

House Committee on Education

State House
82 Smith St.
Providence, RI 02903
17 March 2025

Re: Testimony in Support of H.7480–The Children's Cardiac Safety Act

Dear Chair McNamara and Members of the Committee,

My name is Matt Grant, and I am a resident of Newport. I submit this written testimony in support of H.7480, the Children's Cardiac Safety Act, because I know firsthand how critical early detection of cardiovascular disease can be.

I was diagnosed with obstructive hypertrophic cardiomyopathy (HCM) at age 25, not because of symptoms, but because I had the benefit of regular cardiac screening due to my family history. Many children are not as fortunate. Without appropriate screening, they may never know they are at risk until it is too late.

Hypertrophic cardiomyopathy is a genetic heart condition that is both common and underdiagnosed, affecting an estimated 1 in 250 people in the United States according to the National Institutes of Health. This means that thousands of Rhode Islanders could be living with HCM unknowingly. It is also the leading cause of sudden cardiac death in young athletes.

My family's experience illustrates the stakes of early detection. My mother, Shane Grant, was diagnosed with non obstructive HCM in her early 30s and received a heart transplant in June 2025 to remediate her advanced symptoms.

This disease has already taken members of my family. My maternal grandmother, Patricia LaRoue, died from HCM related sudden cardiac arrest in 1986 at age 42. My great aunt, Marylou Solon, was among the earliest patients to receive a surgical myectomy at the Mayo Clinic, but died days later from a stroke at age 48, another complication linked to HCM.

Sudden cardiac arrest is often the first and only symptom of an undiagnosed heart condition. The American Academy of Pediatrics has emphasized that cardiac risk is not limited to student athletes and that screening should consider all children, not only those participating in sports.

The Children's Cardiac Safety Act aims to address this gap by ensuring that key screening questions about family cardiac history and warning symptoms are incorporated into routine care. The goal is to align Rhode Island with best practices such as the American Heart Association 14 point cardiovascular screening for youth and the AAP's recommended preparticipation physical evaluation. Standardizing these questions within annual and sports physicals can help identify at risk children earlier and ensure appropriate follow up care.

At the same time, it is important to acknowledge the current status of this legislation. The Rhode Island Chapter of the American Academy of Pediatrics remains opposed to the language in H.7480 as it is currently drafted. Their perspective as frontline pediatric providers is critical, and their concerns deserve careful consideration.

For that reason, our goal is continued collaboration. We are committed to working with Rhode Island physicians and all relevant stakeholders to find common ground on this issue. I am confident that we can develop standards that meaningfully improve cardiac safety for children while remaining practical for clinicians and placing minimal burden on the budgets of the Rhode Island Department of Health and the Rhode Island Department of Education.

The good news is that an HCM diagnosis is no longer a death sentence. Advances in treatment, including medication, surgical intervention, and emerging therapies, have made it possible for patients diagnosed early to live long and healthy lives. But early detection is essential.

Rhode Island has an opportunity to strengthen childhood cardiac safety while continuing to work collaboratively with the medical community to get the policy right. I appreciate the committee's consideration and ongoing attention to this important issue.

Thank you for your time and consideration.

Sincerely,

Matt Grant
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House District 73