SADS FOUNDATION
SUPPORTING FAMILIES. SAVING LIVES.

Attention: School Health Professionals

Prevent Sudden Cardiac Death in Your Schools

You may have children in your school(s) with a SADS condition. These children usually appear healthy and, if undiagnosed, the young person and her/his parents have absolutely no idea that something might be wrong. Once diagnosed, these conditions are treatable.

We have included material in this packet that will acquaint you with the facts about sudden cardiac death in young people, how to determine if syncope (fainting) is life-threatening, screening for SADS conditions, and information you can use to make your schools SADS Safe Schools.

We are asking you to add the Risk Assessment questions (see *Is Your Child at Risk?* attached) to your school's physical screening forms. If there are any "yes" answers, the student should have a cardiac screening.

Included in this packet are a teacher and a coach flyer. If you would like more flyers for your teachers and/or coaches—or more *Is Your Child At Risk?* sheets for parents—you can order them online. We are also including a SADS poster and would be happy to send you more posters for all your schools (to hang in halls, gyms, teacher's lounges, school offices, etc.)

We have also included samples of the Individual Care Plans (we have them for each condition) that we recommend for all children with SADS conditions.

You may order more materials at www.StopSADS.org. We will also be happy to answer any questions you may have—thanks for your help!

Genevie Echols, RCIS
Family Support Director SADS Foundation
Genevie@SADS.org

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How You Can Help Create SADS Safe Schools:

- Order & display SADS materials in all schools—in hallways, teachers' lounges, gyms, etc.
- Add SADS Risk Assessment questions to the school's health forms.
- Conduct training with other school nurses and your teachers, and coaches.
- Develop Individualized Care Plans for all children with SADS conditions
- Encourage schools to mandate CPR training for all high school students.
- Refer affected students & their parents to the SADS Support Line:
- 801-948-0654.

Warning Signs:

- A family history of unexplained, sudden death in a young person (under age 40)—including drowning suddenly
- Fainting (syncope) or seizure during exercise, excitement, or startle
- Consistent or unusual pain and/or shortness of breath during exercise.

SADS FOUNDATION
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Patient Support: 801-948-0654
Fax: 801-505-0282
StopSADS.org

SADS Works to Keep
Children Safe at School

The Sudden Arrhythmia Death Syndromes (SADS) Foundation recommends that every child with a SADS condition has a personalized care plan, a school Medical Emergency Plan and an AED in place. We want to ensure that school officials are aware of the implications of SADS and are prepared to respond to an emergency immediately.

SADS has created care plans for children with heart conditions, including: **Long QT Syndrome, kids with ICDs, ARVC/ACM, CPVT, Brugada Syndrome, WPW**, and more. Utilizing these care plans as the basis for an individualized health care plan for all students with a SADS condition will help keep kids safe at school. We also have materials for school nurses, teachers and coaches that will help them understand children with SADS conditions and their needs.

We want every school to be a Heart Safe School

- Every child should have a **risk assessment** history at regular intervals: preschool, before/during middle school, before/during high school and before participation in organized sports
- SADS offers a simple, comprehensive risk assessment form, the "Pediatric Sudden Cardiac Death Risk Assessment Form" that you can download and/or order from our website.
- Every school should have a medical **emergency response plan** in place, which includes a plan for cardiopulmonary resuscitation (CPR) and an automated external defibrillator (AED) in schools. (see sample at www.StopSADS.org).
- Every school child with a SADS condition should have an individualized **care plan** in place. (see samples at www.StopSADS.org)
- All high school students should be trained in CPR and AED protocol as a requirement for graduation.
- Everyone should be aware of the warning signs that may indicate a child at risk of a sudden cardiac arrest.

The SADS Foundation is dedicated to making sure that all children are safe from sudden death due to heart rhythm abnormalities. We need your help to make this a reality.

For more information or to order materials, call (801) 272-3023
or visit **www.StopSADS.org**

Back to School Checklist

For Parents with Students with SADS Conditions

Make sure you do the following to help your school environment be as safe as possible for your SADS child. Ask to meet with the principal, school nurse, and, possibly, the 504 plan team. At the meeting:

___1. Develop an Individualized School Health Care Plan for your child (SADS has recommended plans for you to customize at www.StopSADS.org. This plan may also be called a 504 plan or another name but, no matter what it's called, it should include everything on our recommended plan. To develop the plan:

- Take our plan to your child's physician to complete the activities, etc. **OR**
- Work with your school nurse to complete the plan—using your knowledge of your child's condition and your doctor's recommendations **OR**
- Fill out the plan yourself and take it to the meeting

___2. To ensure that your child's Individualized School Health Care Plan is in place and working, verify the following:

- Who is responsible for receiving the plan (the principal, school nurse)?
- Where is the care plan housed (in a file, binder, etc.)?
- Who is responsible for implementing the plan, if needed?
- How does the school train staff regarding the existence and implementation of individual care plans?
- Ensure the plan includes the buddy system for your child everywhere they go.

___3. Make a plan to ensure that all above recommendations are in place.

- Ensure that all staff have a picture of your child.
- Offer to provide training in existing staff meetings, etc.
- Speak directly to all staff that interact with your student (lunch room and playground aides, coaches or PE teachers, break out teachers, etc.)

___4. Is your school a Heart Safe School?

- If the answer is YES, you are done!
- If the answer is NO:
    - Ask the principal what the school's Emergency Medical Plan is, and whether all staff are trained on their role. (See SADS recommendations for these plans and samples at www.StopSADS.org)
    - Check to see if the school has an AED, a plan for the use of the AED and whether all appropriate staff is trained to use an AED. Make sure there is a plan in place to regularly check expiration dates of AED pads and the battery to keep the AED properly maintained.

If you feel like your school is not able to provide a safe environment and need additional help, call your school district. They will often advocate for your child, and educate you regarding the federal law pertaining to a child with a disability (your child's SADS condition is considered a disability) and your educational rights.

If you aren't able to get your child's school to work with you on this, please let us know. You can file a complaint with your regional Office of Civil Rights of the U.S. Department of Education. If you wish to file a 504 complaint, go to www.ed.gov/about/offices/list/ocr/complaintintro.html or call (800) 421-3481. For additional information about Section 504 visit the Dept. of Ed at www.ed.gov/about/offices/list/ocr/504faq.html.

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 **live and thrive.**
- **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.

Facts About
Sudden Cardiac Arrest in the Young

Your child or a young person you know may be at **risk for sudden cardiac arrest due to an inherited condition**. They 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, more than 356,000 Americans die suddenly and unexpectedly due to cardiac arrhythmias. More than 7,000 of them are young people under age 18. (AHA Heart Disease and Stroke Statistics—2020 Update)
- Every hour, a young person under 18 dies from sudden cardiac arrest.
- Sudden cardiac death is one of the top five leading causes of death in young adults.
- Approximately 10% of sudden infant death syndrome can be attributable to genetic heart diseases. (AHA Heart Disease and Stroke Statistics—2020)
- These conditions include LQTS, Hypertrophic Cardiomyopathy (HCM), Brugada Syndrome, CPVT, and ARVC, among others.

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.
- Genetic heart conditions that may cause sudden death in the young are treatable. **With treatment, people with these conditions can live and thrive.**

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		
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.

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Preventing Sudden Cardiac Death in Your Schools with AEDs

The SADS Foundation wants to make sure that each child grows up happy and healthy!
It is important for all staff members to know: how to recognize a sudden cardiac arrest, that time is critical, who the first responders are, that there is an AED, where the AED is, and enough about the emergency plan to know how to initiate it if they ever witness an unresponsive victim.

Facts about Automated External Defibrillators (AED)

- A shock delivered by an automated external defibrillator (AED) within 3-5 minutes may save these lives. Survival rates decrease by 10% with *each minute* of delay.
- If a shock is not needed, the device will not shock the victim (i.e. if there has been a seizure, injury, or another cause for the victim to collapse). In this case other reasons for the collapse should then be assessed and CPR should be continued if needed.
- AEDs are safe and easy to use. A study published in *Circulation* found that sixth-graders with no training were able to correctly use AEDs, and use them at an only modestly slower pace (90 second versus 67 seconds) than trained EMTs.
- And AEDs work. Survival rates up to 74 percent have been achieved in places that have successfully implemented AED programs.

Why Schools Should be Concerned with Sudden Cardiac Arrest

- Schools are public gathering places where 20% of the general public is present at any given time.
- Unfortunately, anyone can suffer sudden cardiac arrest. SCA is unpredictable and can happen to anyone, anytime.
- The average time it takes emergency crews to arrive is between 8-12 minutes, giving your students and visitors a very minimal chance at survival.

How does an Automated External Defibrillator (AED) save lives?

- The only way to effectively treat sudden cardiac arrest (SCA) is with an electrical shock delivered by a defibrillator. Voltage stored by the defibrillator pushes an electrical current through the heart by means of the electrodes placed on the chest. This brief electrical pulse halts the chaotic activity of the heart, giving it a chance to start beating again with a normal rhythm.
- AEDs are extremely easy to use, difficult to misuse and have been designed specifically for lay responders. This enables anyone to give a defibrillation shock that could save a life.

Can the user of an AED or our School District be held liable?

All 50 states in the U.S. have Good Samaritan laws, giving immunity to lay people who help others in distress. AED programs are included under national Good Samaritan laws. In addition, the federal Cardiac Arrest Survival Act (CASA) provides additional Good Samaritan protection, including limited immunity for those who provide emergency treatment with an AED.

Resources for Schools

- Project S.A.V.E. provides help in developing/revising your plan, including lists and protocols.
- Project A.D.A.M. is a program to help schools become heart safe and provides materials and assistance for programs around the country.
- American Heart Association—AED guidelines, etc. for businesses & schools.
- SADS Foundation—sample emergency plans, links to resources (including the above).

Individualized School Health Care Plan

For Children with Long QT Syndrome

Name of Student:_____ DOB:_____ School Year: _____

School:_____ Homeroom teacher:_____ Grade:_____

Medical Diagnosis/Chronic Health Condition: Long QT Syndrome, an abnormality of the heart's electrical system caused by dysfunction in cardiac ion channels, may result in disturbances of the heart's normal rhythm. These disturbances are due to a disorder of electrolyte flow (potassium, calcium, and sodium ions) through the ion channels. The child is being treated medically for this condition, but still may be at risk of a sudden fainting episode or heart arrhythmia leading to sudden cardiac arrest.

Emergency Plan: Since the child is at risk, however slight, of having a sudden cardiac arrest, it is essential that an emergency plan be in place. This plan should include the entire campus.

- If the student is unresponsive, look at the chest for abnormal, irregular breathing or only gasping. Call 911 and call for an AED. There may also be some jerking movements that look like seizure activity. Lay responders should not check a pulse.
- If the student is unresponsive and not breathing normally, begin CPR with chest compressions. As soon as an AED arrives, turn it on and follow the voice prompts. Time is critical---each minute of delay in response can mean a decreased survival rate of 7-10%. Effective CPR will give you extra time until the AED arrives, protecting brain and heart cells. Again, the plan should include *bringing the AED at the same time as first responders are called*.
- If the student is unconscious, but is breathing normally, call 911, and observe them closely.
- If the child faints but regains consciousness quickly, observe them closely. Parents should be called and advised to seek follow up medical care.
- If the student experiences palpitations, a rapid heart rate, chest pain or shortness of breath, the parents should be notified and advised to seek medical care.

Other considerations:

If child becomes light-headed or dizzy, experiences chest pain or shortness of breath with exercise, she/he should be allowed to sit down, and be observed by the school nurse. Occurrences of dehydration, vomiting, and/or diarrhea should also be monitored.

Because sudden cardiac arrest can occur at any time, the school should have a designated first responder team of at least five staff members, with current CPR and AED skills. All staff should have training in recognizing a sudden cardiac arrest, location of the AEDs and activating the school's emergency response plan.

The AED should be no more than 3 minutes away and placed on the victim as soon as available. CPR can continue while the pads are being placed and until the AED calls for no one to touch the victim. Follow the voice prompts of the AED, and resume CPR when indicated. It will cycle and reevaluate the victim every two minutes. Immediate and constant attendance by first responders is paramount until EMS arrives, and parents should be notified.

This student may be on medications called beta blockers (such as Nadolol, Propranolol, etc.). These medications are quite protective, but do not prevent 100% of episodes of life-threatening arrhythmia. Beta blockers may, on occasion, lower blood sugar, and can aggravate reactive airway disease. These potential side effects should be kept in mind. For a list of medications to avoid that have been found to overly stimulate the heart or to prolong the QT interval in patients with LQTS, please consult our website www.stopsads.org or www.qtdrugs.org.

Emergency Contacts:

Parent/Guardian	Relationship	Phone number	Alternate phone/contact method (including email)

Daily Medications:

Drug name	Dose	When/How Use	Side effects to observe for

Medications In Case of Emergency:_____

Special Considerations and Precautions:

_____

_____

_____

Activity/PE restrictions: Self-limiting physical exercise may be allowed, however this varies from child to child. Competitive sports in many cases may be prohibited.

_____

_____

_____

- If the child becomes fatigued, dizzy, short of breath or complains of chest pain, they must sit down, be allowed to rest, and observed closely for becoming unresponsive. The school nurse should be notified.
- On field trips and other activities away from school, an AED and a trained CPR responder should be available.
- A cell phone or other emergency communication device should always be available.

Other accommodations:

_____

_____

Physician name: _____ **Phone number:** _____

I, this child's parent/guardian hereby authorize the named healthcare provider who has attended my child to furnish to the School Health Services or School Clinic staff any medical information and/or copies of records pertaining to my child's chronic health condition, and for this information to be shared with pertinent school staff. I understand that HIPAA regulations limit disclosure of certain medical information. However I expressly authorize disclosure of information so that my child's medical needs may be served while at school. This authorization expires as of the last day of this school year.

Parent/Guardian Signature:_____***Date:***_____

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Exercise and Sports for People with a SADS Condition

Regular aerobic activity is essential to maintain health and prevent obesity and cardiovascular disease. Restricting athletes with SADS conditions from all competitive sports cannot only severely affect the physical health of the athlete, but also his or her psychological health.

When considering sports…

- **If the person is asymptomatic and taking beta blockers...** it is fine for her/him to participate in sports, PE classes, and other activities as their doctor allows.

- **All LQTS patients...**in general, should never swim alone.

- **ARVC/ARVD...** strenuous and competitive sports, or endurance or vigorous exercise are not recommended for people with ARVC because dangerous arrhythmias are more likely to occur. This type of exercise may also make your heart get worse over time.

"We demonstrate that after thorough evaluation, risk stratification, and tailoring of therapy, athletes and their families can participate in shared decision making and return to their competitive sports safely despite their LQTS diagnosis," *Tobert, et. al, Return to Play for Athletes ...Genetic Heart Diseases Predisposing to Sudden Death, JACC, Vol. 78 No. 6, Aug. 10, 2021: 594-604.)*

What can parents do?

- Make sure your child takes her/his medication as prescribed and at the same time each day. Make sure they drink plenty of water and that they are not taking any medications on the list of drugs to avoid.
- Let coaches, trainers and other sports officials know about your child's SADS condition and what needs to be done, including whether or not he/she has an ICD.
- Know which sports are safe. It may be possible to stay fully active in sports, including competitive sports, after carefully reviewing the risks and benefits with your doctor. In general, people with long QT syndrome should never swim alone.
- Sports are likely to be OK as long as you take a buddy along in case you have a fainting episode. Buddies need to be informed about LQTS and the potential dangers. They should be instructed to call for help, including 911, if a faint occurs. We highly recommend that buddies and all family members learn CPR.
- Make sure your family has an AED (automatic external defibrillator) and/or your child's school district has an AED program in their schools.

hFor more information, see the *Recommendations for Competitive Athletes With Cardiovascular Abnormalities* and other published articles on our website at SADS.org/Living-with-SADS/Sports-Exercise

The more we learn about SADS conditions, the more we realize that each patient is different from the next, and our advice must be tailored to the individual person.

Remember that these are general guidelines that are strongly influenced by whether the individual has ever fainted, whether they are taking medication and their family history. People who continue to faint despite treatment are a particularly high-risk group. When in doubt, discuss the specifics with your own doctor.

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.

Regular aerobic activity is essential to maintain health and prevent obesity and cardiovascular disease. Restricting athletes with SADS conditions from all competitive sports cannot only severely affect the physical health of the athlete, but also his or her psychological health.

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Sudden Loss of Consciousness (Syncope) and Sudden Death in Children

G. Michael Vincent, MD
Founder and Emeritus Trustee of the SADS Foundation

INTRODUCTION

Sudden and unexpected cardiac death in young persons is being recognized with increasing frequency. The sudden death of a young athlete during a sports competition is the most obvious and reported example, but death during non-competitive physical activity, during emotional upsets, or even during sleep are being recognized with progressively greater frequency. These events are usually due to a disturbance of the heart's electrical system, causing an abnormality of the heart beating or rhythm, called an arrhythmia. Fortunately, many of these deaths are preventable if the underlying conditions are correctly recognized and properly treated. Unfortunately, many times the condition is unsuspected and, therefore, not treated, with a tragic sudden death the outcome. A condition known as the **long QT syndrome** is being recognized as a common cause of the loss of consciousness and sudden death episodes, and it is often tragically not recognized prior to a sudden death.

WHAT CAUSES SUDDEN LOSS OF CONSCIOUSNESS?

Cardiac arrhythmias cause loss of consciousness by interfering with the blood pumping function of the heart with the consequence that the blood flow to the vital organs, particularly the brain, is diminished or absent. When the brain is deprived of blood flow for more than a few seconds, loss of consciousness occurs. This form of loss of consciousness is referred to as **syncope**. Syncope can also occur when blood pressure falls dramatically, again resulting in lack of blood flow to the brain. The common faint, known medically as a **vasovagal** event, is primarily due to a fall in blood pressure usually accompanied by a slowing of the heart rate. Another common cause of loss of consciousness is a **seizure**. In seizure disorders, the blood flow to the brain and other organs is normal, but loss of consciousness occurs because of abnormal electrical discharges in the brain.

WHAT ARE THE COMMON CAUSES OF ARRHYTHMIAS AND CARDIAC SYNCOPE IN CHILDREN?

Almost any heart disease can cause arrhythmias and/or syncope. Anatomical (structural) heart disease such as congenital (present at birth) disorders like narrowed or leaking heart valves, a hole in the heart (septal defects), or more severe malformations, or rheumatic heart disease (which affects the heart valves and muscle), are well known examples. Most of the time these conditions are not manifested by sudden loss of consciousness, but instead present as shortness of breath or fatigue, or are indicated through physical exam findings detected by the physician.

Of more concern are inherited diseases, which principally affect the heart's electrical system, such as the long QT syndrome, and the heart muscle, such as hypertrophic cardiomyopathy. The long QT syndrome is particularly of concern because there are no physical abnormalities to detect, only a subtle electrical disturbance which is easily, and therefore often, overlooked.

WHEN SHOULD A LIFE THREATENING CARDIAC PROBLEM BE SUSPECTED?

Vasovagal episodes and seizures must be separated from cardiac arrhythmias, for while they are important, they do not commonly lead to sudden cardiac death. A vasovagal event is most often precipitated by obvious factors such as pain, nausea, or seeing blood or other unpleasant stimuli. The individual becomes dizzy, warm and sweaty, has blurred vision, and usually has time to sit or lie down, which might lessen the symptoms or prevent the loss of

consciousness. If a loss of consciousness does occur, it is very brief, and the person regains consciousness within a few seconds, being alert and oriented almost immediately. Seizures, on the other hand, usually have no obvious precipitating factors, have no preceding symptoms other than occasionally a strange feeling (of various types) and are associated with movement of the extremities such as stiffening of the muscles and/or body and then shaking, and often with tongue biting and loss of urine or bowel control. The event may last around a few seconds to a minute or more. Following the event, the individual is often confused, disoriented and often lethargic for some time.

In contrast, the syncope of life threatening cardiac arrhythmia disorders is sudden, usually without warning, often occurs during or immediately following exercise, and is accompanied by gasping or absence of breathing, absence of a pulse, and in some cases by cyanosis or turning blue. Usually the loss of consciousness lasts from one to several minutes and in some cases requires resuscitation. These differences in presentation usually allow the conditions to be correctly separated, although some cases are confusing. Confusion often exists when a superficial rather than a comprehensive history of the event is obtained.

FAMILY HISTORY

Because these cardiac conditions are often inherited, a family history of syncope or unexplained sudden cardiac death in young persons may be present, and should be inquired about. The absence of a family history of these events, however, does not exclude these diseases.

DIAGNOSIS OF LONG QT SYNDROME

When a cardiac condition is suspected, medical evaluation is of utmost importance to prevent sudden cardiac death. A careful history and physical examination will eliminate many of other causes of syncope. The principle test required is the electrocardiogram (ECG, EKG), and specific observations for a prolonged QT interval and certain T-wave abnormalities. Please note however that 10-40% of long QT syndrome patients have a *normal* QT interval on initial evaluation, so a normal QT interval *does not* exclude the condition. Diagnosis can be further clarified by an exercise EKG (stress test) and often by examining electrocardiograms on parents and siblings. In most cases, one parent is a gene carrier; therefore 50% of siblings would be at risk of inheriting the condition. Once an individual is diagnosed with long QT syndrome, it is extremely important that all members of the extended family be screened by EKG and medical histories gathered to identify others who are at risk of sudden cardiac death.

TREATMENT

Most of the cardiac conditions associated with unexpected sudden cardiac death are treatable, and events can be prevented or diminished. This is particularly true for long QT syndrome, as treatment is very effective in most instances by administration of daily medications.

HOW CAN YOU HELP?

If you observe children who have loss of consciousness, particularly during physical activity or emotional stress, discuss the situation with their parents or other responsible parties such as a school nurse who could then contact parents or other individuals responsible for the child. *A medical examination and careful evaluation may save the life of the child at risk!*

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

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

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Any young person who has experienced unexplained fainting should be tested.

*It is extremely important that **all family members be tested** for these conditions once one family member is identified as having the condition.*

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Who Should be Screened?

All children should be carefully screened, using the Risk Assessment Form (www.StopSADS.org), every few years at these times: preschool, before/during middle school, before/during high school, and before participating in organized sports.

Long QT Syndrome (LQTS), Hypertrophic Cardiomyopathy (HCM), Catecholaminergic Polymorphic Tachycardia (CPVT), and Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) should be considered in any otherwise healthy child or young adult who:

- experiences loss of consciousness (syncopal or near syncopal spells) during or immediately following exercise or emotional distress - particularly in cases where the events are repetitive.
- has a family history of unexplained sudden death in otherwise healthy young persons (under age 40).
- experiences consistent or unusual chest pain and/or shortness of breath during exercise.

The Screening Process

Family History: Using the Risk Assessment Form from SADS (www.StopSADS.org), a parent and the child's physician can work together to determine the family risk of these conditions. This is extremely important and should include unexplained death during swimming, death during seizures, a family history of "seizure" disorders and other sudden deaths or death before age 40 in the extended family. Remember, this history should be taken for both the mother's family & the father's family!

Resting Electrocardiogram: The ECG will detect some people who have the Long QT Syndrome. However, sometimes the resting ECG is not able to diagnose LQTS. In this case, doing serial ECGs (more than 1 ECG in a row on different days) or ECGs on other family members (parents, siblings) will help to diagnose LQTS. An EKG may not detect other SADS conditions. Since these are genetic conditions, most likely a parent and siblings will have the syndrome as well.

Exercise (stress) Electrocardiogram: An exercise test, which allows the person to exercise for 10 to 15 minutes without achieving a heart rate more than 150-160 beats per minute (bpm) works best for this process. The standard treadmill test, which is used for detecting coronary artery disease, is *not as good* for LQTS as is the slower, longer test. This test is used to help diagnose CPVT.

Echocardiogram: This is a non-invasive sound wave imaging test that allows the physician to observe the heart as it is beating. It allows for the measurement of muscle thickness, degree of obstruction, chamber size, valve movement and blood flow. It is also possible to determine pressures inside the heart chambers and major vessels.

Genetic Testing: There are several commercial CLIA-certified labs from which your physician can order your genetic test. As with any healthcare service, it is always a good idea to be a wise consumer and research each company to see which one might be the best choice for you. For a list of companies and other important information, go to https://www.sads.org/living-with-sads/Genetic-Testing

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Supporting families.
Saving lives.

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 ca **live and thrive**.

Most sudden cardiac deaths in children are due to heredita conditions, so **every family member should be tested**.

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

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SADS FOUNDATION
Sudden Arrhythmia Death Syndromes (SADS) Foundation
4527 South 2300 East, Suite 104
Salt Lake City, Utah 84117-4448
Phone: 801-272-3023
Patient Support: 801-948-0654
Fax: 801-505-0282
StopSADS.org

Information for Teachers

You could save a life!

A child in your classroom 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, more than 356,000 Americans die suddenly and unexpectedly due to cardiac arrhythmias. More than 7,000 of them are young people under age 18. (AHA Heart Disease and Stroke Statistics—2020 Update)
- Every hour, a young person under 18 dies from Sudden Cardiac Arrest
- Approximately 10% of sudden infant death syndrome can be attributable to genetic heart diseases. (AHA Heart Disease and Stroke Statistics—2020)
- Sudden cardiac death is one of the top five leading causes of death in young adults.

What you can do:

- 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.
- Ask your school and other sports associations to make this questionnaire mandatory for all kids before they participate in any active sport.
- If a child has any of the warning signs they should see a doctor.

Warning Signs of SADS:

- 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

For more information or if you have any questions, please ask us—we would be happy to help. Call (801) 272-3023 (www.stopsads.org).

Thank you for helping us save the lives of young students!

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 their 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 polymorphic ventricular tachycardia		
Primary pulmonary hypertension		
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: Genevie@SADS.org

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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 **live and thrive**.

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.

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.

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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.

There has been recent media coverage and discussion about increasing athlete deaths. One way to prepare for an emergency event is to ensure that coaches, administration and athletes are all trained in CPR**. It is estimated that the survival rate for a person can be up to 90% if CPR is given in the first 4-6 minutes of a person collapsing—CPR saves lives!**

About sudden cardiac death in the young:

- Each year in the United States, more than 356,000 Americans die suddenly and unexpectedly due to cardiac arrhythmias. More than 7,000 of them are young people under age 18 (AHA Heart Disease and Stroke Statistics - 2020 update). 10-12% of SIDS is due to Long QT Syndrome.
- These conditions include Long QT Syndrome (LQTS), Hypertrophic Cardiomyopathy (HCM), Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC), Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT), and Brugada Syndrome.
- 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.*

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2. If a child has any of the following signs he/she should see a doctor.
3. Ask your school and other sports associations to make this questionnaire mandatory for all kids before they participate in any active sport.
4. **Ensure all team members, coaches, and administration are trained in CPR and know how to use an AED.**

Warning Signs:

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For more information or if you have any questions, please ask us—we would be happy to help. Call 1-800-STOP SAD or email Genevie at Genevie@SADS.org.

Thanks for helping us save the lives of young athletes!

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Genevie at Genevie @SADS.org

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

Supporting Families. Saving Lives
508 E South Temple #202 • Salt Lake City, UT 84102 • 800-STOP SAD • 801-531-0937 • fax 801-531-0945 • www.StopSADS.org