

**STATEMENT FROM LISA SALBERG, CEO AND FOUNDER OF THE HYPERTROPHIC
CARDIOMYOPATHY ASSOCIATION (HCMA) IN SUPPORT OF Rhode Island H 5087, An Act Relating
to Education – The Children’s Cardiac Safety Act**

Before the House Education Committee

Representative Joseph M. McNamara, Chair

Chairman McNamara, First Vice Chair Noret, Second Vice Chair Kislak, and House Education Committee members: Thank you for the opportunity to submit written testimony in support of H 5087, the “Children’s Cardiac Safety 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 fifty-six HCMA-recognized Centers of Excellence in the United States, offering the highest standard of treatment for HCM.

Today, Rhode Island stands ready 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. In Rhode Island, over 5,000 people could be impacted by hypertrophic cardiomyopathy, with likely 4,000 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 Rhode Island is estimated to be greater than 33,000 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.

Children's Cardiac Safety Act

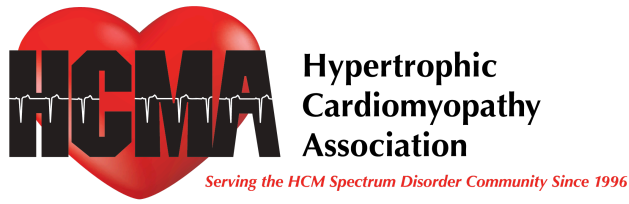
The draft language for H 5087, the "Children's Cardiac Safety Act," has been vetted through the American Heart Association, and they support the language.

H 5087 will:

- Include cardiac questions to be added to the "Well Child" examination for all children under the age of 19.
- Improve professional development for healthcare providers with an online training system.
- Improve student-athlete pre-participation physicals to include family education about signs and symptoms linked to cardiac conditions.
- Improve the ability of healthcare providers to identify children and families at risk for cardiac disorders both genetic and congenital.

H 5087 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.

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.

We are happy to work with key members of the Rhode Island Department of Health, school physicians, and pediatric cardiologists to refine the language to provide tangible benefits for RI families. I am also happy to provide additional information, physician and patient testimony if needed.

Thank you for your kind consideration.

Lisa Salberg

CEO and Founder
Hypertrophic Cardiomyopathy Association