

Committee Print

(SHOWING THE TEXT OF H.R. 6829, AS FAVORABLY FORWARDED BY THE
SUBCOMMITTEE ON HEALTH ON MARCH 12, 2024)

118TH CONGRESS
2D 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.

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

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Cardiomyopathy
3 Health Education, Awareness, and Research, and AED
4 Training in the Schools Act of 2024” or the “HEARTS
5 Act of 2024”.

6 **SEC. 2. CARDIOMYOPATHY HEALTH EDUCATION, AWARE-**
7 **NESS, AND RESEARCH, AND AED TRAINING IN**
8 **SCHOOLS.**

9 (a) IN GENERAL.—The Public Health Service Act is
10 amended by inserting after section 312 (42 U.S.C. 244)
11 the following:

12 **“SEC. 312A. MATERIALS AND RESOURCES TO INCREASE**
13 **EDUCATION AND AWARENESS OF CARDIO-**
14 **MYOPATHY AMONG SCHOOL ADMINISTRA-**
15 **TORS, EDUCATORS, AND FAMILIES.**

16 “(a) MATERIALS AND RESOURCES.—Not later than
17 18 months after the date of the enactment of the
18 HEARTS Act of 2024, the Secretary, in consultation with
19 the Director of the Centers for Disease Control and Pre-
20 vention, shall develop public education materials and re-
21 sources to be disseminated to school administrators, edu-
22 cators, school health professionals, coaches, families,
23 guardians, caregivers, and other appropriate individuals.
24 The materials and resources shall include—

25 “(1) information on the signs, symptoms, and
26 risk factors associated with high-risk cardiac condi-

1 tions and genetic heart rhythm abnormalities that
2 may cause sudden cardiac arrest in children, adoles-
3 cents, and young adults, including—

4 “(A) cardiomyopathy;

5 “(B) long QT syndrome, Brugada syn-
6 drome, catecholaminergic polymorphic ventric-
7 ular tachycardia, short QT syndrome, and
8 Wolff-Parkinson-White syndrome; and

9 “(C) other high-risk cardiac conditions, as
10 determined by the Secretary;

11 “(2) guidelines regarding the placement of
12 automated external defibrillators in schools, early
13 childhood education programs, and child care cen-
14 ters;

15 “(3) training information on automated exter-
16 nal defibrillators and cardiopulmonary resuscitation;
17 and

18 “(4) recommendations for how schools, early
19 childhood education programs, and child care centers
20 can develop and implement a cardiac emergency re-
21 sponse plan.

22 “(b) DISSEMINATION OF MATERIALS AND RE-
23 SOURCES.—Not later than 30 months after the date of
24 the enactment of the HEARTS Act of 2024, the Secretary

1 shall disseminate the materials and resources developed
2 under subsection (a) in accordance with the following:

3 “(1) DISTRIBUTION BY STATE EDUCATIONAL
4 AGENCIES.—The Secretary shall make available such
5 materials and resources to State educational agen-
6 cies to distribute—

7 “(A) to school administrators, educators,
8 school health professionals, coaches, families,
9 guardians, caregivers, and other appropriate in-
10 dividuals, the information developed under sub-
11 section (a)(1);

12 “(B) to parents, guardians, or other care-
13 givers, the cardiomyopathy risk assessment de-
14 veloped pursuant to section 312B(b)(1); and

15 “(C) to school administrators, educators,
16 school health professionals, and coaches—

17 “(i) the guidelines described in sub-
18 section (a)(2);

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

21 “(iii) the recommendations described
22 in subsection (a)(4).

23 “(2) DISSEMINATION TO HEALTH DEPART-
24 MENTS AND PROFESSIONALS.—The Secretary shall
25 make available the materials and resources devel-

1 oped under subsection (a) to State and local health
2 departments, pediatricians, hospitals, and other
3 health professionals, such as nurses and first re-
4 sponders.

5 “(3) POSTING ON WEBSITE.—

6 “(A) CDC.—

7 “(i) IN GENERAL.—The Secretary,
8 through the Director, shall post the mate-
9 rials and resources developed under sub-
10 section (a) on the public Internet website
11 of the Centers for Disease Control and
12 Prevention.

13 “(ii) ADDITIONAL INFORMATION.—

14 The Director is encouraged to maintain on
15 such public Internet website such addi-
16 tional information regarding cardio-
17 myopathy as deemed appropriate by the
18 Director.

19 “(B) STATE EDUCATIONAL AGENCIES.—

20 State educational agencies are encouraged to
21 create public Internet webpages dedicated to
22 cardiomyopathy and post the materials and re-
23 sources developed under subsection (a) on such
24 webpages.

25 “(c) DEFINITIONS.—In this section:

1 “(1) The term ‘cardiomyopathy’ means a heart
2 disease that affects the heart’s muscle (myocar-
3 dium)—

4 “(A) the symptoms of which may vary
5 from case to case, including—

6 “(i) cases in which no symptoms are
7 present (asymptomatic); and

8 “(ii) cases in which there are symp-
9 toms of a progressive condition that may
10 result from an impaired ability of the heart
11 to pump blood, such as fatigue, irregular
12 heartbeats (arrhythmia), heart failure,
13 and, potentially, sudden cardiac death; and

14 “(B) the recognized types of which include
15 dilated, hypertrophic, restrictive,
16 arrhythmogenic right ventricular dysplasia, and
17 left ventricular non-compaction.

18 “(2) The term ‘Director’ means the Director of
19 the Centers for Disease Control and Prevention.

20 “(3) The terms ‘early childhood education pro-
21 gram’, ‘elementary school’, and ‘secondary school’
22 have the meanings given to those terms in section
23 8101 of the Elementary and Secondary Education
24 Act of 1965.

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

6 “(5) The term ‘school health professional’
7 means a health professional serving at an elemen-
8 tary school, secondary school, State-based early
9 childhood education program, or child care center.

10 **“SEC. 312B. ACTIVITIES RELATING TO CARDIOMYOPATHY.**

11 “(a) REPORT ON CDC NATIONAL CARDIOMYOPATHY
12 ACTIVITIES.—

13 “(1) IN GENERAL.—Not later than 18 months
14 after the date of the enactment of the HEARTS Act
15 of 2024, the Secretary, acting through the Director
16 of the Centers for Disease Control and Prevention,
17 shall submit to Congress a report on findings gen-
18 erated from existing activities conducted by the Cen-
19 ters for Disease Control and Prevention to improve
20 the understanding of the prevalence and epidemi-
21 ology of cardiomyopathy across the lifespan, from
22 birth to adulthood, with particular interest in the
23 following:

1 “(A) The natural history of individuals
2 with cardiomyopathy, in both the pediatric and
3 adult population.

4 “(B) Estimates of cardiomyopathy-related
5 emergency department visits and hospitaliza-
6 tions, in both the pediatric and adult popu-
7 lation.

8 “(2) PUBLIC ACCESS.—Subject to paragraph
9 (3), the report submitted under this subsection shall
10 be made available to the public.

11 “(3) PRIVACY PROTECTIONS.—The Secretary
12 shall ensure that this subsection is carried out in a
13 manner that complies with all applicable privacy
14 laws under Federal and State law.

15 “(b) IMPROVING RISK ASSESSMENTS FOR INDIVID-
16 UALS WITH CARDIOMYOPATHY.—

17 “(1) IN GENERAL.—The Secretary shall develop
18 and make publicly available a cardiomyopathy risk
19 assessment for health care providers and individuals.
20 Such risk assessment shall, at a minimum, include
21 the following:

22 “(A) Background information on the prev-
23 alence, incidence, and health impact of cardio-
24 myopathy, including all forms of cardio-

1 myopathy and their effects on pediatric, adoles-
2 cent, and adult individuals.

3 “(B) A worksheet with variables and con-
4 ditions for an individual or health care provider
5 to use in assessing whether an individual is at
6 risk for cardiomyopathy.

7 “(C) A worksheet with variables and
8 stages of progression for an individual or health
9 care provider to use in assessing whether and to
10 what extent cardiomyopathy has progressed in
11 an individual.

12 “(D) Guidelines on cardiomyopathy
13 screenings for individuals who are at risk for,
14 or have a family history of, cardiomyopathy.

15 “(2) STAKEHOLDER INPUT.—In carrying out
16 paragraph (1), the Director of the Centers for Dis-
17 ease Control and Prevention shall seek input from
18 external stakeholders including—

19 “(A) representatives from national patient
20 advocacy organizations expert in all forms of
21 cardiomyopathy;

22 “(B) representatives from medical profes-
23 sional societies that specialize in the care of
24 adults and pediatrics with cardiomyopathy; and

1 “(C) representatives from other relevant
2 Federal agencies.

3 “(c) DEFINITION.—In this section, the term ‘cardio-
4 myopathy’ has the meaning given to such term in section
5 312A.

6 **“SEC. 312C. CARDIOMYOPATHY RESEARCH.**

7 “(a) IN GENERAL.—The Secretary, in consultation
8 with the Director of the National Institutes of Health,
9 may expand and coordinate research and related activities
10 of the National Institutes of Health with respect to cardio-
11 myopathy, which may include research with respect 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) NONDUPLICATION.—The Secretary shall ensure
21 that any research and activities related to cardiomyopathy
22 under this section do not unnecessarily duplicate activities,
23 programs, or efforts of other agencies and offices within
24 the Department of Health and Human Services.

1 “(c) NIH REPORT.—Not later than 18 months after
2 the date of the enactment of the HEARTS Act of 2024,
3 the Secretary, in consultation with the Director of the Na-
4 tional Institutes of Health, shall submit to Congress a re-
5 port—

6 “(1) outlining the ongoing research efforts of
7 the National Institutes of Health regarding cardio-
8 myopathy; and

9 “(2) identifying—

10 “(A) a research agenda regarding adult
11 forms of cardiomyopathy;

12 “(B) plans for researching cardiomyopathy
13 affecting the pediatric population; and

14 “(C) the areas of greatest need for such
15 research.

16 “(d) CARDIOMYOPATHY DEFINED.—In this section,
17 the term ‘cardiomyopathy’ has the meaning given to such
18 term in section 312A.

19 **“SEC. 312D. PROMOTING STUDENT ACCESS TO AEDS AND**
20 **CPR.**

21 “(a) IN GENERAL.—The Secretary shall award
22 grants to eligible entities to develop and implement a com-
23 prehensive program to promote student access to auto-
24 mated external defibrillators (in this section referred to
25 as ‘AEDs’) and cardiopulmonary resuscitation (in this sec-

1 tion referred to as ‘CPR’) in public elementary schools and
2 secondary schools.

3 “(b) USE OF FUNDS.—An eligible entity receiving a
4 grant under subsection (a) may use funds received
5 through such grant to carry out any of the following activi-
6 ties:

7 “(1) Developing and providing comprehensive
8 materials to establish AED and CPR programs in
9 public elementary schools and secondary schools.

10 “(2) Providing support for CPR and AED
11 training programs in such schools for students,
12 staff, and related sports volunteers.

13 “(3) Providing support for developing a cardiac
14 emergency response plan within such schools.

15 “(4) Purchasing AEDs that have been approved
16 under section 515 of the Federal Food, Drug, and
17 Cosmetic Act, cleared under section 510(k) of such
18 Act, or classified under section 513(f)(2) of such
19 Act.

20 “(5) Purchasing necessary AED batteries and
21 performing necessary AED maintenance (such as by
22 replacing AED pads) in accordance with the labeling
23 of the AED involved.

24 “(6) Replacing old and outdated AED and CPR
25 equipment, machinery, and educational materials.

1 “(c) ELIGIBILITY; APPLICATION.—To be eligible for
2 a grant under subsection (a), an entity shall—

3 “(1) be a local educational agency (including a
4 public charter school operating as a local educational
5 agency under State law), in consultation with a
6 qualified health care entity; and

7 “(2) submit to the Secretary an application at
8 such time, in such manner, and containing such in-
9 formation as the Secretary may reasonably require.

10 “(d) DEFINITIONS.—In this section:

11 “(1) ESEA TERMS.—The terms ‘elementary
12 school’, ‘local educational agency’, and ‘secondary
13 school’ have the meanings given such terms in sec-
14 tion 8101 of the Elementary and Secondary Edu-
15 cation Act of 1965.

16 “(2) QUALIFIED HEALTH CARE ENTITY.—The
17 term ‘qualified health care entity’ means a health
18 care entity that—

19 “(A) is—

20 “(i) a public entity; or

21 “(ii) an organization that is described
22 in section 501(c) of the Internal Revenue
23 Code of 1986 and exempt from taxation
24 under section 501(a) of such Code;

1 “(B) demonstrates an ability to develop,
2 train, and implement a comprehensive program
3 to promote student access to defibrillation in
4 public elementary and secondary schools; and

5 “(C) is qualified in providing technical as-
6 sistance in AED and CPR training.”.

7 (b) AUTHORIZATION OF APPROPRIATIONS.—Section
8 312(e) of the Public Health Service Act (42 U.S.C.
9 244(e)) is amended by striking the first sentence and in-
10 serting the following: “For the purpose of carrying out
11 this section and sections 312A, 312B, 312C, and 312D,
12 there is authorized to be appropriated \$25,000,000 for
13 each of fiscal years 2025 through 2029.”.