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Parents' Push for Heart Tests for Young Athletes Splits Doctors

Debate Over Whether EKGs Should Become Standard for Teenagers Before Playing Sports

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Health

As a veteran nurse, Rhina Paredes had no idea that her athletic young son might bear a heart defect until he fell dead at the age of 15.

After Eric Paredes's death in 2009, Ms. Paredes teamed up with a cardiologist at her hospital, John Rogers, and started a program in San Diego to offer free electrocardiogram screenings for teenagers. Of the nearly 12,000 teens they've scanned so far, 121 were found to bear potentially fatal cardiac defects, according to the Eric Paredes Save A Life Foundation.

"If not for the death of Eric Paredes, I wouldn't have had my son screened and I'm not sure he would be alive," says Erin Lawson, a San Diego property manager. A scan of the heart of her soccer-playing 14-year-old, Devin, three years ago found two cardiac defects—one potentially fatal. Within weeks the boy underwent open-chest surgery. He recovered and was cleared to play sports again.

Across the U.S., parents of young athletes who died from hidden cardiac conditions that could have been screened and treated are launching scanning services to keep such tragedies from befalling others.

Teaming up with local cardiologists, they offer free or low-cost electrocardiograms, an electrical study of the heart commonly known as an



Devin Lawson, center, underwent heart surgery three years ago after getting screened. Says his mother, Erin Lawson, left, 'If there were something wrong with my son and I didn't have him checked, I could never forgive myself.'
Sam Hodgson for *The Wall Street Journal*

EKG. Sometimes they add an echocardiogram, which studies the structure of the heart. The scans together detect most—though not all—of the cardiac defects that can cause sudden death in the young, especially heart-stressed young athletes. Those scans aren't included in regular pediatric exams or young athletes' standard pre-participation physicals.

This grass roots medical movement now boasts more than 50 screening organizations in 26 states, nearly all of them launched in the last 10 years, according to Screen Across America, a year-and-a-half-old consortium of

screening groups. "We're gaining unbelievable momentum in terms of getting kids screened," says Michele Snyder, executive director of nine-year-old Parent Heart Watch. Her 17-year-old daughter died on a soccer field in 2008.

Yet the fields of standard cardiology and pediatric cardiology haven't embraced such screenings. Its leaders say that high false-positive rates can burden healthy teens with a scare that only expensive additional testing can dispel. Even those diagnosed with

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known killers such as hypertrophic cardiomyopathy (HCM)—an enlargement of the heart that is the top cause of sudden cardiac death in young American athletes—may not benefit from knowing about it. That knowledge could unnecessarily sideline them from sports, as well as careers in the military or police.

When a young athlete dies from HCM, "it probably could have been detected," says Paul Thompson, a Connecticut-based sports cardiologist who is Hartford Hospital's chief of cardiology. "But when a screen finds it in a young athlete without symptoms, we don't know that it ever would have caused him problems. Meanwhile, he gets labeled a cardiac cripple for life."

Whether to screen young athletes' hearts—as is done in nations such as Italy and Israel—represents one of the hottest debates in American cardiology. Among several disputed issues is how many young athletes fall prey to sudden cardiac death (SCD). Opponents of screening point to published research showing a rate of sudden cardiac death in young athletes of one in 164,000. Proponents counter with a study of NCAA athletes, published in 2011, that found a rate of one in every 43,000.

Now, in what screening proponents are hailing as a victory, the National Institutes of Health and the Centers for Disease Control and Prevention are creating a registry for studying sudden death among those 24 and younger. "It is a crucial first step toward figuring out how to prevent these tragedies," said Jonathan Kaltman, an NIH cardiology chief.

The European Society of Cardiology and the International Olympic Committee recommend that young athletes undergo EKG screening. The American Heart Association and

American College of Cardiology are more cautious. In two position papers—published in 1996 and in 2007—those two organizations argue against systematic EKG screening of young athletes.

A third edition is due out in the coming days. According to a copy of the document reviewed by The Wall Street Journal, this version reinforces that opposition to widespread EKG screening of young athletes. The document argues that no widely accepted standards exist for what constitutes an abnormal EKG in young athletes and that no evidence exists that EKG screening of young athletes would lower mortality rates.

The AHA/ACC argues for continued use of a pre-participation physical evaluation form that asks questions such as whether a young athlete has ever fainted during exercise. Under these guidelines, an affirmative response to such a question would call for further testing, including possibly an EKG.

As evidence that the evaluation form can be useful in identifying defective young hearts, the AHA/ACC points to a 2006 study examining how 711 hypertrophic cardiomyopathy patients were diagnosed with the condition. In 4% of those HCM cases, the diagnosis arose during a pre-participation exam ahead of competitive sports.

But the typical young athlete who falls dead likely underwent a pre-participation exam that didn't include an EKG, notes Jonathan Drezner, a University of Washington family medicine specialist and past president of the American Medical Society for Sports Medicine. In the case of HCM—the most common cause of sudden death in young athletes—published research shows that EKG flags as abnormal up to 90% of hearts stricken

with the condition.

While opposing any mandatory use of EKG in young athletes, the AHA/ACC statement says grass-roots efforts to make such screening available for teens are acceptable, "provided that close physician involvement and sufficient quality control can be achieved."

In the eight years since cardiologist Joseph Marek launched Young Hearts for Life Cardiac Screening in suburban Chicago, the program has screened nearly 110,000 young people, athletes and non-athletes alike. In the beginning, about 2.5% of the EKGs it administered registered as abnormal, a rate that has since fallen to about 1%. Perhaps half of those abnormal findings turned out to be false positives, and there is no guarantee that the screenings found every hidden heart defect.

But the tests are free, nobody is pressured to take them and in some cases they are possibly lifesaving. "We certainly have identified a whole host of kids who had previously undiagnosed conditions, some of them quite serious," says Dr. Marek, a cardiologist with the Advocate Medical Group.

Three years ago at Waubonsie Valley High School in Aurora, Ill., an abnormal EKG in track athlete Christopher Storm led Dr. Marek ultimately to diagnose HCM. After confirming that diagnosis, Mr. Storm underwent the implantation of a defibrillator and followed his doctors' advice to give up competitive athletics.

"I miss competitive running," says Mr. Storm, 18, who graduated high school last month. "But not as much as I would miss my family and friends if I'd collapsed on the track."