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FACT SHEET: Long QT Syndrome (LQTS)

Produced by the SADS Foundation; Approved by the SCAA Medical Advisory Board

- Hundreds of children and young adults die each year in the United States due to Long QT Syndrome
- 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 a family member has been diagnosed.

What is Long QT Syndrome?

LQTS is a disturbance 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. Unfortunately, many times the cause of the syncope is overlooked and the events are called simple fainting spells or seizures. Most often, these events occur during physical exertion, emotional stress or startle (alarm clock). Sometimes they occur during sleep. Fortunately, most deaths are preventable if the condition is recognized and treated.

What are the Symptoms?

- Fainting episodes (syncope) with physical activity
- Fainting as a result of emotional excitement/distress/startle
- Family history of unexplained death below age 40

How is it Diagnosed?

The diagnosis is made from an ECG that has been read by a cardiologist, not a computer. Usually a series of ECGs will enable your doctor to diagnose LQTS. In some cases, an exercise ECG or event monitor will clarify the diagnosis. Finally, a diagnostic genetic test is now available and is the best way to know for sure, as well as assist in the treatment decisions.

How is it Treated?

Treatment is very effective in the vast majority of patients. Medications called betablockers are effective in about 90% of patients. In the remaining cases, an implantable cardioverter defibrillator (ICD) is used.

A child should be seen by a doctor if he/she has family history of unexplained sudden death in a young person, fainting (syncope) or seizure during exercise, excitement or startle, and/or consistent or unusual chest pain, shortness of breath