Hypertrophic Cardiomyopathy Association

Serving the HCM Spectrum Disorder Community Since 1996

STATEMENT OF THE HYPERTROPHIC CARDIOMYOPATHY ASSOCIATION IN SUPPORT OF HOUSE BILL 356

Before the Public Health Policy Committee

Representative Adam Mathews, Chair

Chairman Mathews, Vice Chair Stewart, Ranking Member Liston, and Public Health Policy Committee members: Thank you for the opportunity to present proponent testimony for House Bill 356, the "Healthy Cardiac Monitoring Act", on behalf of the Hypertrophic Cardiomyopathy Association.

My name is Lisa Salberg. I am the Founder and CEO of the Hypertrophic Cardiomyopathy Association (HCMA). The HCMA is a 501c3 nonprofit organization founded in 1996. We support, advocate, and educate patients, families, the medical community, and the public about hypertrophic cardiomyopathy (HCM).

The HCMA has proudly partnered with the Cleveland Clinic Foundation for over 25 years. Ohio is home to two HCMA-recognized Centers of Excellence, offering the highest standard of treatment for HCM: the Cleveland Clinic Foundation (Adult and Pediatrics) and The Christ Hospital. Having two Centers of Excellence makes Ohio one of only eleven states with more than one HCM program in their state.

Ohio was the 2nd state in the US to pass a law designating the fourth Wednesday of February as "Hypertrophic Cardiomyopathy Awareness Day" yearly, for which we are deeply grateful. More than half the states have since followed suit.

It was also Ohio where this Jersey girl sent her father for life-saving surgery in 2006.

Today, Ohio stands ready, once again, to become the 2nd state: this time, to have a sustainable, systematic, and cost-effective plan to help identify those at risk for genetic cardiac disease.

Hypertrophic Cardiomyopathy

Hypertrophic Cardiomyopathy (HCM) is the most common genetic heart disease and can affect anyone regardless of age, gender, race, or ethnicity.

HCM causes the heart muscles to thicken and obstruct blood flow, which can lead to symptoms like chest pain, shortness of breath, and fatigue, as well as a higher risk of blood clots, stroke, and, in rare cases, cardiac arrest. HCM is the most common cause of cardiac death in young people in North America, although most only hear about HCM when a young athlete collapses on the playing field. It is important to know that HCM can be present equally in athletes and non-athletes. A person could be completely asymptomatic or believe, for lack of context, that they are asymptomatic before a severe cardiac event occurs.

The prevalence of HCM in the general population is 1 in 250 people. Unfortunately, far too many, approximately 80% or more, remain undiagnosed. Here in Ohio, over 58,000 people could be impacted by HCM, with likely 45,000 or more remaining undiagnosed, potentially putting them at significant risk.

Other Genetic Cardiac Diseases

In addition to HCM, several other genetic cardiac diseases impact the general population, including Dilated Cardiomyopathy, Arrhythmogenic Right Ventricular Cardiomyopathy, Marfan Syndrome, Long QT Syndrome, Short QT Syndrome, Brugada Syndrome, and Congenital Heart Disease, to name a few. The prevalence of genetic cardiac disease in the state of Ohio is estimated to be greater than 350,000 people.

Early Diagnosis is Key

Knowing the signs, symptoms, and one's family heart health history is the first step to diagnosing genetic heart disease accurately - and timely. Awareness and screening can help children and their families better understand their risk profile and seek potentially life-saving or life-improving treatment when necessary.

According to the American Academy of Pediatrics (AAP), all children should be screened for the risk of cardiac arrest regardless of their athletic status, as stated in the updated AAP policy statement Sudden Death in the Young: Information for the Primary Care Provider.

The policy, from the AAP Section on Cardiology and Cardiac Surgery and the Pediatric & Congenital Electrophysiology Society (PACES), offers primary care providers a strategy for screening, evaluating, and managing the risk of sudden cardiac arrest (SCA) and sudden cardiac death (SCD) in youths.

Failure is not an Option

The Healthy Cardiac Monitoring Act can help healthcare providers intervene in time to help improve and possibly save the lives of those with HCM and other genetic forms of heart disease.

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Early diagnosis could have helped save the life of Jillian Blair.

On February 16, 2022, 17-year-old Jillian Blair's doctor detected a heart murmur during her well-child exam. She was referred to a local pediatric cardiologist.

On March 15, 2022, the cardiologist diagnosed Jillian with hypertrophic cardiomyopathy.

The cardiologist recommended that Jillian have a cardiac MRI, another echocardiogram, and genetic testing before he decided on the next steps. These tests were done on March 28, 2022.

Over the next few weeks, Jillian had symptoms of dizziness and near syncope. Her MRI results showed significant scarring on her heart, but her doctor was still waiting for the results of the genetic test to decide the next steps.

On April 21, 2022, less than three short months after Jillian's doctor detected a heart murmur, Jillian suffered a sudden cardiac arrest and passed away waiting for these next steps.

There were "red flags" all over Jillian's family. A cousin and an uncle both had HCM; her mother, grandfather, and aunt had been diagnosed with atrial fibrillation. What a difference it would have made if healthcare providers had asked the right questions, received the proper training, and knew how to manage her and her family better. If Jillian had been diagnosed even just one year earlier, they would have had the chance to implant a defibrillator in time for Jillian. Having an ICD on that fateful day would likely have saved her life.

To read Jillian's full story: Jillian's Story

Another example of "red flags" that were missed is Derek Armstead.

Derek lost consciousness while playing with his nephews; his fiancé immediately called an ambulance. Derek was taken to the emergency room, and when he regained consciousness, he told the doctors he had "gotten a bad headache" just before passing out. The attending doctors assumed that it may have been a possible seizure and ordered a CT scan. The CT scan did not show anything unusual, so they sent him home with a recommendation that he follow up with a neurologist.

Derek scheduled an appointment with a neurologist who said he would order further testing. Two days later, Derek lost consciousness again, but this time, he wasn't breathing. Derek never regained consciousness and passed away on August 20, 2020. He was only 29 years old. An autopsy revealed that his cause of death was sudden cardiac arrest due to hypertrophic cardiomyopathy.

Derek's mother passed away at 26 years old from an enlarged heart, which his family now suspects could have been due to HCM. Had they known of Derek's family heart history, HCM could have been caught sooner and possibly prevented his tragic death.

To read Derek's full story: Derek's Story

On the other hand: a story about a timely physician screening led to an HCM diagnosis and is credited with saving the life of Bradley Matsinger. Bradley was screened in 2023, at age 16, for one reason: he lived in New Jersey. In 2012, New Jersey passed legislation; the "Scholastic Student-Athlete Safety Act", which added questions about family heart health history and cardiac screening questions to the student athlete preparticipation physical evaluation (PPE). In 2013, New Jersey passed legislation; the "Sudden Cardiac Arrest Prevention Act" which provides student-athletes, parents, and coaches with information on sudden cardiac arrest and establishes protocol concerning removal-from-play for athletes exhibiting symptoms of sudden cardiac arrest. In 2015 New Jersey legislation was broadened to require all well-child exams, not just those for student athletes, to include questions to evaluate every child's family history related to cardiac conditions contained in the PPE form.

Unwelcome diagnoses can still produce a happy ending. That's why we're here today.

Healthy Cardiac Monitoring Act (HCM Act)

The draft language for House Bill 356, the "Healthy Cardiac Monitoring Act," has been vetted through the American Heart Association, and they support the language.

The HCM Act can help find those with undiagnosed genetic cardiac diseases by adding four specific questions regarding a child's biological family heart health history to Ohio's existing Preparticipation Physical Evaluation (PPE), then using the same aforementioned PPE form, with these small modifications to screening questions, as part of the annual well-child examination.

The Healthy Cardiac Monitoring Act will ensure that any medical professional who performs PPE and well-child exams continues their professional development with an emphasis on cardiovascular family history, identifying symptoms, and recognizing structural changes of the heart to identify risks and refer a child to a cardiologist for further assessment if risk factors are identified.

The Healthy Cardiac Monitoring Act will also help educate families about the early warning signs of conditions that can lead to sudden cardiac arrest. It will also educate on treatment and therapy pathways to ensure continuity of care. Families will be better prepared to have meaningful conversations with their chosen healthcare provider.

House Bill 356 has these clear virtues:

- It is highly cost-effective: Adding four questions to a medical exam isn't even a rounding error when it comes to health-care budgeting… but it helps avert the much higher costs of treating an acute cardiac episode and its lasting effects.
- It's proactive: The time to diagnose genetic heart disease is before symptoms present and cause irreversible harm.
- It limits more costly diagnostic procedures to those flagged by screening.
- It promotes pediatric cardiac health overall --not just HCM screening/diagnosis. It should apply to all children, not just student athletes.
- Proof of concept already exists in the highly successful New Jersey legislation.

As noted, it has the express support of the American Heart Association and the American College of Cardiology; and it builds on broad acceptance of the existing PPE.

Conclusion

In conclusion, I urge this committee to support a measure so we can find all children, not just athletes, with undiagnosed genetic cardiac diseases. Your support will help keep families whole by allowing them to learn the risk upfront, and act to avoid tragic outcomes better.

Thank you for the opportunity to appear before you today. I am happy to answer any questions you may have.