

## Sudden Death: Doctors Miss Signs Of Heart Defects In Young Athletes

**Problem Is Both Treatable And Detectable by EKG, But Scans Don't Get Done  
Two Siblings Die, Weeks Apart**

By Kevin Helliker and Kathryn Kranhold, The Wall Street Journal, 2264 words  
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Early this month, Kenny Sirois was jogging beside his identical twin in their hometown of Madawaska, Maine. As the 16-year-olds turned onto their own street, they started sprinting toward home. Kenny never made it.

An emergency-room doctor told Vincent and Wendy Sirois their son had died of a hidden heart defect that couldn't have been detected, the parents say. But two days later, they add, a nurse from the emergency room called and said her conscience required her to tell them Kenny's death probably could have been prevented. She implored them to get their surviving twin tested.

The nurse was right: The cardiac defect that killed the boy, known as hypertrophic cardiomyopathy, is detectable and treatable. And it runs in families. If Kenny's twin has it, as initial tests suggest he might, then a battery of treatments can offer him a nearly normal life span.

HCM, as it's called for short, is a genetic abnormality that enlarges the left ventricle, leading to sometimes-fatal disturbances of the heart rhythm. Young athletes suffer sudden cardiac death at a rate thought to be two to three times as high as their less-active peers. The Siroises say no doctor had suggested that their sons, year-round competitors, undergo a heart scan. "Kenny could still be alive" if they had, says Mrs. Sirois.

American medicine is respected around the world for its all-out war on heart disease, with advanced drugs and procedures plus campaigns that teach the public what to watch for. But in one area of heart disease -- hidden congenital defects that suddenly kill young athletes -- U.S. medicine does relatively little to detect problems or raise awareness, including less than some foreign countries.

In Japan, for instance, doctors routinely give schoolchildren electrocardiograms, or EKGs, which can detect congenital heart defects that a stethoscope cannot. Italy gives EKGs to all youths who want to participate in competitive sports. The International Olympic Committee recently recommended that young athletes have EKGs every two years, and in a March statement in the *European Heart Journal*, about 25 European physicians endorsed a similar proposal. Physicians in Japan and Italy say their

programs save lives. A screening of 33,735 young athletes in the Veneto region of Italy from 1979 to 1996 disqualified from sports 22 who turned out to have HCM; all are believed to be still alive.

In American medicine, it's generally accepted that universal screening of young adults for heart abnormalities wouldn't be a good idea. Far too many healthy athletes would need to be screened to find a single defective heart, cardiologists say.

U.S. cardiologists, instead of widespread screening, favor efforts to raise awareness about the symptoms and risk factors, leading to testing of those at risk. They favor a focus on kids who have cardiac murmurs, fainting spells, chest pain or shortness of breath, plus any who have had sudden cardiac death in their families. "If you screen the ones with symptoms and warning signs, you'll have lower costs and a much higher yield," says Robert Campbell, chief medical officer of Sibley Heart Center of Children's Healthcare of Atlanta.

The problem is that their plan for focused screening emerged nine years ago, after a medical conference, and there is little sign it has raised awareness among either front-line physicians or the general public.

One possible reason: Sudden death in adolescents falls outside the primary mission both of pediatric cardiologists, who treat children, and of adult cardiologists, who focus on the middle-aged and older. In cardiology, adolescence and young adulthood is "a no-man's land," says Robert Myerburg, director of cardiology at the University of Miami School of Medicine.

Word about the risk of sudden death in young athletes bypassed Chris and Sandy Boslet, even though they describe themselves as aggressive in their pursuit of health information. The suburban Atlanta couple made sure their son, Ryan, never missed a vaccination or annual checkup, and he, too, was focused on health and fitness. A star defensive lineman on his high-school football team, he received his first college recruiting letter in 2003 -- one day before he collapsed and died during a workout.

Mr. Boslet, a sales manager for General Mills Inc., could certainly have afforded a scan that might have detected it. An EKG costs as little as \$25. One drawback, however, is that it will flag most but not all cases of HCM. The gold standard -- a scan that is excellent at detecting not only HCM but aortic aneurysms and various other conditions - is the comprehensive echocardiogram, which costs about \$900.

But a new, portable echocardiogram that cardiologists say is surprisingly effective is available nowadays for as little as \$35. Today, Mr. Boslet is lending his support, and the power of his son's tragic story, to a nonprofit scanning program in Atlanta called Heart Screens For Teens that offers portable echocardiograms for \$58. "If we'd known this was something to look out for, we'd have gotten that scan in a minute," says Mr. Boslet, who, looking back, remembers kidding Ryan about occasional bouts of shortness of breath. Now he knows this can be a symptom of HCM.

The treatment, when HCM is detected, includes giving up vigorous sports. It also may entail drugs called beta-blockers that deter rapid heartbeat, and in some cases an implanted defibrillator.

When a young athlete dies suddenly, local news outlets typically seek comment from doctors, who typically fail to mention that the main cause is detectable by EKG. A review of dozens of such newspaper stories finds that the doctors who were quoted almost never mentioned either that fact, the ability to treat HCM, or the common warning signs.

This is a sore subject for Patricia Sims of Columbia, S.C. While at a basketball tournament with her husband and 17-year-old son, she watched a boy on another team collapse and die. She and her husband drove home shaken, wondering if their son faced this risk, too, and whether they could do anything about it. A newspaper story quoted the county coroner as saying, "These things happen."

Four months later, in April of 2003, their son, Vick Sims Jr., a college-bound basketball star, collapsed on a court near home. After hours of trying to revive him, a young emergency-room physician had to be pulled away from his body. "The doctor couldn't believe a boy this young and healthy had just dropped dead," says Vick Sims Sr. "To me, that doctor was a hero."

He and his wife later came to believe the medical profession had done too little, after a friend surfing the Internet learned that HCM is detectable with an EKG. "Somebody should have told us," Mrs. Sims says.

It appears that many doctors underestimate the frequency of sudden cardiac deaths in young athletes. No government agency keeps count. But Barry Maron, a Minneapolis cardiologist who is one of the world's leading authorities on HCM, has been compiling news reports for a registry. So far, he says, his count suggests there are between 200 and 300 sudden deaths in young athletes per year in the U.S.

Most doctors are more likely to say there are 100 or fewer. Some physicians cite the National Federation of State High School Associations as saying there are only 10 to 25 per year. The federation says it has never characterized its statistics as complete.

A lower figure still comes from the American Academy of Pediatrics -- whose members do many pre-participation sports physicals. The academy says on its Web site only 10 to 13 such sudden deaths are reported a year. The academy attributes this to the National Center for Catastrophic Sport Injury Research at the University of North Carolina. But that center's director, Frederick Mueller, says the 10- to-13 figure is too low and that he doesn't "know where that came from."

The danger of understated numbers, says Dr. Maron, is that doctors think this isn't something to worry about: "The wrong numbers have been very destructive."

Most school sports programs give students a pre-participation form to be filled out by a doctor. These forms traditionally have focused on muscle, bone and joint issues. A big part of the cardiologists' 1996 recommendations was that the forms should add several heart-related questions, such as whether the student has a heart murmur, has experienced chest pain, shortness of breath or fainting spells, or has a relative who died a sudden cardiac death. If so, they should be given an EKG or in some cases an echocardiogram.

But many school and sports administrators continue giving would-be athletes pre-participation forms that lack cardiac questions. Atlanta's Dr. Campbell says that 80 different forms are being used in Georgia, only a small share of them having most of the questions the cardiologists want asked.

Another problem, some experts say, is that many doctors don't recognize shortness of breath as a symptom of congenital heart disease. During a soccer game, Louis Savino, 15, had such shortness of breath that his coach sidelined him, says his mother, Antoinette Pellegrini. She says she took him to a pediatrician who diagnosed the boy with exercise-induced asthma and prescribed an asthma medication. According to a lawsuit she later filed, now pending in the Court of Common Pleas in Philadelphia, Louis actually had HCM and died on the soccer field a month later.

Cardiologists say many front-line doctors also fail to appreciate familial risk. After 19-year-old Jackie Ward of Hampton, Va., dropped dead on a running track last November, her parents say no one told them that a cardiac defect in children can run in families. Two months later, her 17-year-old brother, Joseph Ward, also fell dead while running.

The diagnosis was a heart-rhythm disorder called "long QT syndrome." EKGs of three remaining siblings suggested that they had it, too. They now have implanted defibrillators to shock any erratic rhythm back to normal. "If the medical examiner who called had mentioned . . . getting the other kids scanned, I can't help thinking Joe might still be alive," says his father, also named Joseph Ward.

Stuart Berger, chief of pediatric cardiology at Medical College of Wisconsin in Milwaukee, began campaigning five years ago to put defibrillators in all of the state's high schools. He says news coverage of the program led one woman to seek a test for her granddaughter, a high-school girl who sometimes fainted on the basketball court but had been reassured there was little to worry about. An exam found a dangerous congenital defect that was then easily fixed. "Awareness is vital," says Dr. Berger, who adds that southeastern Wisconsin alone has had 19 sudden cardiac deaths in young athletes in recent years.

Some parents -- such as Sharon Bates in Arizona, whose 20-year-old son died of HCM -- have become activists, organizing clinics that offer free or low-cost scans. They offer not just EKGs but also the new, inexpensive variety of echocardiogram given with a hand-held device. The quality is good enough to detect a possible abnormality that can be examined more fully with a comprehensive echocardiogram in a laboratory.

Some cardiologists who feel their profession has been remiss about sudden death in young athletes have volunteered at these free clinics. Last year at a free clinic run by a nonprofit Phoenix group called TOPS, William Rappaport, from the Arizona Heart Institute in Phoenix, identified HCM in a 17-year-old baseball player named Doug McWhorter. Screening of the rest of the family found the condition in two others, including the father, Gene McWhorter. Today, three McWhorters wear implanted defibrillators and Mr. McWhorter credits the free clinic with saving their lives.

Yet turnout is often dismal at clinics. Before a volunteer group called Ultrascan Inc. came to the Atlanta International School, a letter went out to parents telling them that sudden cardiac death strikes only 10 to 13 young athletes a year in America. Only 24 students showed up for the screening.

If mass screenings ever did become popular, the beneficiaries would be not only the occasional kid who's found to have a cardiac defect but also scanning-equipment makers and cardiologists, to whom abnormal scans would be referred.

Dr. Maron, the Minneapolis HCM expert, supports these community screening efforts featuring low costs and volunteer cardiologists. Still, he doubts that greater awareness will solve the low-turnout problem, partly because both parents and the kids get so juiced about participating in school sports. "Sports are intoxicating," he says.

Indeed, noting that his now-grown sons were once competitive swimmers, Dr. Maron admits that he himself never did scans on their hearts. Remembering the thrill of watching his young sons compete, he muses that perhaps he feared finding a condition that would have disqualified them from competition. "Am I proud of that?" he asks. "No."

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Deborah Ball in Padua, Italy, and Miho Inada in Tokyo contributed to this article.

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## **Failing to Ask**

**High schools often neglect to ask young athletes about symptoms or risk factors for cardiac defects. A form from a district in Maine asks only these questions.**

-- Have you ever had an injury such as a fracture or a serious accident?

-- Have you ever been hospitalized?

-- Have you ever had an operation?

- Do you have an illness or an allergy for which you are being treated?
- Are you taking medication on a daily basis?
- Do you use an inhaler on a daily basis?
- Do you participate in a full physical-education program?
- Do you have any kind of medical problem that we should know about?  
(examples: diabetes, history of low blood sugar, history of panic attacks,  
fainting easily)