To amend the Public Health Service Act to authorize and support the creation and dissemination of cardiomyopathy education, awareness, and risk assessment materials and resources to identify more at-risk families, to authorize research and surveillance activities relating to cardiomyopathy, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 10, 2020

Mr. Kim (for himself and Mr. Barr) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to authorize and support the creation and dissemination of cardiomyopathy education, awareness, and risk assessment materials and resources to identify more at-risk families, to authorize research and surveillance activities relating to cardiomyopathy, and for other purposes.

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, Research, and Training in the Schools Act of 2020” or the “HEARTS Act of 2020”.

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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–7. 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, in conjunction with the Director of the Centers for Disease Control and Prevention (in this section referred to as the ‘Director’) shall develop public education materials and resources to be disseminated to school administrators, educators, school health professionals, coaches, families, guardians, caregivers, 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) guidelines regarding the placement of automated external defibrillators in schools, early
childhood education programs, and child care centers;

“(3) training information on automated external defibrillators and cardiopulmonary resuscitation; and

“(4) recommendations for how schools, early childhood education programs, and child care centers can develop and implement a cardiac emergency response plan.

“(b) 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 developed under subsection (a) in accordance with the following:

“(1) DISTRIBUTION BY STATE EDUCATIONAL 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, families, guardians, caregivers, and other appropriate individuals, the cardiomyopathy education and awareness materials and resources developed under subsection (a)(1);
“(B) to parents, guardians, or other care-
givers, the risk assessment for individuals with
or at risk for cardiomyopathy developed pursu-
ant to section 399V–8(b)(1); and

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

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

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

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

“(2) DISSEMINATION TO HEALTH DEPART-
MENTS AND PROFESSIONALS.—The Secretary shall
make available the materials and resources de-
veloped under subsection (a) to State and local health
departments, pediatricians, hospitals, and other
health professionals, such as nurses and first re-
sponders.

“(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 additional information regarding cardiomyopathy as deemed appropriate by the Director.

“(B) STATE EDUCATIONAL 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.

“(c) DEFINITIONS.—In this section:

“(1) The term ‘school administrator’ means a principal, director, manager, or other supervisor or leader within an elementary school, secondary school, State-based early childhood education program, or child care center.

“(2) The term ‘school health professional’ means a health professional serving at an elementary school, secondary school, State-based early childhood education program, or child care center.
“(3) The terms ‘early childhood education program’, ‘elementary school’, and ‘secondary school’ have the meanings given to those terms in section 8101 of the Elementary and Secondary Education Act of 1965.

“(d) Authorization of Appropriations.—For carrying out this section and section 399V–8, there is authorized to be appropriated $1,000,000 for each of fiscal years 2021 through 2025.”.

SEC. 3. RESEARCH AND SURVEILLANCE ACTIVITIES RELATING TO CARDIOMYOPATHY.

(a) CDC Research and Surveillance.—Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.), as amended by section 2, is further amended by adding at the end the following new section:

“SEC. 399V–8. RESEARCH AND SURVEILLANCE ACTIVITIES RELATING TO CARDIOMYOPATHY.

“(a) Reports on CDC National Cardiomyopathy Surveillance Research Activities.—

“(1) Initial report.—Not later than June 1, 2021, the Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall submit to Congress an initial report on findings and data generated from surveillance and research activities conducted by the Centers for Dis-
ease Control and Prevention to improve the understanding of the prevalence and epidemiology of cardiomyopathy across the lifespan, from birth to adulthood, with particular interest in the following:

“(A) The health care costs, utilization, and natural history of individuals with cardiomyopathy, in both the pediatric and adult population.

“(B) The number of adults and children affected by cardiomyopathy, as well as age-specific mortality.

“(2) FINAL REPORT.—Not later than January 1, 2026, the Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall submit to Congress a final report on the content described in paragraph (1).

“(3) PUBLIC ACCESS.—Subject to paragraph (4), the reports submitted under this subsection shall be made available to the public.

“(4) PATIENT PRIVACY.—The Secretary shall ensure that this subsection is carried out in a manner that complies with the requirements applicable to a covered entity under the regulations promulgated pursuant to section 264(c) of the Health Insurance Portability and Accountability Act of 1996.
“(b) Improving Risk Assessments for Individuals With Cardiomyopathy.—

“(1) In General.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall develop and make publicly available a risk assessment for individuals with or at risk for cardiomyopathy. Such risk assessment shall, at a minimum, include the following:

“(A) Background information of the prevalence, incidence, and health impact of cardiomyopathy, including all forms of cardiomyopathy and their effects on pediatric, adolescent, and adult individuals.

“(B) A worksheet with variables and conditions for an individual or health care provider to use in assessing whether the individual is at risk for cardiomyopathy.

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

“(D) Guidelines on cardiomyopathy screenings for individuals who are at risk for, or have a family history of, cardiomyopathy.
“(2) Stakeholder input.—In carrying out paragraph (1), the Director of the Centers for Disease Control and Prevention shall seek input from external stakeholders including—

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

“(B) representatives from medical professional societies that specialize in the care of adults and pediatrics with cardiomyopathy; and

“(C) representatives from other relevant Federal agencies.

“(c) Cardiomyopathy defined.—For purposes of this section, the term ‘cardiomyopathy’ means a heart disease that affects the heart’s muscle (myocardium)—

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

“(A) cases in which no symptoms are present (asymptomatic); and

“(B) cases in which there are symptoms of a progressive condition that may result from an impaired ability of the heart to pump blood, such as fatigue, irregular heartbeats (arrhythmia), heart failure, and, potentially, sudden cardiac death; and
“(2) the recognized types of which include di-
lated, hypertrophic, restrictive, arrhythmogenic right
ventricular dysplasia, and left ventricular non-com-
paction.”.

(b) FEDERAL WORKING GROUP.—

(1) IN GENERAL.—Not later than one year
after the date of the enactment of this Act, the Sec-
retary of Health and Human Services shall convene
an interdisciplinary working group for the purpose
of expanding cardiomyopathy research.

(2) DUTIES.—The working group shall—

(A) develop a research strategy to address
the gaps in knowledge on the molecular and ge-
netic causes of cardiomyopathy in children;

(B) identify approaches that could result
in the development of preventive and disease-di-
rected therapies specific to pediatric cardiomy-
opathies and heart failure; and

(C) explore novel clinical trial methodolo-
gies and end points in an effort to optimize suc-
cessful completion of clinical trials in this rare
patient population.

(3) MEMBERSHIP.—The Secretary shall appoint
to the working group members representing a range
of stakeholders outside of the Federal Government
with subject matter expertise relating to cardiomyopathy, including—

(A) pediatric cardiologists with expertise in the diagnosis and treatment of children with cardiomyopathies and heart failure and clinical trials related to the pediatric population;

(B) geneticists with expertise in pediatric cardiomyopathy and heart failure;

(C) cardiovascular molecular biologists;

(D) pharmacologists;

(E) research scientists with expertise in cardiomyopathy and heart failure; and

(F) other stakeholders with relevant expertise, as determined by the Secretary.

(4) Report to Congress.—Not later than 2 years after the date of the enactment of this Act, the Working Group shall publish and submit to Congress a report that contains—

(A) a description of the activities of the working group;

(B) the findings and recommendations of the working group with respect to each of the topics described in paragraph (2); and

(C) the recommendations of the working group relating to actions that Federal agencies
and Congress can take to implement the recommendations described in subparagraph (B).

(5) NO COMPENSATION.—A member of the working group shall serve without compensation.

(6) TERMINATION.—The working group shall terminate on the date on which the working group submits the report under paragraph (4).

(7) CARDIOMYOPATHY DEFINED.—For purposes of this subsection, the term ‘‘cardiomyopathy’’ means a heart disease that affects the heart’s muscle (myocardium)—

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

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

(ii) cases in which there are symptoms of a progressive condition that may result from an impaired ability of the heart to pump blood, such as fatigue, irregular heartbeats (arrhythmia), heart failure, and, potentially, sudden cardiac death; and

(B) the recognized types of which include dilated, hypertrophic, restrictive, arrhythmogen-
ic right ventricular dysplasia, and left ventricular non-compaction.