

Personal Statement in Support of H 5087 (Children’s Cardiac Safety Act) Submitted by Matt Grant, Newport, RI on behalf of the HCMA

Chair McNamara and Members of the Committee,

My name is Matt Grant, and I am a resident of Newport. I am here today in strong support of the Children’s Cardiac Safety Act because I know firsthand how critical early detection of cardiovascular diseases can be. I was diagnosed with obstructive hypertrophic cardiomyopathy at age 25, not because of symptoms, but because I had the benefit of regular cardiac screenings due to my family history. Many children, however, are not as fortunate. Without proper screening, they may never know they are at risk—until it is too late.

Cardiovascular disease is the leading cause of death in Rhode Island and a major threat to children and young adults, especially those with undiagnosed heart conditions. Hypertrophic cardiomyopathy, or HCM, is just one example. It is a genetic heart condition that is both common and underdiagnosed, with an estimated prevalence of 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, making standardized cardiac screening an essential public health measure.

My family’s experience is a testament to the life-or-death stakes of early detection. My mother, Shane Grant, was diagnosed with non-obstructive HCM in her early 30s. Today, she is in end-stage HCM, battling severe complications, including life-threatening arrhythmias. She is now on the path to a heart transplant—the only option left to sustain her life. 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—at a time when much less was known about the disease. My great-aunt, Marylou Solon, was one of the first patients in the country to receive a myectomy at the Mayo Clinic, a groundbreaking procedure at the time. Though she survived the surgery, within days she died of a stroke at age 48—another complication often linked to HCM.

Hypertrophic cardiomyopathy is also the leading cause of sudden cardiac death in young athletes, but it is not the only dangerous and undiagnosed heart condition affecting children. Sudden cardiac arrest is often the first and only symptom of an undiagnosed heart condition, and by then, it is too late. The American Academy of Pediatrics (AAP) warns that cardiac screening should not be limited to student-athletes, as sudden cardiac arrest can affect any child, regardless of physical activity. Despite this, routine screening is inconsistent and often dependent on whether a family already knows to ask the right questions. This is where the Children’s Cardiac Safety Act can save lives. We have already seen evidence of success from similar legislation in other states. In 2015, New Jersey enacted the Scholastic Student-Athlete Safety Act, which mandated cardiac screenings as part of preparticipation physical examinations. Since its passage, New Jersey has seen positive results in identifying at-risk children earlier and reducing the number of sudden cardiac deaths among young people. Rhode Island now has the opportunity to follow this proven model and become a national leader in childhood cardiac safety.

This bill ensures that critical screening questions about family cardiac history and symptoms become a standard part of annual physicals and preparticipation physical examinations. It is designed to align with best practices from the American Heart Association’s 14-point screening for heart disease in youth and the AAP’s recommended preparticipation physical evaluation. By formalizing this process into Rhode Island’s healthcare and school systems, we can ensure that children who are at risk are identified early and receive appropriate follow-up care before tragedy strikes.

At the same time, I recognize the challenges facing primary care in Rhode Island. We know that many physicians have left the state in search of better wages and working conditions, and that these shortages disproportionately affect pediatrics. That is why we are working closely with Rhode Island pediatricians to refine the language of this bill—ensuring that it is both durable and effective, while also not overburdening our physicians, who are already stretched thin. This legislation is not about adding unnecessary bureaucracy, but rather about making life-saving screenings a standard part of care in a way that is practical and sustainable.

The good news is that an HCM diagnosis is no longer a death sentence. Thanks to medical advancements, patients who are diagnosed early can live full, healthy lives. I am fortunate to be a patient of Dr. Martin Maron at Beth Israel Lahey Medical Center, one of the world's leading experts in HCM. According to Dr. Maron, ongoing research and advancements in treatment—such as lifestyle modifications, medication, surgical interventions, and even new gene therapies—mean that this once-dire condition is now highly manageable. But early detection is everything. Without proper screening, we are leaving families uninformed and unprepared to protect their children's health. Rhode Island has an opportunity to be a national leader in childhood cardiac safety. By passing the Children's Cardiac Safety Act, this legislature can take a proactive and life-saving step forward. We have the knowledge, we have the medical best practices, and now, we have the opportunity to make sure that no family loses a child to a preventable cardiac condition. I urge you to pass this bill and ensure that no more lives are lost to undiagnosed heart conditions. Thank you for your time and consideration.