



XX School
Principal

Dear **Mr./Mrs.** _____:

My child, _____, has **Long QT Syndrome**, an abnormality of the heart's electrical system causing an abnormality of the heartbeat, or rhythm of the heart. Because of this abnormality, affected people are vulnerable to sudden fainting (syncope) and even death. **He/she** 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.

I am writing to you today to let you know about some precautions that are needed to protect my **daughter/son** while attending school.

Emergency Plan: Since my **daughter/son** is at risk, however slight, of having a sudden cardiac arrest, it is essential that an emergency medical plan be in place for **her/him**.

- If **he/she** should faint **he/she** should be laid flat and **his/her** vital signs should be immediately obtained. Specifically the heart rate should be determined.
- If a pulse is not present and **he/she** is unconscious, someone should call 911, start immediate CPR and utilize the AED if it determines that the rhythm is abnormal.
- If **he/she** is unconscious, but has a normal heart rate or blood pressure, someone should call 911 and have the emergency technicians treat him/her appropriately.
- If **he/she** should faint but regain consciousness, someone should obtain his/her vital signs. **I** should be notified immediately or my **wife** should be notified and we will call our **son/daughter's** physician.
- If my **son/daughter** is experiencing palpitations, feeling a rapid heart rate, has chest pain but has normal vital signs, and normal mentation, my **husband or I** should be notified and advised to seek medical care.

Other considerations:

1. If my **son/daughter** 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.
2. Because sudden cardiac arrest can occur at anytime, all teachers should be trained in CPR with an AED.
3. The school should have at least one AED that should be no more than 3 minutes away from any part of the school and grounds. It should be applied to the victim's body as soon as available. If indicated by the machine, a shock should be delivered. Immediate and constant attendance by first responders is paramount until EMS arrives, at which time my **husband or I** should be notified.
4. My **son/daughter** is on medications called beta blockers. 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 make asthma worse. These potential side effects should be kept in mind.
5. On field trips and other activities away from school, an AED and a trained CPR responder should be available.

Supporting Families. Saving Lives

6. A cell phone or other emergency communication device should always be available.
7. Consider becoming Heart Safe School Accredited (HSSA). Find out more at www.sads.org/HSSA.

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

My **son/daughter** needs to avoid medications that have been found to overly stimulate the heart or to prolong the QT interval in patients with LQTS. For a list of these medications, please consult the SADS Foundation website www.stopsads.org or www.qtdrugs.org.

Thanks for your consideration in this matter and for helping to keep my **son/daughter** safe at school.

Sincerely,

XXX

About sudden cardiac death in the young

- Each year in the United States, over 1,000 young people (and 360 infants with SIDS) die suddenly and unexpectedly due to cardiac arrhythmias (that's 4 deaths per day).
- These conditions include Long QT Syndrome (LQTS), Hypertrophic Cardiomyopathy (HCM), Arrhythmogenic Right Ventricular Displasia (ARVD) and others.
- **LQTS is 3 times more common than childhood leukemia (ALL) in the US and occurs 1/3 as often as cystic fibrosis and twice as often as PKU.**
- 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 percent (from 2,719 in 1989 to 3,000 in 1996) in people between the ages of 15 and 34.

Fast facts about these silent killers:

- 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. Thus, the opportunity to diagnose and treat LQTS and related disorders is missed.

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