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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,
SECTION 1. SHORT TITLE.

This Act may be cited as the “Cardiomyopathy Health Education, Awareness, Risk Assessment, and Training in the Schools (HEARTS) Act of 2013”.

SEC. 2. MATERIALS AND RESOURCES TO INCREASE EDUCATION AND AWARENESS OF CARDIOMYOPATHY AMONG SCHOOL ADMINISTRATORS, EDUCATORS, AND FAMILIES.

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

“SEC. 399V–6. MATERIALS AND RESOURCES TO INCREASE EDUCATION AND AWARENESS OF CARDIOMYOPATHY AMONG SCHOOL ADMINISTRATORS, EDUCATORS, AND FAMILIES.

“(a) MATERIALS AND RESOURCES.—Not later than 18 months after the date of the enactment of this section, the Secretary of Health and Human Services (in this section referred to as the ‘Secretary’), in conjunction with the Director of the Centers for Disease Control and Prevention (in this section referred to as the ‘Director’) and in consultation with national patient advocacy and health professional organizations expert in all forms of cardiomyopathy, shall develop public education and awareness materials and resources to be disseminated to school administrators, educators, school health professionals, coach-
es, families, and other appropriate individuals. The mate-
rials and resources shall include—

“(1) background information to increase edu-
cation and awareness of cardiomyopathy and other
related causes of sudden cardiac death among school
administrators, educators, and families;

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

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

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

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

“(b) Development of Materials and Re-
sources.—The Secretary, through the Director, shall de-
vvelop and update as necessary and appropriate the mate-
rials and resources under subsection (a) and, in support
of such effort, the Secretary is encouraged to—

“(1) establish an advisory panel composed of—
“(A) representatives from multiple national patient advocacy organizations and medical professionals expert in all forms of cardiomyopathy;

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

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

“(2) engage in a memorandum of understanding or cooperative agreement with a national nonprofit advocacy organization expert in all forms of cardiomyopathy.

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

“(1) DISTRIBUTION BY STATE EDUCATION AGENCIES.—The Secretary shall make available such materials and resources to State educational agencies to distribute—

“(A) to school administrators, educators, school health professionals, coaches and parents, guardians, or other caregivers, the cardio-
myopathy education and awareness materials
and resources under subsection (a);

“(B) to parents, guardians, or other care-
givers, 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 DEPART-
MENTS AND PROFESSIONALS.—The Secretary shall
make available such materials and resources to State
and local health departments, pediatricians, hos-
pitals, 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 mate-
rials and resources developed under sub-
section (a) on the public Internet website
of the Centers for Disease Control and
Prevention.

“(ii) ADDITIONAL INFORMATION.—
The Director is encouraged to maintain on
such public Internet website such addi-
tional information regarding cardio-
myopathy as deemed appropriate by the
Director.

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

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

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

“(1) CARDIOMYOPATHY.—The term ‘cardio-
myopathy’ means a rare heart condition, which is a
disease of the heart muscle (myocardium)—
“(A) the symptoms of which may vary from case to case, including—

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

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

“(B) the recognized types of which include dilated, hypertrophic, restrictive, arrhythmogenic right ventricular dysplasia, and left ventricular noncompaction.

“(2) School Administrators.—The term ‘school administrator’ means a principal, director, manager, or other supervisor or leader within an elementary school or secondary school (as such terms are defined under section 9101 of the Elementary and Secondary Education Act of 1965 (20 U.S.C. 7801)), State-based early education program, or child care center.

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

“(4) NATIONAL NONPROFIT ADVOCACY ORGANIZATIONS EXPERT IN ALL FORMS OF CARDIOMYOPATHY.—The term ‘national nonprofit advocacy organizations expert in all forms of cardiomyopathy’ means organizations that provide support services to families or fund research, and work to increase public awareness and education regarding all types of cardiomyopathy.

“(f) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated $1,000,000 for fiscal year 2014, $750,000 for fiscal year 2015, and $500,000 for each of fiscal years 2016 through 2018.”.