

CHILDREN'S CARDIOMYOPATHY FOUNDATION

Cardiomyopathy HEARTS Act Talking Points

- My name is [Name]. As a constituent and a parent/grandparent/caregiver/advocate of a child with cardiomyopathy, I am here/calling today to request Representative [representative's last name]'s support of the Cardiomyopathy Health Education, Awareness, Risk Assessment, and Training in the Schools (HEARTS) Act (H.R. 6166).
- Cardiomyopathy is a chronic disease of the heart muscle that affects the heart's ability to pump blood through the body. Cardiomyopathy is a term used to classify several separate diseases that affect the heart muscle. It may lead to heart failure, irregular heartbeats (arrhythmia), and a heart transplant in severe cases.
- Cardiomyopathy has been referred to as the "silent killer" because symptoms for cardiomyopathy are not always obvious and may stay undiagnosed for years. Tragically, some families are only made aware of the disease after their child collapses and dies.
- It is estimated that 30,000 children in the United States are living with some form of cardiomyopathy. However, this number may be underestimated as children without symptoms or those who die of sudden cardiac arrest have not been diagnosed and accounted for.
- The issue is that not enough at-risk children are being diagnosed and treated. It has been recommended that families review their cardiac health history and be aware of the signs and symptoms of cardiomyopathy to determine whether they are at higher risk for sudden cardiac death.
- The Cardiomyopathy HEARTS Act aims to raise awareness of cardiomyopathy where children are most often - in school. The bill will provide parents, school personnel, and health professionals with information on cardiomyopathy and sudden cardiac arrest and guidelines on what to do in a cardiac emergency. Specifically, it will direct the Centers for Disease Control and Prevention (CDC) to implement a public awareness campaign that includes developing educational materials on the symptoms of cardiomyopathy, risk factors for sudden cardiac arrest, placement of automated external defibrillators (AEDs), CPR/AED training in schools, and guidelines on implementing a cardiac emergency response plan. These resources will be disseminated to school administrators, educators, school nurses, coaches, and families through state educational agencies, health departments, and other medical/ health professionals.
- Little is known about how many children are affected by cardiomyopathy, its genetic causes, and reasons for variability. The Cardiomyopathy HEARTS Act will also evaluate current cardiomyopathy research initiatives funded by the National Institutes of Health (NIH) and request the Centers for Disease Control and Prevention (CDC) to collect and analyze surveillance data related to the impact, prevalence, and epidemiology of cardiomyopathy across a patient's lifespan. and establishes a federal workgroup to develop innovative cardiomyopathy research strategies.
- [Explain how cardiomyopathy affects your family and how the Cardiomyopathy HEARTS Act will help improve the lives of children with cardiomyopathy.]
- As your constituent, I hope that I can count on your support for H.R. 6166. The Cardiomyopathy HEARTS Act can help us to better understand this serious heart condition and identify at-risk children so they don't fall victim to sudden cardiac death. This bill means a lot to me and to thousands of children with cardiomyopathy, including my own child/a child dear to me.