

Transcript Details

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One Foundation's Approach to Preventing Sudden Cardiac Death in Young Athletes

DR. BROWN:

Sudden cardiac arrest is a fatal condition that can occur without any prior cardiac events. And while it's rare in our younger patients, it remains one of the leading causes of death in young athletes. You're listening to *Heart Matters* on ReachMD, I'm Dr. Alan Brown. And joining me to take a look at sudden cardiac arrest in young adults and, in particular, young athletes is Dr. Joseph Marek. Joseph is a clinical cardiologist and senior medical director of cardiopulmonary services at Advocate Medical Group. And he's also the founder and medical director of the Young Hearts for Life Foundation, that is a charitable foundation aiming to prevent sudden cardiac arrest in young adults and, in particular, young athletes. So Joe, thanks a lot for joining me today for this interview.

DR. MAREK:

Glad to be here.

DR. BROWN:

Yeah, so obviously, being colleagues, I've watched from the inception when you got involved in developing Young Hearts for Life. And I suppose there was some event that prompted you to decide to focus on sudden death in athletes. I wonder if you could share with the audience what got you interested in this in the first place? And then a little bit about your journey as you started to develop Young Hearts for Life program?

DR. MAREK:

Sure. Well, Al, as you well know, as a group, we had always been concerned about this. There'd be deaths in our community of soccer players or football players. And I think we've always struggled with was there something that we could have done to prevent one of these deaths. And you may recall, I think, was in the 1990s, that we undertook a program at one of the Naperville schools to do echocardiograms. And the belief then was that the most common cause of sudden cardiac death was hypertrophic cardiomyopathy. And they could be detected with screening echoes. And these were done with before they were digital was videotapes, and there were about 1,000 of them, and you have read them all. And we didn't find a single one. And so that effort was sort of echoed with what was in the medical literature at the time that there was really no effective way of doing the screening.

And then fast forward to 2005, and there was a young man in the Naperville area who had sudden cardiac death. And the mom approached us and said, 'Why couldn't you do something?' We once again looked in the literature, and there was nothing.

And then interestingly there was an article in the *Wall Street Journal* about what was happening in Europe, where they were doing EKG screening. And I actually thought that the editor had it wrong, that it was echo screening, I didn't know that EKGs could be useful. And then a week later, there was another article in the *Wall Street Journal* on the same topic. And that same day, there was an article in *The New York Times*. And I sort of felt like someone was wagging their finger at me to look at this. And so I dug up the experience in Italy, and found that by doing a quick, simple, painless ECG, they could reduce the incidence of sudden death in these young athletes by 85 percent. So that's when we thought of going to our foundation at the time, which was searching for some projects to do. And I presented this project, and I was told to go ahead and run with it. And the rest was history, we developed the program.

DR. BROWN:

So, I know that you were committed to looking at high school athletes, who would be the people that were most worried about, and I think that was pertinent to the mother who approached you. And it was quite a big project to think about doing ECGs on all of those folks, and what that might cost and how we would get them into the office. So my recollection is you came up with some very clever ways to get the parents involved and volunteers involved, and actually go out to the children and screen them in their schools. So maybe you could tell us a little bit about how you did that?

DR. MAREK:

Sure. Well, as you know, these conditions that we're looking for that could cause sudden cardiac death, although they're not rare, they're not common. So, if you're going to find these individuals, you're going to have to sift through a large number of young adults. And that made it easy in terms of selecting where we were going to screen, would be the high schools where there is a larger concentration of students athletes.

And then it became an issue of how we could do all these ECGs. We did a pilot screening at one of the local junior high schools, and we use staff from the office and medical residents and so on. And we were able to screen 85 kids. And we demonstrated that we could do it pretty efficiently, about five minutes per ECG. But then the question was how to scale it up.

And I was in the airport waiting for a flight that was canceled. I had a cup of coffee and a chocolate brownie, and I was very highly caffeinated. And it dawned on me that when I was a medical student, my partner Lou McKeever, taught me how to do an EKG when I was a junior medical student in about five minutes. And I thought for a moment, I realized that I could teach parents on how to do the EKGs. If you know how to use a cell phone, you could certainly learn how to do an ECG. So, I developed a program where we train parent volunteers, and they provide the workforce that could perform all these EKGs in an efficient way at a high school. And we developed a program, 90 minutes beginning to end, they walk out of there with hands-on experience on how to do an ECG, they understand the background. And then the next day, they're there doing the EKGs. And they do them efficiently, and they do them at high quality. And we're able to do anywhere from 700 to 2,200 ECGs a day.

DR. BROWN:

For those just joining us, you're listening to *Heart Matters* on ReachMD. I'm Dr. Alan Brown, and I'm speaking with Dr. Joseph Marek about sudden cardiac arrest in young adult athletes and his foundation, Young Hearts for Life.

So Joe, let's talk a little bit more about what you find and what you're looking for to try and identify student athletes who might be at risk for sudden death.

DR. MAREK:

Well, we're looking for ECG changes of the common conditions that could cause sudden cardiac death. And at the time we started the program, it was believed that the most common cause was hypertrophic cardiomyopathy that was responsible for 35 percent of these deaths. And so, we thought we would find a large number of these but as we did more and more ECGs and identified more students, we realized that we were not finding as many young adults with HCM, but we were finding other conditions that can produce sudden cardiac death. And they were things like prolonged QT intervals, WPW. Those are really the two big ones along with changes on the ECG that would suggest hypertrophic cardiomyopathy. And as it turns out, with the advances with the knowledge about sudden death in these young adults, it became apparent that the most common cause, 40 percent of the cases, would be autopsy negative, basically some electrical issues like long QT or like WPW. And actually, WPW is the most common cause that we'd find. And that was striking for me because as an adult cardiologist, when we would see someone with a WPW, if they weren't having a lot of symptoms, it was pretty benign. But it's a very different animal in these young adults. It is associated with a higher incidence of potentially life-threatening rhythm disturbances and sudden cardiac death. So those are the things— that we tend to come across most commonly.

DR. BROWN:

Right. And those would be asymptomatic until the event probably unless they had a run of SVT or something I assume. So— did you find that there were any kids that actually had symptoms that forewarned of an event? –

DR. MAREK:

Well, you know, a lot of these young adults that we identify with ECG abnormalities that need more evaluation, some of them will have had symptoms, but they were dismissive of them. They're young adults, they don't understand what's normal or abnormal, what their body's doing, particularly when they're pushing themselves in athletics. You know, it's that thing that the coaches tell us, no pain, no gain. So if they feel like they're getting dizzy, or if they're having their heart pounding, they think that they're giving that 110 percent they're supposed to be doing.

So I find when I see some of these young adults, that they have had symptoms, but they just ignored them or dismissed them. And about half of them don't seem to have any symptoms at all.

DR. BROWN:

So let me ask you about some of the kids that you've identified. Can you give us a rough idea of how many kids screened to identify a person with a problem? Tell us about some of your successes in terms of kids that you've screened.

DR. MAREK:

So number wise, currently, with the standards for ECG interpretation that we use, we identify about one and a half percent findings that need more evaluation. We are careful that we don't call it abnormal. And then, of these young adults, probably a third or more will actually have some cardiac conditions.

So one of our earliest cases was a young man, he was a freshman at one of the region high schools, he was a track runner and he would get dizzy, as he would be approaching near the end of his runs, but he thought he's just giving it all and he had hypertrophic cardiomyopathy. And he had a defibrillator put in by one of our pediatric cardiologists. And he's been a big advocate for the program. He's spoken to students and parents and trying to encourage them. The interesting thing is that, as you can imagine, it was a huge shock for this young man to be told that he can't participate in sports. And it turned his life around. He decided he was going to go into medicine. And he's a nurse practitioner now and is very much a proponent for our screening program and screening programs elsewhere.

So we have stories like that over and over again. And they're very comforting to know that we're out there and we're making a difference for some of these young adults.

DR. BROWN:

Yeah, those are great stories. Before we finish, let's talk a little bit about Young Hearts for Life foundation. So, can you give us a little bit of a feel for the support that you either have or need and then share with our audience how they might support the foundation if they're interested?

DR. MAREK:

Sure. Initially, there was a great deal of interest at the hospitals in our region to support the program. And so they provided the seed money that allowed us to purchase ECG machines and hire some staff. But my focus was to make this as low cost as possible. And we did that by heavily utilizing volunteers.

Our focus has always been to make it free for the students. I didn't want a situation where some young adult didn't get the ECG because his parents didn't think that they could afford it. So it's free for the students, but the community supports it. And it's businesses, it's the schools, it's foundations, it's community, people donating money for us to do this. We have a great website. It's yh4l.org. They could go there and they could find a donate button. And I would be very grateful, and so would the families whose kids we might identify, would be grateful as well. So we appreciate everything we can get.

DR. BROWN:

Well, thank you so much for what you've done. I've had the pleasure of being your colleague to watch you develop this over the years with unbelievable vigor and really provide a wonderful service to the community. And I appreciate you sharing all the details with us

about the journey from 2005 till now.

Those important considerations will help us improve care for the cardiovascular health of our younger patients, and particularly our young athletes. So I'd like to thank our guest, Dr. Joseph Marek, for sharing his insights and providing more information on the Young Hearts for Life foundation. Joe, it's been a pleasure speaking with you today and thanks again for taking time to talk with us.

DR. MAREK:

Thank you, Al.

DR. BROWN:

For reach MD. I'm Dr. Alan Brown. To access this and other episodes in our series, visit reachmd.com/heartmatters, where you can Be Part of the Knowledge. Thanks very much for listening.