

saving

Lives

one heart at a time

When one of my daughters died from a rare heart condition, I knew that I had to do whatever I could to protect the other two—and anyone else who might be at risk

by Mary Lynn Grizzell, as told to Amy Paturel

PHOTOGRAPHS BY GARY MATOSO

I'LL NEVER FORGET THE HOLLOW LOOK ON MY daughter Rachel's face the first time she lost consciousness. It was a hot summer day, and we were hosting her baptism at a creek near where we live. Family and friends surrounded 10-year-old Rachel while the minister briefly dunked her into the cold water and lifted her back up. Rachel was happy and excited. Then, without warning, she fell forward and passed out.

Her eyes were fixed and dilated, and she didn't have a pulse. I would have completely panicked had it not been for two close family friends—an EMT and a cardiac nurse—who started performing CPR almost instantly. Moments later, Rachel's heart began pumping again.

We rushed Rachel to the hospital, where doctors examined her and performed a slew of tests. Everything came back normal, but just to be sure, my husband Richard and I took her to a cardiologist for a more thorough workup. He said she was fine. Yet over the next year and a half, Rachel passed out three more times.

taking us seriously

Every time Rachel passed out, her eyes dilated and her mind seemed kind of foggy for a day or two, but then she'd be OK. We always took her to the emergency room, but we never got much help. In fact, one of the nurses told me she thought Rachel was fainting to get attention. We loved living in our *(Please turn to 80)*

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CONTINUED rural town in Washington state—we own a farm and 50 acres of rolling hills in Walla Walla—but I was beginning to worry that if we didn't get Rachel out of this town she was going to die and no one would know why.

The day Rachel fainted during a piano recital, everything changed. Like many parents, Richard and I had brought a video recorder. We had no idea that we'd end up catching one of her fainting episodes on tape.

Rachel passed out just as she started to play, falling backward off the piano bench. There was a rush to the stage and we started CPR, but it wasn't working. When paramedics arrived, they used a defibrillator and got her heart going again—but she had already been down for 15 minutes. People rarely survive that.

Rachel was airlifted to Seattle Children's Hospital, where she was in a coma for three days. When she finally opened her eyes, she looked around and didn't seem to recognize anybody. Miraculously, about a week later she appeared to have fully recovered. But we still didn't know what was wrong with her.

The only good part was that we now had proof that Rachel's condition was real and very serious. Doc-



Mary Lynn with husband Richard and daughters Sarah, left, and Rachel, center.

tors at the hospital referred us to a specialist at the University of Washington, where she was finally diagnosed with ventricular arrhythmia (VA)—an abnormality of the heart's electrical system.

dangerous beats

People with VA are in danger of going into ventricular fibrillation, which means that their heart starts beating so fast that they faint or go into sudden cardiac arrest. For some people, their first "symptom" of VA is sudden cardiac death, so Rachel was lucky. To keep her safe, she had surgery to implant a defibrillator—a device that would automatically shock her heart during an episode.

Rachel's doctors explained that there was a very good chance that her sisters also had VA, though neither one had symptoms. And although Richard and I haven't had any fainting episodes ourselves, at least one of us is probably carrying a gene mutation that hasn't been discovered yet. In fact, my grandfather was one of eight siblings—but only two of them survived past age 9. We'll never know for sure, but it's highly likely that they suffered sudden cardiac death as a result of VA.

We brought Talitha, then 10, and Sarah, then 6, in for testing, but everything came back normal. Still, Rachel's doctors urged us to buy an automated external defibrillator (AED)—a 5-pound shocking system that you can store in your home or keep with you in the car. Unfortunately, back then an AED cost \$4,500, which was much more than we could afford, and our insurance wouldn't cover it.

the worst day

In the six years following Rachel's diagnosis, her sister Talitha had two fainting episodes. We couldn't confirm that she had VA, but it seemed awfully coincidental. Richard and I knew that we had no choice but to find some way to pay for an AED. We decided that we would use the money from the upcoming wheat harvest. *(Please turn to 82)*

what is ventricular arrhythmia?

Ventricular arrhythmia (VA) is an abnormality of the heart's electrical system that is often but not always inherited. It is very hard to diagnose because it only shows up on an EKG if a patient's heart is going into fibrillation (beating dangerously fast) during the test.

A diagnosis of VA is usually made based on symptoms, such as multiple fainting episodes or sudden cardiac

arrest. Some people with VA die after going into sudden cardiac arrest without ever having had any symptoms or knowing that they had the condition.

Many experts believe that VA is responsible for some otherwise unexplained deaths in children and young adults—a drowning of a child, for example, or even sudden infant death syndrome (SIDS).

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CONTINUED Just a month before the harvest, we were at the St. Joe River in Idaho. Sixteen-year-old Talitha and our youngest daughter, Sarah, were jumping into the water to ride the wakes as the boats passed by. At one point Sarah swam toward the dock. Just then, Talitha came up and said, "I need out." Sarah moved aside to let her pass, but it was too late: Talitha was facedown in the water.

Sarah, who was then 12 years old, and Rachel, then 18, started crying and screaming. Even today, I can still hear their screams. Sarah grabbed Talitha by the hair and pulled her head up out of the river. Rachel and I ran over and pulled Talitha up onto the dock. She was unconscious.

Our friends started performing CPR, and they kept it up until an ambulance arrived an excruciating 20 minutes later. The paramedics used their defibrillator but they couldn't get a heartbeat. By the time we arrived at the local hospital, Talitha had been down for almost an hour.

After several tries, the emergency room staff finally got a sustained heartbeat. My first thought was, *There's no way she could survive after being down for so long*, but I prayed for a miracle as Talitha was airlifted to a larger hospital in Spokane. I watched as they hooked her up to an EEG machine to measure her brain activity. It was totally flat. I shouldn't have been surprised, but I felt stunned.

The doctors told us they could keep her on life support, but Talitha was already gone. As we sat in the ICU thinking about what to do, Sarah reminded us that Talitha had said, "If I can't live but my organs can help somebody else live, then that's what I want." So we decided to donate her kidneys, pancreas, corneas and liver.

A month after Talitha's death, we took Sarah to Seattle so she could



Mary Lynn with the user-friendly defibrillator she inspired Philips to produce.

and bulkiness of the AED would deter most people from buying one.

a silver lining

The girls' doctors urged us to share our story with the people at Philips (the AED's manufacturer) to encourage them to make a smaller, less expensive model. So between 1998 and 2000 I traveled to Seattle, Boston, San Diego and Las Vegas to meet with representatives from Philips. For my presentations, I created a video that mixes pictures of the girls with footage of Rachel going into cardiac arrest during her piano recital. It also shows Talitha playing

the piano, and concludes by fading to black as the words *if only* appear on the screen.

The people at Philips told me that they were moved by my presentation, and just a few years later, in 2002, HeartStart Home Defibrillator hit the market. Weighing in at 3 pounds, it's the first defibrillator specifically designed for a layperson to use. It gives clear voice instructions that guide you through every step of the process. And while it's not cheap at \$1,275, it costs a lot less than the older, bulkier models.

Today Rachel and Sarah are happy and relatively healthy, but Rachel did go into cardiac arrest about six months ago. Fortunately, her implanted defibrillator kicked in and she's fine. As for Talitha, we all miss her desperately, but I try to focus on her life rather than her death. I'll always remember her as a vivacious girl whose idea of a great day was riding horses with her sisters. I can still picture her throwing her arms up into the air and yelling, "Mama! Watch this!" as she came roaring over the hills. She truly loved life, and now she lives on in those who were saved by her organs and everyone whose life has been saved by an AED. **wd**

be prepared

If someone in your house has heart disease or a condition like VA, buy an AED. More than 450 people die every day from cardiac arrest, and, according to the American Heart Association, about 80% of sudden cardiac arrests happen at home. The AED shocks the heart into beating again so the brain isn't deprived of oxygen while you're waiting for an ambulance. If you can't afford the \$1,275 price tag, join forces with neighbors and buy one to share. And learning CPR is always a good idea.

have a defibrillator implanted. We didn't want to find out she had VA after it was too late. We also bought an AED in case another family member or friend ever needed it. (According to the American Heart Association, every minute spent after sudden cardiac arrest without CPR and defibrillation reduces chances of survival by 7 to 10%.) We wanted to tell everyone we knew to do the same, but we knew all too well that the expense

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