

113TH CONGRESS
1ST SESSION

H. R. 565

To amend title III of the Public Health Service Act to authorize and support the creation of cardiomyopathy education, awareness, and risk assessment materials and resources by the Secretary of Health and Human Services through the Centers for Disease Control and Prevention and the dissemination of such materials and resources by State educational agencies to identify more at-risk families.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 6, 2013

Mr. PALLONE introduced the following bill; which was referred to the
Committee on Energy and Commerce

A BILL

To amend title III of the Public Health Service Act to authorize and support the creation of cardiomyopathy education, awareness, and risk assessment materials and resources by the Secretary of Health and Human Services through the Centers for Disease Control and Prevention and the dissemination of such materials and resources by State educational agencies to identify more at-risk families.

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, Risk Assessment, and
4 Training in the Schools (HEARTS) Act of 2013”.

5 **SEC. 2. MATERIALS AND RESOURCES TO INCREASE EDU-**
6 **CATION AND AWARENESS OF CARDIO-**
7 **MYOPATHY AMONG SCHOOL ADMINISTRA-**
8 **TORS, EDUCATORS, AND FAMILIES.**

9 Part P of title III of the Public Health Service Act
10 (42 U.S.C. 280g et seq.) is amended by adding at the end
11 the following new section:

12 **“SEC. 399V-6. 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 this section,
18 the Secretary of Health and Human Services (in this sec-
19 tion referred to as the ‘Secretary’), in conjunction with
20 the Director of the Centers for Disease Control and Pre-
21 vention (in this section referred to as the ‘Director’) and
22 in consultation with national patient advocacy and health
23 professional organizations expert in all forms of cardio-
24 myopathy, shall develop public education and awareness
25 materials and resources to be disseminated to school ad-
26 ministrators, educators, school health professionals, coach-

1 es, families, and other appropriate individuals. The mate-
2 rials and resources shall include—

3 “(1) background information to increase edu-
4 cation and awareness of cardiomyopathy among
5 school administrators, educators, and families;

6 “(2) a cardiomyopathy risk assessment work-
7 sheet for use by parents, guardians, or other care-
8 givers;

9 “(3) guidelines regarding the placement of
10 automated external defibrillators in schools and child
11 care centers;

12 “(4) training information on automated exter-
13 nal defibrillators and cardiopulmonary resuscitation;
14 and

15 “(5) recommendations for how schools and child
16 care centers can develop and implement a cardiac
17 emergency response plan.

18 “(b) DEVELOPMENT OF MATERIALS AND RE-
19 SOURCES.—The Secretary, through the Director, shall de-
20 velop and update as necessary and appropriate the mate-
21 rials and resources under subsection (a) and, in support
22 of such effort, the Secretary is encouraged to—

23 “(1) establish an advisory panel composed of—

24 “(A) representatives from multiple national
25 patient advocacy organizations and medical pro-

1 professionals expert in all forms of cardio-
2 myopathy;

3 “(B) a representative from the Centers for
4 Disease Control and Prevention; and

5 “(C) representatives from other relevant
6 Federal agencies; and

7 “(2) engage in a memorandum of under-
8 standing or cooperative agreement with a national
9 nonprofit advocacy organization expert in all forms
10 of cardiomyopathy.

11 “(c) DISSEMINATION OF MATERIALS AND RE-
12 SOURCES.—Not later than 30 months after the date of
13 the enactment of this section, the Secretary, through the
14 Director, shall disseminate the materials and resources
15 under subsection (a) in accordance with the following:

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

20 “(A) to school administrators, educators,
21 school health professionals, coaches and par-
22 ents, guardians, or other caregivers, the cardio-
23 myopathy education and awareness materials
24 and resources under subsection (a);

“(B) to parents, guardians, or other caregivers, the cardiomyopathy risk assessment worksheet described in subsection (a)(2); and

“(C) to school administrators and school health professionals, the—

“(i) guidelines described in subsection (a)(3);

“(ii) training information described in subsection (a)(4); and

“(iii) recommendations described in subsection (a)(5).

“(2) DISSEMINATION TO HEALTH DEPARTMENTS AND PROFESSIONALS.—The Secretary shall make available such materials and resources to State and local health departments, pediatricians, hospitals, and other health professionals, such as nurses and first responders.

“(3) POSTING ON WEBSITE.—

“(A) CDC.—

“(i) IN GENERAL.—The Secretary, through the Director, shall post the materials and resources developed under subsection (a) on the public Internet website of the Centers for Disease Control and 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 EDUCATION AGENCIES.—State
8 educational agencies are encouraged to create
9 public Internet webpages dedicated to cardio-
10 myopathy and post the materials and resources
11 developed under subsection (a) on such
12 webpages.

13 “(d) REPORT TO CONGRESS.—Not later than 1 year
14 after the date of the enactment of this Act, and annually
15 thereafter, the Secretary shall submit to Congress a report
16 identifying the steps taken to increase public education
17 and awareness of cardiomyopathy as outlined under this
18 section.

19 “(e) DEFINITIONS.—For purposes of this section:

20 “(1) CARDIOMYOPATHY.—The term ‘cardio-
21 myopathy’ means a rare heart condition, which is a
22 disease of the heart muscle (myocardium)—

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

1 “(i) in some cases, the presentation of
2 no symptoms (asymptomatic); and

3 “(ii) in many cases, the symptoms of
4 a progressive condition that may result in
5 an impaired ability of the heart to pump
6 blood, fatigue, irregular heart-beats (ar-
7 rhythmia), and, potentially, sudden cardiac
8 death or heart failure; and

9 “(B) the recognized types of which include
10 dilated, hypertrophic, restrictive, arrhythmogen-
11 ic right ventricular dysplasia, and left ventric-
12 ular noncompaction.

13 “(2) SCHOOL ADMINISTRATORS.—The term
14 ‘school administrator’ means a principal, director,
15 manager, or other supervisor or leader within an ele-
16 mentary school or secondary school (as such terms
17 are defined under section 9101 of the Elementary
18 and Secondary Education Act of 1965 (20 U.S.C.
19 7801)), State-based early education program, or
20 child care center.

21 “(3) SCHOOLS.—The term ‘school’ means an
22 early education program, child care center, or ele-
23 mentary school or secondary school (as such terms
24 are so defined).

1 “(4) NATIONAL NONPROFIT ADVOCACY ORGANI-
2 ZATIONS EXPERT IN ALL FORMS OF CARDIO-
3 MYOPATHY.—The term ‘national nonprofit advocacy
4 organizations expert in all forms of cardiomyopathy’
5 means organizations that provide support services to
6 families or fund research, and work to increase pub-
7 lic awareness and education regarding all types of
8 cardiomyopathy.

9 “(f) AUTHORIZATION OF APPROPRIATIONS.—To
10 carry out this section, there are authorized to be appro-
11 priated \$1,000,000 for fiscal year 2014, \$750,000 for fis-
12 cal year 2015, and \$500,000 for each of fiscal years 2016
13 through 2018.”.

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