



Cardiomyopathy Health Education, Awareness, Risk Assessment, and Training in the Schools (HEARTS) Act of 2023

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, Risk Assessment, and Training in the Schools (HEARTS) Act** (H.R. 6829) was introduced in December 2023 by Representatives Frank Pallone (D-NJ-06) and Andy Kim (D-NJ-03).

Bill Summary

Increasing awareness and family education on the health risks are critical to limiting the number of childhood deaths attributed to cardiac arrests and Cardiomyopathy.

- The Cardiomyopathy Health Education, Awareness, Risk Assessment, and Training in the Schools (HEARTS) Act requires the Secretary of Health and Human Services (HHS) to coordinate with the Centers for Disease Control and Prevention (CDC), as well as patient advocacy and health professional organizations, to develop educational materials and resources on cardiomyopathy for public awareness and distribute materials to schools, teachers, and parents. This would include an improved risk assessment for cardiomyopathy.
- The bill calls for guidelines regarding the placement of lifesaving automated external defibrillators in schools and information on cardiopulmonary resuscitation (CPR) training. And it authorizes the CDC to conduct research and surveillance activities to better understand cardiomyopathy.
- The bill also encourages the National Institutes of Health (NIH) to expand, intensify, and coordinate research of the illness and to submit a report to Congress no later than 18 months after the date of enactment. The CDC would be required to provide an initial report on findings and data generated within one year of enactment and provide a final report to Congress five years after enactment.

Congress can increase awareness and educate families on potentially deadly cardiac arrests and Cardiomyopathy by passing the HEARTS Act.

- The Hearts Act will provide parents, school personnel and health professionals with information to increase awareness of cardiomyopathy and SCA and be prepared in the event of an adverse cardiac event.
- This information will encourage families to evaluate their cardiac history, check for cardiomyopathy symptoms and know when to seek medical screening.

- With these efforts, more individuals with cardiomyopathy will be diagnosed and appropriately treated before they fall victim to sudden cardiac death.

Background

What is Cardiomyopathy?

- A chronic and sometimes progressive disease in which the heart muscle is abnormally enlarged, thickened, and/or stiffened.
- There are five types of cardiomyopathy: dilated (DCM), hypertrophic (HCM), restrictive (RCM), arrhythmogenic cardiomyopathy (AC), and left ventricular non-compaction (LVNC).
- 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 American Pediatric Cardiomyopathy Registry (PCMR), 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.