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.

Be it enacted by the Senate and House of Representa-

ives 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 materials and resources shall include—

“(1) background information to increase education and awareness of cardiomyopathy among school administrators, educators, and families;

“(2) a cardiomyopathy risk assessment worksheet for use by parents, guardians, or other caregivers;

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

“(4) training information on automated external 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 Resources.—The Secretary, through the Director, shall develop and update as necessary and appropriate the materials 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 pro-
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 cardiomyopathy education and awareness materials 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.
“(ii) ADDITIONAL INFORMATION.—

The Director is encouraged to maintain on such public Internet website such additional information regarding cardiomyopathy as deemed appropriate by the Director.

“(B) STATE EDUCATION AGENCIES.—State educational agencies are encouraged to create public Internet webpages dedicated to cardiomyopathy 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 Act, and annually thereafter, the Secretary shall submit to Congress a report identifying the steps taken to increase public education and awareness of cardiomyopathy as outlined under this section.

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

“(1) CARDIOMYOPATHY.—The term ‘cardiomyopathy’ 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); and

“(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, arrhythmogenenic 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 elementary 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.”.