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Following the death of his son to sudden cardiac arrest in May 2012, Scott Stephens has barnstormed the state on behalf of the group that bears his son's name – the Cody Stephens Go Big or Go Home Memorial Foundation.

His impassioned testimony to both the University Interscholastic League's Legislative Council and its medical advisory committee was a driving force behind the creation of a new awareness form about sudden cardiac arrest (SCA), included this year as part of the UIL's pre-season packet.

The two-page form – which outlines the causes and symptoms of SCA, the leading cause of sudden death in young athletes – requires a signature from a parent or guardian before a high school student can participate in a UIL athletic activity. It is seen as a positive addition by both heart screening advocates and cardiologists.

The debate, however, lies with what comes next. Is it the first step to changing the high school physical by adding additional cardiac tests, specifically an electrocardiogram? Or is the form a starting point for an awareness campaign on cardiac health in student-athletes?

Convinced that an electrocardiogram (alternately known as ECG or EKG) probably would have saved his son's life, Stephens is pushing for statewide adoption of ECGs as part of the standard physical. The form is a "fantastic first step," Stephens said, but it's not enough.

"There's no greater pain than, basically, losing your hero," Stephens said. "And that's what he was to me – 18 years old and ready to conquer the world. And I know there are other kids just like him. I know the pain their family will face when it happens. I take it personal."

For those in the medical community – including the UIL's medical advisory board – the data behind recommending mandated ECG screening just isn't there.

Ron Courson, the senior associate athletic director for sports medicine at the University of Georgia, said any such mandate is a long way off.

"In the cardiology community, they're so divided on it right now," Courson said. "If it was a situation right now that medically this needed to happen, it would be much easier to push. But there's not a consensus."

WHAT'S ON THE FORM?

As described by the UIL's new form, sudden cardiac arrest is a sudden electrical malfunction of the heart, disrupting blood flow to critical organs and potentially leading to a loss of consciousness and death if not treated within minutes. In some cases, there are warning signs – including chest pain, heart palpitations, dizziness and fainting. However, there are cases of SCA which are asymptomatic.

The underlying causes for SCA can be a myriad of heart conditions – either inherited, present at birth or developed over the course of the student's lifetime. The most common, accounting for nearly one-third of sudden deaths, is hypertrophic cardiomyopathy (HCM), a thickening of the heart muscle that makes it more difficult to pump blood.

Scott Stephens' son, Cody, died from HCM while taking a nap in their home. A 6-9, 289-pound tackle at Crosby, 20 miles northeast of Houston, Cody had signed to play football at Tarleton State.

Like many of the issues regarding the condition, SCA's frequency is debated within the medical community – ranging from 0.8 to 6.2 events per year per 100,000 people younger than 25. Estimated mortality rates also vary significantly between studies.

Drawn up by Arnold Fenrich – a member of the UIL's medical advisory committee and a doctor at Children's Cardiology Associates of Austin, part of Pediatrix Medical Group – the UIL's form gives information about SCA, also assuring parents that the league's current screening efforts are in

compliance with what is recommended by the American Heart Association. As part of the physical, the AHA recommends 12 cardiac elements, all of which the UIL requires.
Additional diagnostic tools such as electrocardiograms and echocardiograms are mentioned on the UIL's form as "readily available to all athletes," with a listing of web sites for additional information on screenings. But the form states that those tests are "not mandatory."

IS THE CURRENT PHYSICAL ENOUGH?
The UIL's reliance on the AHA's guidelines as the main screening method is a point of contention. Critics point to several problems with the league's approach, including the reliability of self-reporting about the student's medical history, the expertise of those performing examinations, and the inadequacy of basic tests.
Currently, the UIL's pre-participation physical form requires a student – with a parent or guardian's assistance – to answer a series of questions about their medical history, attempting to flag if the student has developed any potentially serious medical conditions. Questions range from whether the student has had chest pain during or after exercising, to the presence of high blood pressure or cholesterol, with students checking boxes labeled "yes" or "no". An examination by a physician, physician's assistant, registered nurse or chiropractor is required at least three times during a student's junior high and high school careers, during which blood pressure is checked, as is the heart through a stethoscope.
During a routine physical in August 2012, Flower Mound volleyball player Elizabeth Boyd told her doctor she'd been experiencing an occasional chest pain for a few seconds once or twice a month.
"Just to be sure, they sent me to a cardiologist – and they wouldn't clear me until I went," Boyd said.
After an ECG and echocardiogram, Boyd was found to have an atrial septal defect – a three-centimeter hole between the upper chambers of her heart. Ironically, her cardiologist said that her chest pains were likely a result of growing pains, and not her condition.
Boyd underwent successful open-heart surgery later that month, returning a little over two months later to play in the final district game of her sophomore season.
Not all students are as forthright, said Pat Shuff, the chief operating officer for the Cypress ECG Project, a non-profit organization out of the Houston-area that is one of the state's largest screening providers. Shuff said of the several hundred students that his group flagged for follow-up tests over the past few years, "I think maybe five of them had a check mark that said 'I've got a family history.'"
"Even a kid with stitches down his chest, their answer is, 'No, no problems,'" Shuff said. "The fact that you have stitches on your chest from a surgery when you were three years old because of a heart condition, shouldn't you have answered yes?"
In completing a large packet of pre-season paperwork, Stephens said, parents and students may not spend time accurately answering questions about family history.
"My fear is that it's going to be one of 20 forms that the kids are going to get or their parents are going to get," Stephens said.
Jonathan Drezner, professor in the Department of Family Medicine at the University of Washington and one of the nation's leading proponents of ECG testing on student-athletes, called the basic physical examination "very insensitive," because "most of the conditions that cause this tragedy don't have any warning symptoms."
"If you are asking kids if they have cardiovascular-related symptoms, at the very start of the evaluation, we are gonna miss the majority of kids at risk." Drezner said. "The physical exam doesn't pick up things that put kids at risk either."

IS THE ECG THE ANSWER?
An electrocardiogram is seen – in varying degrees – by Drezner, Shuff and Stephens as a necessary supplement to the current physical, given its relatively low cost and the ease that the test can be

administered. The test measures both the time and volume of electric activity through the heart, and can be performed for as little as $15 per student. If an ECG shows concerns, patients are recommended for follow-up testing with a pediatric cardiologist, who might perform echocardiograms, genetic testing, and other exams.

Those follow-ups aren't cheap, however, potentially costing hundreds or thousands of dollars – although they are usually covered by insurance. For those without coverage, some screening groups have agreements with pediatric cardiologists to see a certain percentage of cases pro bono.

Even heart screening advocates like Stephens acknowledge some of the ECG's drawbacks. While conductivity problems – like Long-QT syndrome and Wolff-Parkinson-White syndrome – can be identified by an ECG, the test won't find any coronary artery anomalies, the second-leading cause of sudden cardiac death behind HCM. According to Fenrich, an ECG could miss as much as 1/3 of the cases of HCM.

Echocardiograms and MRIs, more expensive tests, are required for finding structural anomalies.

Fenrich said, at this time, the science doesn't indicate that ECGs significantly reduce the mortality rates from sudden cardiac arrest. Both Italy and Israel have national ECG screening of all 12- to 35-year-old athletes, and their mortality rates from SCA are similar to those found in the United States, Fenrich said.

The sudden death of a student-athlete in Texas, while shocking, is still quite rare, Fenrich said, quoting a conventional – but debated – estimate of 1 in 300,000 young athletes at risk.

"To some extent," Fenrich said. "there's some sensationalizing of these events." Efforts to reduce more common causes of teen death – such as accidents, suicide or drug and alcohol abuse – would do more to reduce mortality rates in the population, he said.

A high false positive rate –between five to 10 percent – is also a major concern, said Benjamin Levine, director of the Institute for Exercise and Environmental Medicine at Texas Health Presbyterian and professor of medicine and cardiology at UT Southwestern Medical Center.

By using ECGs to disqualify students from participation in athletics until follow-up tests could occur, the number of false positives could be significantly higher than those who harbor a condition that needs treatment, Levine said.

"It's not a black-and-white picture," said Levine, who helped edit the UIL's new cardiac form. "There are many shades of gray, even for the best of cardiologists, using the best methods. When you translate [the false positive rate] to all kids that participate in sports in Texas, it's a very large number."

Every parent should feel perfectly comfortable choosing to have their children screened by ECG if they have concerns, Levine said. But in doing so, parents should accept the risks and costs of inappropriate diagnosis or therapy, he added.

For Stephens, the risks and costs are overshadowed by the death of any student-athlete.

"It's not a perfect test, and we understand that," Stephens said. "But it's better than what we are doing. I can tell you the cost for not doing these tests. It's extremely high."

WHAT'S NEXT?

Fenrich is part of a study examining the feasibly of creating a statewide registry, the Texas Adolescent Athete Heart Screening Registry, to collect data to assess the effectiveness of current screening methods.

"Until we have more answers on where we should go with pre-participation testing and screening, we've implemented the [automated external defibrillator] program within the UIL-based schools in the state of Texas," said Fenrich, referencing the 2006 UIL amendment requiring defibrillators on each public high school campus. "That, at least, provides a way to save someone who has a sudden cardiac event."

With the release of the UIL's new form, Shuff said he has seen an increase in the number of schools interested in ECG screening. His personal opinion is that ECGs should be offered during physical exams,

but not required. A change in the UIL's pre-participation form, allowing medical practitioners to check a box labeled "Cardiac Screen recommended" would prompt more screens, Shuff said.
Stephens, though, has a much grander goal: mandated ECGs in Texas.
Working with Rep. Sylvester Turner (D-Houston), Stephens pushed for that in the most recent session of the Texas Legislature. House Bill 1319, or "Cody's Law," would have required athletic participants in UIL events to have two ECGs during their high school careers, coinciding with their physical exams. The bill did not get out of the public education committee in the House.
"We are considering all our options," Stephens said. "And yes, 2015, there's a very good possibility that we will try again. But, I will say that if this form takes off, and schools start screening and there's a domino effect, I don't need a law just for a law's sake."

Staff writer David Just contributed to this story.
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Additional trinkets

Questions in the UIL's pre-participation physical relating to cardiovascular health:

Have you ever passed out during or after exercise?
Have you ever had chest pain during or after exercise?
Do you get tired more quickly than your friends do during exercise?
Have you ever had racing of your heart or skipped heartbeats?
Have you had high blood pressure or high cholesterol?
Have you ever been told you have a heart murmur?
Has any family member or relative died of heart problems or of sudden unexpected death before age 50?
Has any family member been diagnosed with enlarged heart (dilated cardiomyopathy), hypertrophic cardiomyopathy, long QT syndrome or other ion channelpathy (Brugada syndrome, etc.), Marfan's syndrome, or abnormal heart rhythm?
Have you had a severe viral infection (for example, myocarditis or mononucleosis) within the last month?
Has a physician ever denied or restricted your participation in sports for any heart problems?

ECG screening groups:
AugustHeart (www.augustheart.org)
Championship Hearts Foundation (www.championshipheartsfoundation.org)
Cody Stephens Go Big or Go Home Memorial Foundation (www.codystephensfoundation.org)
Cypress ECG Project (www.cypressecgproject.org)
Living For Zachary (www.living4zachary.org)