

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 6829
OFFERED BY MR. PALLONE OF NEW JERSEY**

Strike all after the enacting clause and insert the following:

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

1 the Director of the Centers for Disease Control and Pre-
2 vention, shall develop public education materials and re-
3 sources to be disseminated to school administrators, edu-
4 cators, school health professionals, coaches, families,
5 guardians, caregivers, and other appropriate individuals.

6 The materials and resources shall include—

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

12 “(A) cardiomyopathy;

13 “(B) long QT syndrome, Brugada syn-
14 drome, catecholaminergic polymorphic ventric-
15 ular tachycardia, short QT syndrome, and
16 Wolff-Parkinson-White syndrome; and

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

19 “(2) guidelines regarding the placement of
20 automated external defibrillators in schools, early
21 childhood education programs, and child care cen-
22 ters;

23 “(3) training information on automated exter-
24 nal defibrillators and cardiopulmonary resuscitation;
25 and

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

5 “(b) DISSEMINATION OF MATERIALS AND RE-
6 SOURCES.—Not later than 30 months after the date of
7 the enactment of the HEARTS Act of 2024, the Secretary
8 shall disseminate the materials and resources developed
9 under subsection (a) in accordance with the following:

10 “(1) DISTRIBUTION BY STATE EDUCATIONAL
11 AGENCIES.—The Secretary shall make available such
12 materials and resources to State educational agen-
13 cies to distribute—

14 “(A) to school administrators, educators,
15 school health professionals, coaches, families,
16 guardians, caregivers, and other appropriate in-
17 dividuals, the information developed under sub-
18 section (a)(1);

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

22 “(C) to school administrators, educators,
23 school health professionals, and coaches—

24 “(i) the guidelines described in sub-
25 section (a)(2);

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

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

5 “(2) DISSEMINATION TO HEALTH DEPART-
6 MENTS AND PROFESSIONALS.—The Secretary shall
7 make available the materials and resources devel-
8 oped under subsection (a) to State and local health
9 departments, pediatricians, hospitals, and other
10 health professionals, such as nurses and first re-
11 sponders.

12 “(3) POSTING ON WEBSITE.—

13 “(A) CDC.—

14 “(i) IN GENERAL.—The Secretary,
15 through the Director, shall post the mate-
16 rials and resources developed under sub-
17 section (a) on the public Internet website
18 of the Centers for Disease Control and
19 Prevention.

20 “(ii) ADDITIONAL INFORMATION.—

21 The Director is encouraged to maintain on
22 such public Internet website such addi-
23 tional information regarding cardio-
24 myopathy as deemed appropriate by the
25 Director.

1 “(B) STATE EDUCATIONAL AGENCIES.—
2 State educational agencies are encouraged to
3 create public Internet webpages dedicated to
4 cardiomyopathy and post the materials and re-
5 sources developed under subsection (a) on such
6 webpages.

7 “(c) DEFINITIONS.—In this section:

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

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

13 “(i) cases in which no symptoms are
14 present (asymptomatic); and

15 “(ii) cases in which there are symp-
16 toms of a progressive condition that may
17 result from an impaired ability of the heart
18 to pump blood, such as fatigue, irregular
19 heartbeats (arrhythmia), heart failure,
20 and, potentially, sudden cardiac death; and

21 “(B) the recognized types of which include
22 dilated, hypertrophic, restrictive,
23 arrhythmogenic right ventricular dysplasia, and
24 left ventricular non-compaction.

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

3 “(3) The terms ‘early childhood education pro-
4 gram’, ‘elementary school’, and ‘secondary school’
5 have the meanings given to those terms in section
6 8101 of the Elementary and Secondary Education
7 Act of 1965.

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

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

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

18 “(a) REPORT ON CDC NATIONAL CARDIOMYOPATHY
19 ACTIVITIES.—

20 “(1) IN GENERAL.—Not later than 18 months
21 after the date of the enactment of the HEARTS Act
22 of 2024, the Secretary, acting through the Director
23 of the Centers for Disease Control and Prevention,
24 shall submit to Congress a report on findings gen-
25 erated from existing activities conducted by the Cen-

1 ters for Disease Control and Prevention to improve
2 the understanding of the prevalence and epidemi-
3 ology of cardiomyopathy across the lifespan, from
4 birth to adulthood, with particular interest in the
5 following:

6 “(A) The natural history of individuals
7 with cardiomyopathy, in both the pediatric and
8 adult population.

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

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

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

20 “(b) IMPROVING RISK ASSESSMENTS FOR INDIVID-
21 UALS WITH CARDIOMYOPATHY.—

22 “(1) IN GENERAL.—The Secretary shall develop
23 and make publicly available a cardiomyopathy risk
24 assessment for health care providers and individuals.

1 Such risk assessment shall, at a minimum, include
2 the following:

3 “(A) Background information on the prev-
4 alence, incidence, and health impact of cardio-
5 myopathy, including all forms of cardio-
6 myopathy and their effects on pediatric, adoles-
7 cent, and adult individuals.

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

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

17 “(D) Guidelines on cardiomyopathy
18 screenings for individuals who are at risk for,
19 or have a family history of, cardiomyopathy.

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

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

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

7 “(C) representatives from other relevant
8 Federal agencies.

9 “(c) DEFINITION.—In this section, the term ‘cardio-
10 myopathy’ has the meaning given to such term in section
11 312A.

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

13 “(a) IN GENERAL.—The Secretary, in consultation
14 with the Director of the National Institutes of Health,
15 may expand and coordinate research and related activities
16 of the National Institutes of Health with respect to cardio-
17 myopathy, which may include research with respect to—

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

20 “(2) long-term health outcomes in individuals
21 with cardiomyopathy, including infants, children,
22 teenagers, adults, and elderly individuals; and

23 “(3) studies using longitudinal data and retro-
24 spective analysis to identify effective treatments and
25 outcomes for individuals with cardiomyopathy.

1 “(b) NONDUPLICATION.—The Secretary shall ensure
2 that any research and activities related to cardiomyopathy
3 under this section do not unnecessarily duplicate activities,
4 programs, or efforts of other agencies and offices within
5 the Department of Health and Human Services.

6 “(c) NIH REPORT.—Not later than 18 months after
7 the date of the enactment of the HEARTS Act of 2024,
8 the Secretary, in consultation with the Director of the Na-
9 tional Institutes of Health, shall submit to Congress a re-
10 port—

11 “(1) outlining the ongoing research efforts of
12 the National Institutes of Health regarding cardio-
13 myopathy; and

14 “(2) identifying—

15 “(A) a research agenda regarding adult
16 forms of cardiomyopathy;

17 “(B) plans for researching cardiomyopathy
18 affecting the pediatric population; and

19 “(C) the areas of greatest need for such
20 research.

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

1 **“SEC. 312D. PROMOTING STUDENT ACCESS TO AEDS AND**
2 **CPR.**

3 “(a) IN GENERAL.—The Secretary shall award
4 grants to eligible entities to develop and implement a com-
5 prehensive program to promote student access to auto-
6 mated external defibrillators (in this section referred to
7 as ‘AEDs’) and cardiopulmonary resuscitation (in this sec-
8 tion referred to as ‘CPR’) in public elementary schools and
9 secondary schools.

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

14 “(1) Developing and providing comprehensive
15 materials to establish AED and CPR programs in
16 public elementary schools and secondary schools.

17 “(2) Providing support for CPR and AED
18 training programs in such schools for students,
19 staff, and related sports volunteers.

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

22 “(4) Purchasing AEDs that have been approved
23 under section 515 of the Federal Food, Drug, and
24 Cosmetic Act, cleared under section 510(k) of such
25 Act, or classified under section 513(f)(2) of such
26 Act.

1 “(5) Purchasing necessary AED batteries and
2 performing necessary AED maintenance (such as by
3 replacing AED pads) in accordance with the labeling
4 of the AED involved.

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

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

9 “(1) be a local educational agency (including a
10 public charter school operating as a local educational
11 agency under State law), in consultation with a
12 qualified health care entity; and

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

16 “(d) DEFINITIONS.—In this section:

17 “(1) ESEA TERMS.—The terms ‘elementary
18 school’, ‘local educational agency’, and ‘secondary
19 school’ have the meanings given such terms in sec-
20 tion 8101 of the Elementary and Secondary Edu-
21 cation Act of 1965.

22 “(2) QUALIFIED HEALTH CARE ENTITY.—The
23 term ‘qualified health care entity’ means a health
24 care entity that—

25 “(A) is—

1 “(i) a public entity; or

2 “(ii) an organization that is described
3 in section 501(c) of the Internal Revenue
4 Code of 1986 and exempt from taxation
5 under section 501(a) of such Code;

6 “(B) demonstrates an ability to develop,
7 train, and implement a comprehensive program
8 to promote student access to defibrillation in
9 public elementary and secondary schools; and

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

12 (b) AUTHORIZATION OF APPROPRIATIONS.—Section
13 312(e) of the Public Health Service Act (42 U.S.C.
14 244(e)) is amended by striking the first sentence and in-
15 serting the following: “For the purpose of carrying out
16 this section and sections 312A, 312B, 312C, and 312D,
17 there is authorized to be appropriated \$25,000,000 for
18 each of fiscal years 2025 through 2029.”.

