

113TH CONGRESS  
1ST SESSION

# S. 254

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 SENATE OF THE UNITED STATES

FEBRUARY 7, 2013

Mr. MENENDEZ (for himself and Mr. LAUTENBERG) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

---

## 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 and other  
5 related causes of sudden cardiac death among school  
6 administrators, educators, and families;

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

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

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

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

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

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

1           “(A) representatives from multiple national  
2           patient advocacy organizations and medical pro-  
3           fessionals expert in all forms of cardio-  
4           myopathy;

5           “(B) a representative from the Centers for  
6           Disease Control and Prevention; and

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

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

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

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

22                         “(A) to school administrators, educators,  
23                         school health professionals, coaches and par-  
24                         ents, guardians, or other caregivers, the cardio-

1 myopathy education and awareness materials  
2 and resources under subsection (a);

3 “(B) to parents, guardians, or other care-  
4 givers, the cardiomyopathy risk assessment  
5 worksheet described in subsection (a)(2); and

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

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

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

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

14 “(2) DISSEMINATION TO HEALTH DEPART-  
15 MENTS AND PROFESSIONALS.—The Secretary shall  
16 make available such materials and resources to State  
17 and local health departments, pediatricians, hos-  
18 pitals, and other health professionals, such as nurses  
19 and first responders.

20 “(3) POSTING ON WEBSITE.—

21 “(A) CDC.—

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

1 of the Centers for Disease Control and  
2 Prevention.

3 “(ii) ADDITIONAL INFORMATION.—

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

9 “(B) STATE EDUCATION AGENCIES.—State  
10 educational agencies are encouraged to create  
11 public Internet webpages dedicated to cardio-  
12 myopathy and post the materials and resources  
13 developed under subsection (a) on such  
14 webpages.

15 “(d) REPORT TO CONGRESS.—Not later than 1 year  
16 after the date of the enactment of this section, and annu-  
17 ally thereafter, the Secretary shall submit to Congress a  
18 report identifying the steps taken to increase public edu-  
19 cation and awareness of cardiomyopathy as outlined under  
20 this section.

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

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

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

3                   “(i) in some cases, the presentation of  
4                   no symptoms (asymptomatic);

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

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

15                  “(2) SCHOOL ADMINISTRATORS.—The term  
16                  ‘school administrator’ means a principal, director,  
17                  manager, or other supervisor or leader within an ele-  
18                  mentary school or secondary school (as such terms  
19                  are defined under section 9101 of the Elementary  
20                  and Secondary Education Act of 1965 (20 U.S.C.  
21                  7801)), State-based early education program, or  
22                  child care center.

23                  “(3) SCHOOLS.—The term ‘school’ means an  
24                  early education program, child care center, or ele-

1       mentary school or secondary school (as such terms  
2       are so defined).

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

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

○