115TH CONGRESS
1ST SESSION

S. 477

To amend the Public Health Service Act to coordinate Federal congenital heart disease research and surveillance efforts and to improve public education and awareness of congenital heart disease, and for other purposes.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 28, 2017

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

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A BILL

To amend the Public Health Service Act to coordinate Federal congenital heart disease research and surveillance efforts and to improve public education and awareness of congenital heart disease, 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 ''Congenital Heart Futures Reauthorization Act of 2017''.

SEC. 2. NATIONAL CONGENITAL HEART DISEASE COHORT STUDY, SURVEILLANCE, AND AWARENESS CAMPAIGN.

Section 399V–2 of the Public Health Service Act (42 U.S.C. 280g–13) is amended—

(1) by amending the section heading to read as follows: ''**NATIONAL CONGENITAL HEART DISEASE COHORT STUDY, SURVEILLANCE SYSTEM, AND AWARENESS CAMPAIGN**'';

(2) by amending subsection (a) to read as follows:

''(a) IN GENERAL.—

''(1) ACTIVITIES.—The Secretary shall—

''(A) enhance and expand research and surveillance infrastructure to study and track the epidemiology of congenital heart disease (in this section referred to as 'CHD') across the lifespan; and

''(B) plan and implement a public outreach and education campaign regarding CHD across the lifespan.

''(2) GRANTS.—The Secretary may award grants to eligible entities to carry out the activities described in subsections (b), (c), and (d).'';

(3) in subsection (b)—

(A) in the heading, by striking ''PURPOSE'' and inserting ''NATIONAL CONGENITAL HEART DISEASE SURVEILLANCE SYSTEM''; and

(B) by striking ''The purpose of the Congenital Heart Disease Surveillance System shall be to facilitate'' and inserting the following:

''(1) IN GENERAL.—The Secretary shall establish a Congenital Heart Disease Surveillance System for the purpose of facilitating'';

(4) in subsection (c)—

(A) in paragraph (2), by redesignating subparagraphs (A) through (E) as clauses (i) through (v), respectively, and adjusting the margins accordingly;

(B) by redesignating paragraphs (1) through (3) as subparagraphs (A) through (C), respectively, and adjusting the margins accordingly; and

(C) by redesignating such subsection (c) as paragraph (2) of subsection (b) and adjusting the margin accordingly;

(5) by striking subsections (d) and (e) and inserting the following:

''(c) NATIONAL CONGENITAL HEART DISEASE COHORT STUDY.—

''(1) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall plan, develop, implement, and submit annual reports to the Congress on research and surveillance activities of the Centers for Disease Control and Prevention, including a cohort study to improve understanding of the epidemiology of CHD across the lifespan, from birth to adulthood, with particular interest in the following:

''(A) Health care utilization and natural history of individuals affected by CHD.

''(B) Demographic factors associated with CHD, such as age, race, ethnicity, gender, and family history of individuals who are diagnosed with the disease.

''(C) Outcome measures, such that analysis of the outcome measures will allow derivation of evidence-based best practices and guidelines for CHD patients.

''(2) PERMISSIBLE CONSIDERATIONS.—The study under this subsection may—

''(A) gather data on the health outcomes of a diverse population of those affected by CHD;

"(B) consider health disparities among those affected by CHD which may include the consideration of prenatal exposures; and

"(C) incorporate behavioral, emotional, and educational outcomes of those affected by CHD.

"(3) PUBLIC ACCESS.—Subject to appropriate protections of personal information, including protections required under paragraph (4), data generated from the study under this subsection and through the Congenital Heart Disease Surveillance System under subsection (b) shall be made available for purposes of CHD research and to the public.

"(4) PATIENT PRIVACY.—The Secretary shall ensure that the study under this subsection and the Congenital Heart Disease Surveillance System under subsection (b) are 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.

"(d) CONGENITAL HEART DISEASE AWARENESS CAMPAIGN.—

"(1) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease

Control and Prevention, shall establish and implement an awareness, outreach, and education campaign regarding CHD across the lifespan. The information expressed through such campaign may—

''(A) emphasize the prevalence of CHD;

''(B) identify CHD as a condition that affects those diagnosed throughout their lives; and

''(C) promote the need for pediatric, adolescent, and adult individuals with CHD to seek and maintain lifelong, specialized care.

''(2) PERMISSIBLE ACTIVITIES.—The campaign under this subsection may—

''(A) utilize collaborations or partnerships with other agencies, health care professionals, and patient advocacy organizations that specialize in the needs of individuals with CHD; and

''(B) include the use of print, film, or electronic materials distributed via television, radio, Internet, or other commercial marketing venues.'';

(6) by redesignating subsection (f) as subsection (e); and

(7) by adding at the end the following:

''(f) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated such sums as may be necessary for each of fiscal years 2017 through 2021.''.

SEC. 3. CONGENITAL HEART DISEASE RESEARCH.

Section 425 of the Public Health Service Act (42 U.S.C. 285b–8) is amended by adding the end the following:

''(d) REPORT FROM NIH.—Not later than 1 year after the date of enactment of the Congenital Heart Futures Reauthorization Act of 2017, the Director of NIH, acting through the Director of the Institute, shall provide a report to Congress—

''(1) outlining the ongoing research efforts of the National Institutes of Health regarding congenital heart disease; and

''(2) identifying—

''(A) future plans for research regarding congenital heart disease; and

''(B) the areas of greatest need for such research.''.

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