

## Teen's Death Raises Cardiac Screening Issue

Aug. 4--The sudden death in early June of 16-year-old Kenny Sirois of Madawaska dealt a blow to the whole tight-knit community. Handsome, smart, popular and an accomplished athlete, Sirois collapsed and died while running home in an impromptu race with his twin brother, Mark.

Though rare, the genetic heart condition that caused his death, known as hypertrophic cardiomyopathy, or HCM, kills an estimated 200 to 300 Americans a year and affects many others.

It is most likely to turn lethal in young athletes who push themselves hard and disregard subtle signs that something may be wrong.

In most cases, it can be detected with a standard electrocardiogram, or ECG, readily available in many medical offices.

But family physicians and pediatricians rarely include an ECG as part of a routine sports physical, and it may be up to student athletes and their families to report the seemingly innocuous symptoms that could save their lives.

HCM is an inherited disorder that affects males and females equally, passed to the next generation with a single dominant gene from either parent.

Because symptoms can be mild or absent altogether, the familial connection isn't always clear. But having blood relatives who have died before age 40 of heart-related conditions should raise concerns.

In HCM, the left ventricle of the heart becomes enlarged, oxygen-starved and ineffective at pumping blood to the rest of the body. The condition worsens with maturity and is aggravated by physical exertion.

Tragically, some people collapse and die without warning.

But some, especially athletic teens and young adults, do develop symptoms -- disproportionate shortness of breath with or without exertion, chest pain, heart palpitations, light-headedness and fainting.

Many, but not all, develop a heart murmur that can be detected with a stethoscope.

Kenny Sirois' mother Wendy said last week that her son, always active in school sports, had complained of breathlessness and chest pains from time to time.

"We always thought 'Oh, well, he's been exerting himself,' or 'It's just growing pains,'" she said. "We know now we should have had him checked."

A positive diagnosis of HCM can be life-altering -- as well as life-saving -- for an aspiring young athlete. To reduce strain on the heart, patients are advised to engage in less aerobic activities -- like golf or bowling -- instead of football, basketball, track or other physically strenuous sports.

Typically, they would also be prescribed medication to decrease the overgrown heart muscle's dangerous demand for oxygen and to increase the flow of blood to the rest of the body.

According to a recent article in the Wall Street Journal, routine pre-sports ECG screenings in Japan and Italy have successfully identified a number of cases of HCM, allowing young would-be athletes to redirect their energies and take other steps to protect themselves. But such widespread screenings pose tremendous cost issues, especially when relatively few cases of HCM may be identified.

No one knows how common the condition really is, but a prominent researcher in Minneapolis estimates that each year in the United States, between 200 and 300 young athletes die suddenly from HCM.

In Maine, according to pediatric cardiologist Dr. Richard McFaul of Damariscotta, it's a fair guess that HCM will kill two or three teens or young adults each year.

The out-of-pocket cost of a standard ECG in Maine ranges from \$60 to \$135, depending on where it's performed. The statewide average is right around \$100.

"So the issue is, do you really want to screen 200,000 kids each year with ECGs or ultrasounds in this depleted health care system?" McFaul asked.

A more realistic response, he said, is for health practitioners to be more vigilant in asking about the symptoms of HCM as well as listening carefully for the telltale heart murmur that develops in many cases.

Though many heart murmurs are completely harmless, he said, it's essential for physicians or other practitioners to correctly identify all murmurs through ECG or other diagnostic testing.

Schools, too, have a critical role to play in screening student athletes for heart problems. While each school district develops its own sports policies, many look to the recommendations of the Maine Principals Association for guidance. According to its Web site, the MPA "has served as the governing body of high school athletics in this state since 1921."

In its most recent guidelines, developed by the Massachusetts Interscholastic Athletic Association, the MPA recommends that student athletes have a complete physical every two years, using a comprehensive physician form endorsed by the American Academy of Pediatrics, the American Academy of Family Physicians and a number of other medical groups.

A physical exam just once during the four high school years is minimally acceptable, according to the MPA.

In the years they don't have a complete exam, the MPA says students should meet with the school nurse to check height, weight and blood pressure and to discuss a specific list of health factors, noting any changes in the student's medical status. Any significant concerns, such as new cardiac symptoms, would trigger referral to a physician.

MPA Assistant Executive Director Larry Labrie this week said school districts choose whether or not to abide by the organization's recommendations.

"It's up to individual school boards and school committees to choose what they do. ... If we said every youngster had to have a complete physical every year, that would be too pricey for lots of families, especially those with two or three kids participating in school sports," he said.

LaBrie said there's no way of knowing how many schools in Maine adhere to MPA recommendations, but added he'd be surprised if most schools didn't. "When we make the recommendations, you want to follow them, because you can be found negligent if you don't," he cautioned.

But at least some schools in Maine do not comply with recommendations for optimal student health and safety. The Wall Street Journal article, for instance, featured a student questionnaire from an unidentified school district in Maine that asks would-be athletes about accidents, fractures, surgeries, allergies, medications, panic attacks -- everything, seemingly, except the key symptoms of a potentially fatal heart disorder.

At sports-minded Bangor High School, athletic director Stephen Vanidestine said student athletes are required to have just one complete physical during

the high school years, usually in ninth grade. Barring significant changes, the only required follow-up is an annual health form that asks students and parents to report any new concerns.

If the school, or the state, were to mandate more frequent physicals, Vanidestine said, it would pose a financial burden on many students and their families.

He said the combination of parental observation and professional medical assessment works well to keep Bangor High athletes healthy and safe, but he noted that some students -- and some parents -- are reluctant to identify any problem that could potentially sideline them.

"Parents now are so much into their kids' lives; they forget sports should be fun and enjoyable. Kids are under a lot of pressure to perform, and they don't always take care of themselves," he said.

Wendy Sirois said last week that though her family members are still grieving their loss, one small silver lining has emerged: physicians at a local medical practice have proposed running routine ECGs on all area teens who come in for sports physicals.

"That's very gratifying," she said. "We're stressing the importance of this all the time, telling any parents who'll listen that they need to get their kids checked."

Kenny Sirois' twin brother Mark has undergone a series of heart tests locally as well as in Bangor and Portland. While the results are still inconclusive, Mark Sirois said "it's looking pretty good" and that he doesn't spend much time worrying about his health.

He plans on participating in sports as usual this coming school year, he said, and will start training with a new regional football club later this month.

More information about hypertrophic cardiomyopathy is available online at [www.4hcm.org](http://www.4hcm.org).