

Union Calendar No. 432

118TH CONGRESS
2^D SESSION

H. R. 6829

[Report No. 118–520]

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

MAY 22, 2024

Additional sponsors: Mr. BISHOP of Georgia, Mr. POSEY, and Mr. DOGGETT

MAY 22, 2024

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italic*]

[For text of introduced bill, see copy of bill as introduced on December 14, 2023]

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 Health*
5 *Education, Awareness, and Research, and AED Training*
6 *in the Schools Act of 2024” or the “HEARTS Act of 2024”.*

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

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

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

17 *“(a) MATERIALS AND RESOURCES.—Not later than 18*
18 *months after the date of the enactment of the HEARTS Act*
19 *of 2024, the Secretary, in consultation with the Director*
20 *of the Centers for Disease Control and Prevention, shall de-*
21 *velop public education materials and resources to be dis-*
22 *seminated to school administrators, educators, school health*
23 *professionals, coaches, families, guardians, caregivers, and*
24 *other appropriate individuals. The materials and resources*
25 *shall include—*

1 “(1) information on the signs, symptoms, and
2 risk factors associated with high-risk cardiac condi-
3 tions and genetic heart rhythm abnormalities that
4 may cause sudden cardiac arrest in children, adoles-
5 cents, and young adults, including—

6 “(A) cardiomyopathy;

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

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

13 “(2) guidelines regarding the placement of auto-
14 mated external defibrillators in schools, early child-
15 hood education programs, and child care centers;

16 “(3) training information on automated external
17 defibrillators and cardiopulmonary resuscitation; 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 the
24 enactment of the *HEARTS Act of 2024*, the Secretary shall

1 *disseminate the materials and resources developed under*
2 *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 agencies*
6 *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 devel-*
14 *oped 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 DEPARTMENTS*
24 *AND PROFESSIONALS.—The Secretary shall make*
25 *available the materials and resources developed under*

1 subsection (a) to State and local health departments,
2 pediatricians, hospitals, and other health profes-
3 sionals, such as nurses and first responders.

4 “(3) *POSTING ON WEBSITE.*—

5 “(A) *CDC.*—

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

12 “(ii) *ADDITIONAL INFORMATION.*—The
13 Director is encouraged to maintain on such
14 public Internet website such additional in-
15 formation regarding cardiomyopathy as
16 deemed appropriate by the Director.

17 “(B) *STATE EDUCATIONAL AGENCIES.*—

18 State educational agencies are encouraged to cre-
19 ate public Internet webpages dedicated to cardio-
20 myopathy and post the materials and resources
21 developed under subsection (a) on such webpages.

22 “(c) *DEFINITIONS.*—In this section:

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

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

3 “(i) cases in which no symptoms are
4 present (asymptomatic); and

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

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

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

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

22 “(4) The term ‘school administrator’ means a
23 principal, director, manager, or other supervisor or
24 leader within an elementary school, secondary school,

1 *State-based early childhood education program, or*
2 *child care center.*

3 “(5) *The term ‘school health professional’ means*
4 *a health professional serving at an elementary school,*
5 *secondary school, State-based early childhood edu-*
6 *cation program, or child care center.*

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

8 “(a) *REPORT ON CDC NATIONAL CARDIOMYOPATHY*
9 *ACTIVITIES.—*

10 “(1) *IN GENERAL.—Not later than 18 months*
11 *after the date of the enactment of the HEARTS Act*
12 *of 2024, the Secretary, acting through the Director of*
13 *the Centers for Disease Control and Prevention, shall*
14 *submit to Congress a report on findings generated*
15 *from existing activities conducted by the Centers for*
16 *Disease Control and Prevention to improve the under-*
17 *standing of the prevalence and epidemiology of car-*
18 *diomyopathy across the lifespan, from birth to adult-*
19 *hood, with particular interest in the following:*

20 “(A) *The natural history of individuals*
21 *with cardiomyopathy, in both the pediatric and*
22 *adult population.*

23 “(B) *Estimates of cardiomyopathy-related*
24 *emergency department visits and hospitaliza-*

1 *tions, in both the pediatric and adult popu-*
2 *lation.*

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

6 “(3) *PRIVACY PROTECTIONS.*—*The Secretary*
7 *shall ensure that this subsection is carried out in a*
8 *manner that complies with all applicable privacy*
9 *laws under Federal and State law.*

10 “(b) *IMPROVING RISK ASSESSMENTS FOR INDIVIDUALS*
11 *WITH CARDIOMYOPATHY.*—

12 “(1) *IN GENERAL.*—*The Secretary shall develop*
13 *and make publicly available a cardiomyopathy risk*
14 *assessment for health care providers and individuals.*
15 *Such risk assessment shall, at a minimum, include*
16 *the following:*

17 “(A) *Background information on the preva-*
18 *lence, incidence, and health impact of cardio-*
19 *myopathy, including all forms of cardio-*
20 *myopathy and their effects on pediatric, adoles-*
21 *cent, and adult individuals.*

22 “(B) *A worksheet with variables and condi-*
23 *tions for an individual or health care provider*
24 *to use in assessing whether an individual is at*
25 *risk for cardiomyopathy.*

1 “(C) *A worksheet with variables and stages*
2 *of progression for an individual or health care*
3 *provider to use in assessing whether and to what*
4 *extent cardiomyopathy has progressed in an in-*
5 *dividual.*

6 “(D) *Guidelines on cardiomyopathy*
7 *screenings for individuals who are at risk for, or*
8 *have a family history of, cardiomyopathy.*

9 “(2) *STAKEHOLDER INPUT.—In carrying out*
10 *paragraph (1), the Director of the Centers for Disease*
11 *Control and Prevention shall seek input from external*
12 *stakeholders including—*

13 “(A) *representatives from national patient*
14 *advocacy organizations expert in all forms of*
15 *cardiomyopathy;*

16 “(B) *representatives from medical profes-*
17 *sional societies that specialize in the care of*
18 *adults and pediatrics with cardiomyopathy; and*

19 “(C) *representatives from other relevant*
20 *Federal agencies.*

21 “(c) *DEFINITION.—In this section, the term ‘cardio-*
22 *myopathy’ has the meaning given to such term in section*
23 *312A.*

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

2 “(a) *IN GENERAL.*—*The Secretary, in consultation*
3 *with the Director of the National Institutes of Health, may*
4 *expand and coordinate research and related activities of the*
5 *National Institutes of Health with respect to cardio-*
6 *myopathy, which may include research with respect to—*

7 “(1) *causation of cardiomyopathy, including ge-*
8 *netic causes and molecular biomarkers;*

9 “(2) *long-term health outcomes in individuals*
10 *with cardiomyopathy, including infants, children,*
11 *teenagers, adults, and elderly individuals; and*

12 “(3) *studies using longitudinal data and retro-*
13 *spective analysis to identify effective treatments and*
14 *outcomes for individuals with cardiomyopathy.*

15 “(b) *NONDUPLICATION.*—*The Secretary shall ensure*
16 *that any research and activities related to cardiomyopathy*
17 *under this section do not unnecessarily duplicate activities,*
18 *programs, or efforts of other agencies and offices within the*
19 *Department of Health and Human Services.*

20 “(c) *NIH REPORT.*—*Not later than 18 months after*
21 *the date of the enactment of the HEARTS Act of 2024, the*
22 *Secretary, in consultation with the Director of the National*
23 *Institutes of Health, shall submit to Congress a report—*

24 “(1) *outlining the ongoing research efforts of the*
25 *National Institutes of Health regarding cardio-*
26 *myopathy; and*

1 “(2) *Providing support for CPR and AED train-*
2 *ing programs in such schools for students, staff, and*
3 *related sports volunteers.*

4 “(3) *Providing support for developing a cardiac*
5 *emergency response plan within such schools.*

6 “(4) *Purchasing AEDs that have been approved*
7 *under section 515 of the Federal Food, Drug, and*
8 *Cosmetic Act, cleared under section 510(k) of such*
9 *Act, or classified under section 513(f)(2) of such Act.*

10 “(5) *Purchasing necessary AED batteries and*
11 *performing necessary AED maintenance (such as by*
12 *replacing AED pads) in accordance with the labeling*
13 *of the AED involved.*

14 “(6) *Replacing old and outdated AED and CPR*
15 *equipment, machinery, and educational materials.*

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

18 “(1) *be a local educational agency (including a*
19 *public charter school operating as a local educational*
20 *agency under State law), in consultation with a*
21 *qualified health care entity; and*

22 “(2) *submit to the Secretary an application at*
23 *such time, in such manner, and containing such in-*
24 *formation as the Secretary may reasonably require.*

25 “(d) *DEFINITIONS.—In this section:*

1 “(1) *ESEA TERMS*.—The terms ‘elementary
2 school’, ‘local educational agency’, and ‘secondary
3 school’ have the meanings given such terms in section
4 8101 of the *Elementary and Secondary Education*
5 *Act of 1965*.

6 “(2) *QUALIFIED HEALTH CARE ENTITY*.—The
7 term ‘qualified health care entity’ means a health care
8 entity that—

9 “(A) is—

10 “(i) a public entity; or

11 “(ii) an organization that is described
12 in section 501(c) of the *Internal Revenue*
13 *Code of 1986* and exempt from taxation
14 under section 501(a) of such Code;

15 “(B) demonstrates an ability to develop,
16 train, and implement a comprehensive program
17 to promote student access to defibrillation in
18 public elementary and secondary schools; and

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

21 (b) *AUTHORIZATION OF APPROPRIATIONS*.—Section
22 312(e) of the *Public Health Service Act (42 U.S.C. 244(e))*
23 is amended by striking the first sentence and inserting the
24 following: “For the purpose of carrying out this section and
25 sections 312A, 312B, 312C, and 312D, there is authorized

- 1 *to be appropriated \$25,000,000 for each of fiscal years 2025*
- 2 *through 2029.”.*

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A BILL

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