and 34.

what you can do

- 1. We are asking you to add the questions from the form on the back to your physical screening forms. If you get a "yes" to any of the questions, the child should see a doctor for a cardiac evaluation.
- 2. If a child has any of the following signs he/she should see a doctor.

Warning Signs:

- 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
- 3. Ask your school and other sports associations to make this questionnaire a mandatory for all kids before they participate in any active sport.

For more information or if you have any questions, please ask us—we would be happy to help. Call 1-800-STOP SAD (<u>www.stopsads.org</u>).

Thanks for helping us save the lives of young athletes!

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		

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: 1-800-STOP SAD (<u>www.StopSADS.org</u>)

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

Supporting Families. Saving Lives

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