



## The Sudden Arrhythmia Death Syndromes (SADS) Foundation

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**SADS**  
FOUNDATION

## STORIES OF THE LONG QT SYNDROME

### Andrew

My son Andrew was a healthy, happy, athletic teenager whose heart abruptly stopped beating one summer afternoon. Two weeks later, we discovered why our beloved son was taken from us so suddenly when we were told that our two other children, Katy and Doug, had LQTS.

The loss of our son in conjunction with the diagnosis of this disease in our remaining children was nearly an overwhelming blow. However, in the midst of great tragedy and disappointment, we remained grateful and hopeful about the long-term health of Katy and Doug. They continue to thrive, live very normal lives, and do well on their daily medication.

*-Richard Stafford Phoenix, AZ*

### Dawn & Kelly

On a warm July morning my youngest daughter Dawn collapsed and died. She was a healthy, active 17-year-old and there was no explanation for her sudden and tragic death. One short week later, my other daughter Kelley died in her sleep, just two days after her sister's funeral. The sudden loss of my vivacious, young children caused unbearable pain to my family. While we mourned the lives that Kelley, as a new mother, and Dawn, as a graduating senior, had ahead of them, I was terribly frightened for the lives of my other children because this devastation seemed intent upon destroying our entire family.

Shortly after their deaths we learned that Dawn and Kelley had died from the Long QT Syndrome (LQTS), a potentially fatal, but treatable genetic cardiac disorder. We also discovered that several members of our family, including my daughter Michelle and her son have the disorder and had been at risk of sudden death before being diagnosed with this silent killer.

*-Wilhemina Taylor Philadelphia, PA*

### Margaret, Tommy & Russell

My sister, Margaret, and my brothers, Tommy and Russell, all died as teenagers in the 1960's. They were healthy, active people and no one could tell us why our beloved family was dying. It wasn't until after living through over 20 years of suffering, fear and frustration that we found out half of my family had died of LOTS.

We also discovered that several family members, including myself, have the disorder and have unknowingly been living a very tenuous existence. We consider ourselves lucky that no one else was lost.

*-Patricia O'Dell New Orleans, LA*

### Evelyn & Josh

My sister Evelyn's heart suddenly stopped beating on December 2, 1979. She was 36. Thirteen years later, the nightmare recurred when my sweet, shy, 19 year old son, Josh, passed away abruptly in his sleep. No one, including the doctors and coroners, could tell me why my healthy, active loved ones were taken from me so suddenly. The pain of not knowing what had killed my son and sister, in conjunction with fear for my other sons, was nearly overwhelming.

In October of 1992, I read an article about the SADS Foundation and a family that had lost two children to LQTS. I could not believe what I was reading: it was just like my life story. We immediately went to a knowledgeable cardiologist and discovered that my son, Israel, all of my brother's 4 children, and I and several other extended family members are affected by LQTS and had been at risk for sudden death for several years.

*-Toni DeBilzan Laguna Beach, CA*

### Stacey

My daughter, Stacey, fainted and broke her jaw on May 31, 1995. She had fainted before and the episodes had been attributed to puberty. Because of the force of her fall, the emergency room physicians ordered a full neurological work-up: her CT-scan and EEG appeared normal. During surgery on her jaw the following day, the anesthesiologists noted an irregular heartbeat. Within the week she had a stress test that was also pronounced normal, however, 7 days later she had a cardiac arrest. She died on June 20, 1995. She was 15 years old.

While she was in a coma she was diagnosed with the Long QT Syndrome. Her stress test had obviously shown LQTS, but the cardiologist did not recognize it. Before her cardiac arrest, Stacey had seen almost 10 doctors and not one suggested the Long QT Syndrome. Please help the SADS Foundation prevent other families from being tormented by such devastating loss.

*-Ellen Mitchell Miami, FL*