



# A Family with Heart

Researchers gain valuable insights from family with four generations of hypertrophic cardiomyopathy

Sarah (Steel) Anderson is one of the few people in the world who can say she's nearly "died" three times and lived to tell the tale.

In August 1994, Sarah was an active 12-year-old who had enjoyed a childhood filled with softball, basketball, swimming and dancing. A few days after returning from a cheerleading camp, Sarah went outside to exercise in her front yard. Her mother, Diana, was ironing. Her father, Jeff, was napping after a round of golf.

Minutes later, Sarah staggered inside and collapsed at her mother's feet. Without exhibiting any previous signs of heart trouble, Sarah had gone into cardiac arrest.

"At first, I thought she was just being dramatic about how hot it was outside. But then she didn't respond and I screamed for my husband," Diana says.

Jeff fell back upon 18 years of experience as a paramedic to perform CPR for Sarah, not once, but twice. A life squad later used a defibrillator to shock Sarah's heart back into rhythm. Once Sarah arrived at Cincinnati Children's, she became the first child in Cincinnati to receive an implanted defibrillator.

Now 29, Sarah teaches dance classes. She and her husband, Grant, have two sons.

"I truly believe God had a hand in this," Sarah says. "The series of circumstances that allowed me to be here today is amazing."

## Inherited condition detected

Doctors initially diagnosed Sarah with an arrhythmia (irregular heartbeat) with an unknown cause. Years later, doctors discovered more was going on when Sarah's second son, Noah, was born with heart trouble.

An echocardiogram revealed that Noah, now nearly 2 years old, was born with hypertrophic cardiomyopathy, a thickening of the heart muscle that can lead to heart-stopping electrical malfunctions. Athletes who suddenly collapse and die often have this condition.

A genetic test confirmed that Sarah and Noah share a gene mutation known to be linked to hypertrophic cardiomyopathy. However, Sarah's oldest son, Alex, age 3, does not.

Further testing traced the gene back to Sarah's father, Jeff. Doctors believe that Jeff inherited the gene from his mother, who died 17 years ago after years of heart problems.



Diana and Jeff Steel (at left) worried their daughter, Sarah (Steel) Anderson, might not survive a teenage cardiac arrest. Now 29, Sarah is married to Grant Anderson and is the mother of two boys, Noah and Alex. Jeff, Sarah and Noah are three generations of heart patients at Cincinnati Children's.

## Contributing to understanding

While the test results were disturbing, they also offered peace of mind. Thanks to a new program that expands certain cardiac services to adults, all three family members now receive care through the Heart Institute at Cincinnati Children's.

Over the years, many doctors have closely followed Sarah's unusual case. Her experience with broken wires helped change how surgeons implant defibrillators in children. Family concerns about whether the implanted defibrillator was working helped inspire the device maker, Medtronic, Inc., to add alarm features to new defibrillators.

For Noah, doctors have prescribed beta blockers to help prevent him from following his mother's path. The family expects to be monitored for years to come.

"We don't want anyone to have to experience the sudden death of their child," Diana says. "We're just hoping people will learn from our family that there are genetic tests you can take to know who is safe and who is at risk."

**WATCH ONLINE** to hear the story of three generations of Cincinnati Children's heart patients: Sarah Anderson, her son, Noah, and her dad, Jeff Steel, at [www.cincinnatichildrens.org/story](http://www.cincinnatichildrens.org/story)