Together... We can Prevent Sudden Cardiac Death in the Young!

BY PAM HUSBAND

It was hard to believe, standing there, my eyes following the never-ending bricks. I was standing on the one man-made structure that can be seen from outer space. At the age of 16, I had travelled to China. Life takes its own twists and turns, just as the great wall has to twist around the tall mountains it runs through. My life has presented me with several large mountains. To date, the most significant two have been my diagnosis with Long QT* syndrome, and my implantation with an ICD**. (Find Ginelle Johnston’s complete article on the SADS Foundation website, www.sads.ca.)

Ginelle is one of the lucky ones. Her condition was found and diagnosed while she was still alive. Often conditions that can predispose a young person to a sudden cardiac are not identified until after a family death has occurred. When Sudden Cardiac Death (SCD) occurs in young children and adolescents it is particularly devastating. The reported incidence for the pediatric population has varied from 0.8 to 6.2 cases/100,000 population per year but, in actual fact, the true number of SCDs in children and young adults in North America is not known. However, it is now believed that the rate of SCD in the pediatric population is more common than once thought.

Warning Signs

Recognition of The Warning Signs and early medical intervention are the keys to preventing SCD in children and young adults:

- **Fainting (syncope) or seizure** during physical activity.
- **Fainting (syncope) or seizure** resulting from emotional excitement, emotional distress, or startle.
- **Family history of unexpected sudden death** during physical activity or during seizure, or any other unexplained sudden death of an otherwise healthy young person.

A young person who has experienced any of these “Warning Signs” should be referred to a cardiologist or an electrophysiologist for a complete cardiac assessment. This assessment should include an analysis of the heart rhythm and, where indicated, cardiac imaging and exercise testing.

Important Facts

- Incidence of inherited rhythm disorders in the population has been estimated to be as high as 1 in 500 live births.
- With proper medical assessment, many of these disorders are identifiable and treatable.
- It has been estimated that up to 60% of children and young adults who die suddenly from sudden cardiac arrest had symptoms prior to their deaths. Often these symptoms were either ignored or misdiagnosed.
- Recognition of the Warning Signs and early medical intervention are the keys to preventing sudden cardiac death in children and young adults.

Most common causes of SCDs in the pediatric population:

- Hypertrophic Cardiomyopathy (HCM): a progressive condition, most often inherited, that affects the heart muscle and may eventually cause a fatal arrhythmia, particularly in individuals whose disease was not identified during life.
- Congenital defects of the heart: again, sometimes not recognized until autopsy.
- Inherited cardiac rhythm disorders: Long QT Syndrome, ARVC, CPVT, Brugada Syndrome to name several.

It is now estimated that as many as 60% of young people who experience SCD had symptoms prior to their event. These symptoms may have been either misdiagnosed or dismissed as insignificant.

As leaders, you can help. Report any incidents of fainting immediately to parents, and recommend the child be referred to a cardiologist for a complete cardiac assessment. For further information, please refer to The Canadian SADS Foundation website at www.sads.ca, email info@sads.ca or call 1-877-525-5995.

— Pam Husband is the Executive Director of The Canadian SADS Foundation.

Ginelle’s Condition

Long QT Syndrome (LQTS) is an uncommon heart condition that is estimated to affect about 1 in 3,500 or less people. In the case of Long QT Syndrome, the electrocardiogram (ECG) would show an irregular rhythm that can be identified by experts who know how to analyze the results of an ECG test. LQTS is one of many cardiac conditions that can predispose an individual to a sudden cardiac death.

** ICD – a battery-powered electrical impulse generator which is implanted in patients who are at risk of sudden cardiac death. This device detects when the heart is in a dangerous rhythm and sends a jolt of electricity to the heart in an attempt to shock the heart back into normal, healthy rhythm.

Photo: Canadian SADS