

118TH CONGRESS  
1ST SESSION

# H. R. 6829

To amend the Public Health Service Act to authorize and support the creation and dissemination of cardiomyopathy education, awareness, and risk assessment materials and resources to identify more at-risk families, to authorize research and surveillance activities relating to cardiomyopathy, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

DECEMBER 14, 2023

Mr. PALLONE (for himself and Mr. KIM of New Jersey) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to authorize and support the creation and dissemination of cardiomyopathy education, awareness, and risk assessment materials and resources to identify more at-risk families, to authorize research and surveillance activities relating to cardiomyopathy, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Cardiomyopathy  
5 Health Education, Awareness, Research, and Training in  
6 the Schools Act of 2023” or the “HEARTS Act of 2023”.

1 **SEC. 2. MATERIALS AND RESOURCES TO INCREASE EDU-**  
2 **CATION AND AWARENESS OF CARDIO-**  
3 **MYOPATHY AMONG SCHOOL ADMINISTRA-**  
4 **TORS, EDUCATORS, AND FAMILIES.**

5 Part P of title III of the Public Health Service Act  
6 (42 U.S.C. 280g et seq.) is amended by adding at the end  
7 the following new section:

8 **“SEC. 399V-8. MATERIALS AND RESOURCES TO INCREASE**  
9 **EDUCATION AND AWARENESS OF CARDIO-**  
10 **MYOPATHY AMONG SCHOOL ADMINISTRA-**  
11 **TORS, EDUCATORS, AND FAMILIES.**

12 “(a) MATERIALS AND RESOURCES.—Not later than  
13 18 months after the date of the enactment of this section,  
14 the Secretary, in consultation with the Director of the  
15 Centers for Disease Control and Prevention (in this sec-  
16 tion referred to as the ‘Director’) shall develop public edu-  
17 cation materials and resources to be disseminated to  
18 school administrators, educators, school health profes-  
19 sionals, coaches, families, guardians, caregivers, and other  
20 appropriate individuals. The materials and resources shall  
21 include—

22 “(1) background information to increase edu-  
23 cation and awareness of cardiomyopathy;

24 “(2) guidelines regarding the placement of  
25 automated external defibrillators in schools, early

1 childhood education programs, and child care cen-  
2 ters;

3 “(3) training information on automated exter-  
4 nal defibrillators and cardiopulmonary resuscitation;  
5 and

6 “(4) recommendations for how schools, early  
7 childhood education programs, and child care centers  
8 can develop and implement a cardiac emergency re-  
9 sponse plan.

10 “(b) DISSEMINATION OF MATERIALS AND RE-  
11 SOURCES.—Not later than 30 months after the date of  
12 the enactment of this section, the Secretary shall dissemi-  
13 nate the materials and resources developed under sub-  
14 section (a) in accordance with the following:

15 “(1) DISTRIBUTION BY STATE EDUCATIONAL  
16 AGENCIES.—The Secretary shall make available such  
17 materials and resources to State educational agen-  
18 cies to distribute—

19 “(A) to school administrators, educators,  
20 school health professionals, coaches, families,  
21 guardians, caregivers, and other appropriate in-  
22 dividuals, the background materials developed  
23 under subsection (a)(1);

24 “(B) to parents, guardians, or other care-  
25 givers, the risk assessment for individuals with

1 or at risk for cardiomyopathy developed pursu-  
2 ant to section 399V–9(b)(1); and

3 “(C) to school administrators, educators,  
4 school health professionals, and coaches—

5 “(i) the guidelines described in sub-  
6 section (a)(2);

7 “(ii) the training information de-  
8 scribed in subsection (a)(3); and

9 “(iii) the recommendations described  
10 in subsection (a)(4).

11 “(2) DISSEMINATION TO HEALTH DEPART-  
12 MENTS AND PROFESSIONALS.—The Secretary shall  
13 make available the materials and resources devel-  
14 oped under subsection (a) to State and local health  
15 departments, pediatricians, hospitals, and other  
16 health professionals, such as nurses and first re-  
17 sponders.

18 “(3) POSTING ON WEBSITE.—

19 “(A) CDC.—

20 “(i) IN GENERAL.—The Secretary,  
21 through the Director, shall post the mate-  
22 rials and resources developed under sub-  
23 section (a) on the public Internet website  
24 of the Centers for Disease Control and  
25 Prevention.

1                   “(ii) ADDITIONAL INFORMATION.—

2                   The Director is encouraged to maintain on  
3                   such public Internet website such addi-  
4                   tional information regarding cardio-  
5                   myopathy as deemed appropriate by the  
6                   Director.

7                   “(B) STATE EDUCATIONAL AGENCIES.—

8                   State educational agencies are encouraged to  
9                   create public Internet webpages dedicated to  
10                  cardiomyopathy and post the materials and re-  
11                  sources developed under subsection (a) on such  
12                  webpages.

13                  “(c) DEFINITIONS.—In this section:

14                  “(1) The term ‘school administrator’ means a  
15                  principal, director, manager, or other supervisor or  
16                  leader within an elementary school, secondary  
17                  school, State-based early childhood education pro-  
18                  gram, or child care center.

19                  “(2) The term ‘school health professional’  
20                  means a health professional serving at an elemen-  
21                  tary school, secondary school, State-based early  
22                  childhood education program, or child care center.

23                  “(3) The terms ‘early childhood education pro-  
24                  gram’, ‘elementary school’, and ‘secondary school’  
25                  have the meanings given to those terms in section

1 8101 of the Elementary and Secondary Education  
2 Act of 1965.

3 “(4) The term ‘cardiomyopathy’ has the mean-  
4 ing given such term in section 399V–9(c).

5 “(d) AUTHORIZATION OF APPROPRIATIONS.—For  
6 carrying out this section and section 399V–9, there is au-  
7 thorized to be appropriated \$5,000,000 for each of fiscal  
8 years 2025 through 2028.”.

9 **SEC. 3. RESEARCH AND SURVEILLANCE ACTIVITIES RELAT-**  
10 **ING TO CARDIOMYOPATHY.**

11 (a) CDC RESEARCH AND SURVEILLANCE.—Part P  
12 of title III of the Public Health Service Act (42 U.S.C.  
13 280g et seq.), as amended by section 2, is further amended  
14 by adding at the end the following new section:

15 **“SEC. 399V–9. RESEARCH AND SURVEILLANCE ACTIVITIES**  
16 **RELATING TO CARDIOMYOPATHY.**

17 “(a) REPORTS ON CDC NATIONAL CARDIO-  
18 MYOPATHY SURVEILLANCE RESEARCH ACTIVITIES.—

19 “(1) INITIAL REPORT.—Not later than June 1,  
20 2024, the Secretary, acting through the Director of  
21 the Centers for Disease Control and Prevention,  
22 shall submit to Congress an initial report on find-  
23 ings and data generated from surveillance and re-  
24 search activities conducted by the Centers for Dis-  
25 ease Control and Prevention to improve the under-

1 standing of the prevalence and epidemiology of car-  
2 diomyopathy across the lifespan, from birth to adult-  
3 hood, with particular interest in the following:

4 “(A) The health care costs, utilization, and  
5 natural history of individuals with cardio-  
6 myopathy, in both the pediatric and adult popu-  
7 lation.

8 “(B) Estimates of cardiomyopathy-related  
9 emergency department visits and hospitaliza-  
10 tions, in both the pediatric and adult popu-  
11 lation.

12 “(2) FINAL REPORT.—Not later than January  
13 1, 2029, the Secretary, acting through the Director  
14 of the Centers for Disease Control and Prevention,  
15 shall submit to Congress a final report on the con-  
16 tent described in paragraph (1).

17 “(3) PUBLIC ACCESS.—Subject to paragraph  
18 (4), the reports submitted under this subsection  
19 shall be made available to the public.

20 “(4) PRIVACY PROTECTIONS.—The Secretary  
21 shall ensure that this subsection is carried out in a  
22 manner that complies with all applicable privacy  
23 laws under Federal and State law.

24 “(b) IMPROVING RISK ASSESSMENTS FOR INDIVID-  
25 UALS WITH CARDIOMYOPATHY.—

1           “(1) IN GENERAL.—The Secretary shall develop  
2 and make publicly available a risk assessment for in-  
3 dividuals with or at risk for cardiomyopathy. Such  
4 risk assessment shall, at a minimum, include the fol-  
5 lowing:

6           “(A) Background information of the preva-  
7 lence, incidence, and health impact of cardio-  
8 myopathy, including all forms of cardio-  
9 myopathy and their effects on pediatric, adoles-  
10 cent, and adult individuals.

11           “(B) A worksheet with variables and con-  
12 ditions for an individual or health care provider  
13 to use in assessing whether the individual is at  
14 risk for cardiomyopathy.

15           “(C) A worksheet with variables and  
16 stages of progression for an individual or health  
17 care provider to use in assessing whether and to  
18 what extent cardiomyopathy has progressed in  
19 the individual.

20           “(D) Guidelines on cardiomyopathy  
21 screenings for individuals who are at risk for,  
22 or have a family history of, cardiomyopathy.

23           “(2) STAKEHOLDER INPUT.—In carrying out  
24 paragraph (1), the Director of the Centers for Dis-



1 ease Control and Prevention shall seek input from  
2 external stakeholders including—

3 “(A) representatives from national patient  
4 advocacy organizations expert in all forms of  
5 cardiomyopathy;

6 “(B) representatives from medical profes-  
7 sional societies that specialize in the care of  
8 adults and pediatrics with cardiomyopathy; and

9 “(C) representatives from other relevant  
10 Federal agencies.

11 “(c) **CARDIOMYOPATHY DEFINED.**—For purposes of  
12 this section, the term ‘cardiomyopathy’ means a heart dis-  
13 ease that affects the heart’s muscle (myocardium)—

14 “(1) the symptoms of which may vary from  
15 case to case, including—

16 “(A) cases in which no symptoms are  
17 present (asymptomatic); and

18 “(B) cases in which there are symptoms of  
19 a progressive condition that may result from an  
20 impaired ability of the heart to pump blood,  
21 such as fatigue, irregular heartbeats (arrhyth-  
22 mia), heart failure, and, potentially, sudden car-  
23 diac death; and

24 “(2) the recognized types of which include di-  
25 lated, hypertrophic, restrictive, arrhythmogenic right

1 ventricular dysplasia, and left ventricular non-com-  
2 paction.”.

3 (b) NIH RESEARCH.—Part A of title IV of the Public  
4 Health Service Act (42 U.S.C. 281 et seq.) is amended  
5 by inserting after section 404E the following new section:

6 **“SEC. 404F. CARDIOMYOPATHY RESEARCH.**

7 “(a) IN GENERAL.—The Director of NIH may ex-  
8 pand, intensify, and coordinate research and related activi-  
9 ties of the National Institutes of Health with respect to  
10 cardiomyopathy, which may include research with respect  
11 to—

12 “(1) causation of cardiomyopathy, including ge-  
13 netic causes and molecular biomarkers;

14 “(2) long-term health outcomes in individuals  
15 with cardiomyopathy, including infants, children,  
16 teenagers, adults, and elderly individuals; and

17 “(3) studies using longitudinal data and retro-  
18 spective analysis to identify effective treatments and  
19 outcomes for individuals with cardiomyopathy.

20 “(b) CARDIOMYOPATHY DEFINED.—For purposes of  
21 this section, the term ‘cardiomyopathy’ means a heart dis-  
22 ease that affects the heart’s muscle (myocardium)—

23 “(1) the symptoms of which may vary from  
24 case to case, including—

1           “(A) cases in which no symptoms are  
2 present (asymptomatic); and

3           “(B) cases in which there are symptoms of  
4 a progressive condition that may result from an  
5 impaired ability of the heart to pump blood,  
6 such as fatigue, irregular heartbeats (arrhyth-  
7 mia), heart failure, and, potentially, sudden car-  
8 diac death; and

9           “(2) the recognized types of which include di-  
10 lated, hypertrophic, restrictive, arrhythmogenic right  
11 ventricular dysplasia, and left ventricular non-com-  
12 paction.”.

13       (c) NIH REPORT.—Not later than 18 months after  
14 the date of the enactment of this Act, the Director of the  
15 National Institutes of Health shall submit to Congress a  
16 report—

17           (1) outlining the ongoing research efforts of the  
18 National Institutes of Health regarding cardio-  
19 myopathy; and

20           (2) identifying—

21               (A) a research agenda regarding adult  
22 forms of cardiomyopathy;

23               (B) plans for researching cardiomyopathy  
24 affecting the pediatric population; and

- 1 (C) the areas of greatest need for such re-
- 2 search.

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