



Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act of 2020

Issue

According to the Centers for Disease Control and Prevention (CDC), sudden cardiac arrest (SCA) is a leading cause of death on school property. Many children who suffer SCA have an undetected heart condition such as cardiomyopathy, a chronic disease of the heart muscle that affects the heart's ability to pump blood. Symptoms for cardiomyopathy are not always obvious, and the disease may stay undiagnosed for years. Tragically, some families are only made aware of the disease after their child collapses or dies. While an estimated 30,000 children in the United States are living with cardiomyopathy, not enough is known about the impact of this "silent killer," and too many at-risk children are not being diagnosed and treated.

To determine the prevalence and epidemiology of cardiomyopathy and raise public awareness of the disease, the **Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act** (H.R. 6166) was introduced March 2020 by Representatives Andy Kim (D-NJ-03) and Andy Barr (R-KY-06) and is the first bipartisan legislation introduced on cardiomyopathy.

Bill Summary

The Cardiomyopathy HEARTS Act focuses on the research and education components that are necessary to improve survival for children with cardiomyopathy. The bill aims to educate school personnel and families about cardiomyopathy through the development and dissemination of educational materials and resources. The bill also requests that the National Institutes of Health to arrange a working group on pediatric cardiomyopathy and the Centers for Disease and Control and Prevention (CDC) to conduct surveillance research on cardiomyopathy across a patient's lifespan.

Create cardiomyopathy education and awareness materials and resources

The bill requires the Secretary of Health and Human Services (HHS), the Director of the CDC, and national patient advocacy and health professional organizations with expertise in all forms of cardiomyopathy to implement an awareness campaign that includes developing educational materials on the signs and symptoms of cardiomyopathy, risk factors for sudden cardiac arrest, guidelines on the placement of automated external defibrillators (AEDs), cardiopulmonary resuscitation (CPR)/AED training in schools, and the implementation of school cardiac emergency response plans. These lay resources would be disseminated to state education agencies, health departments, and medical/health professionals within 18 months of the bill's enactment.

Report on cardiomyopathy research and surveillance activities

The bill calls for reporting on the prevalence of cardiomyopathy across the lifespan from birth to adulthood, including health care costs, utilization, natural history of individuals with cardiomyopathy, the number of adults and children affected by cardiomyopathy, and age specific mortality. An initial report would be released within 18 months of the enactment of the bill, and a final report 5 years after the bill's enactment.

Create a Cardiomyopathy Federal Working Group

The bill requests that the National Institutes of Health organize an interdisciplinary working group at the National Heart, Lung, and Blood Institute comprised of health care professionals with an expertise in pediatric cardiomyopathy. The purpose of the working group is to develop a research strategy to address the gaps in knowledge in pediatric cardiomyopathy, identify approaches that would aid in the development of therapies for pediatric cardiomyopathy and heart failure, and explore different methods to maximize successful clinical trials.

Background

What is Cardiomyopathy?

- A chronic and sometimes progressive disease in which the heart muscle is abnormally enlarged, thickened, and/or stiffened.
- There are four main types of cardiomyopathy: dilated (DCM), hypertrophic (HCM), restrictive (RCM) and arrhythmogenic right ventricular (ARVC). Left ventricular non-compaction (LVNC) is increasingly being recognized as a fifth form.
- There are many causes for cardiomyopathies affecting children; it can be inherited through one or both parents or acquired through a viral infection or cancer chemotherapy.

Who has cardiomyopathy?

- It can affect any adult or child at any stage of life.
- It is estimated that there are at least 30,000 children living with some form of cardiomyopathy. According to the North America Pediatric Cardiomyopathy Registry, 1 out of 100,000 are affected annually.
- Numbers may be underestimated because many cases are not accounted for because cardiomyopathy is difficult to detect and may be missed.

How is Cardiomyopathy Related to Sudden Cardiac Arrest?

- According to the Centers for Disease Control and Prevention (CDC), it is estimated that approximately 2,000 people younger than 25 will die of sudden cardiac arrest (SCA) every year in the U.S.
- Cardiomyopathy is a leading cause of sudden cardiac arrest, especially among youth during athletic participation.
- Most sudden cardiac deaths are caused by abnormal heart rhythms called arrhythmias, which is more common in advanced stages of cardiomyopathy.