

World Heart Rhythm Day: Wednesday 13th of June 2007

At the age of 15, Natalie had her first collapse and seizure on a bus. Over the next 13 years, she got on with her life, got married and had a daughter, but kept on having seizures. Her husband, Nathan describes how he'd wake to find her having a fit right beside him in bed. The seizures usually came on during the night or when woken suddenly from sleep, especially by an alarm or a telephone ringing. A neurologist didn't think it was epilepsy, but didn't have an alternative diagnosis and unfortunately didn't suggest any further investigations to find the cause. One night in 2003, Natalie died following one of her seizures. Nathan had two questions- why did she die? - and will the same thing happen to his daughter?

After her death, an ECG (electrocardiograph) which had been taken a month before she died, was reviewed by a heart rhythm specialist- Dr Ian Crozier of Christchurch public Hospital. The ECG showed clear evidence of long QT syndrome. Nathan found out that had this diagnosis been made earlier, she could have taken beta blocker medication, or had a defibrillator pacemaker implanted, and would probably still be alive today. He heard that long QT syndrome is inherited and was concerned for his daughter, Isha.

Isha had never had any blackouts or seizures, but her ECG was reviewed by Dr Skinner, children's heart specialist from the Starship Children's hospital. The ECG showed that she also has the condition. Genetic tests, funded through research backed by Cure Kids, have confirmed that both she and Natalie carry the defective gene.

Recurrent collapses, seizures and even sudden death due to conditions like long QT syndrome are not uncommon. Researchers estimate that about 100 1 to 40-year-olds die suddenly and unexpectedly in New Zealand each year from unexpected heart rhythm problems. 10-15% of sudden infant deaths are due to long QT syndrome. These conditions usually run in the family, with half of the family members carrying a defective gene. Clinicians such as Dr Crozier and Dr Skinner, want patients and medical practitioners throughout New Zealand to be aware of these conditions because such young sudden deaths can be prevented with relatively simple medical interventions. The key is to recognise them in the first place.

June 13th is World heart rhythm awareness Day. This initiative was started in the United Kingdom by a group of charities supporting work into heart rhythm conditions. The arrhythmia alliance is one (www.heartrhythmcharity.org.uk), CRY and STARS are others (cardiac risk in the young, www.c-r-y.org.uk, Syncope Trust And Reflex anoxic Seizures www.stars.org.uk). Whilst much is written in the press about the importance of coronary artery disease, and surgical interventions such as coronary bypass surgery and coronary angioplasty, relatively little is written about heart rhythm problems in the media.

In New Zealand each year around 1500 cardiac pacemakers are implanted for people who have hearts which go too slow. Around 200 pacemaker defibrillators are implanted for people at risk of cardiac arrest from a heart rhythm problem- budget limitations constrain the number of these defibrillators implanted in New Zealand, and the rate of implantation

is lower than in Australia. Another common problem is attacks of very fast heart rhythm known as ' SVT ' which, while not usually life threatening, affect people of all ages. Many of these conditions can be cured using a keyhole entry technique known as catheter ablation. These are complex procedures requiring dedicated staff and facilities. They are able to cure many arrhythmias and greatly improve patients' lives.

Currently these procedures are performed at three centres in New Zealand, Christchurch, Auckland and Hamilton, and approximately 600 are performed in New Zealand every year

New technologies have opened up the possibility of curing even more people with such heart rhythm problems; a new computer-based system allows a three-dimensional construction of the heart and this allows specialist heart rhythm doctors to treat very complex rhythms which before were untreatable. Examples include atrial fibrillation, the commonest heart rhythm problem; affecting thousands of New Zealanders and a major risk factor for stroke. Ablation of atrial fibrillation was introduced to New Zealand by Dr Ian Crozier over six years ago. Such procedures are time-consuming and the equipment is expensive. Each catheter that is used can cost up to \$6,000, and may only be used once.

On World Heart Rhythm Day, Drs Crozier and Skinner say we should celebrate the expertise we have in New Zealand and we must continue to campaign for adequate resources to help the thousands of New Zealanders with heart rhythm problems. They have established the New Zealand Cardiac Inherited Disease Group (www.cidg.org) whose core aim is the reduction of young sudden death.

Nathan and Isha and their wider family want us to think about heart rhythm problems on World Heart Rhythm Day. They don't want Natalie's death to be in vain. Isha is now being kept safe by her medication, but they know there are others out there also at risk.

All of us should be aware of the features of collapse caused by a heart rhythm problem rather than epilepsy or a common faint, so these are shown below. If you are unsure, seek advice from the website of the Cardiac Inherited Disease Group New Zealand who are sponsored by Cure Kids (www.cidg.org), or visit www.sads.com.au. Your local cardiologist will be pleased to see you.

Faints, collapse and seizures

Many people- perhaps as many as 25% of us will have a faint at sometime in our life. Most are not life-threatening. A common faint usually starts with a feeling of nausea or dizziness, most commonly occurs when we are hungry, hot, or thirsty, after standing for a long time, or after a severe pain. Such faints are not dangerous, and can be managed with adequate food and fluid intake- and early recognition of the warning signs so you can sit or lie down until they settle down. Epilepsy seizures usually start with stiffness and twitching of the arms and legs. The dangerous, heart rhythm type of collapses, usually have a sudden onset, little or no warning, with a sudden collapse to the ground. The person may be unconscious before hitting the ground- so facial injuries sometimes occur.

A seizure may follow due to shortage of blood getting to the brain. Sudden collapses during or after sporting activity, especially swimming, are very suspicious, as are seizures which occur during the night. There may be a family history of a young sudden death. For further information, visit the websites listed in this article.

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