

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

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.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Congenital Heart Fu-
5 tures Reauthorization Act of 2017”.

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

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

6 (1) by amending the section heading to read as
 7 follows: “**NATIONAL CONGENITAL HEART DIS-**
 8 **EASE COHORT STUDY, SURVEILLANCE SYSTEM,**
 9 **AND AWARENESS CAMPAIGN**”;

10 (2) by amending subsection (a) to read as fol-
 11 lows:

12 “(a) IN GENERAL.—

13 “(1) ACTIVITIES.—The Secretary shall—

14 “(A) enhance and expand research and
 15 surveillance infrastructure to study and track
 16 the epidemiology of congenital heart disease (in
 17 this section referred to as ‘CHD’) across the
 18 lifespan; and

19 “(B) plan and implement a public outreach
 20 and education campaign regarding CHD across
 21 the lifespan.

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

25 (3) in subsection (b)—

1 (A) in the heading, by striking “PURPOSE”
 2 and inserting “NATIONAL CONGENITAL HEART
 3 DISEASE SURVEILLANCE SYSTEM”; and

4 (B) by striking “The purpose of the Con-
 5 genital Heart Disease Surveillance System shall
 6 be to facilitate” and inserting the following:

7 “(1) IN GENERAL.—The Secretary shall estab-
 8 lish a Congenital Heart Disease Surveillance System
 9 for the purpose of facilitating”;

10 (4) in subsection (c)—

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

15 (B) by redesignating paragraphs (1)
 16 through (3) as subparagraphs (A) through (C),
 17 respectively, and adjusting the margins accord-
 18 ingly; and

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

22 (5) by striking subsections (d) and (e) and in-
 23 serting the following:

24 “(c) NATIONAL CONGENITAL HEART DISEASE CO-
 25 HORT STUDY.—

1 “(1) IN GENERAL.—The Secretary, acting
2 through the Director of the Centers for Disease
3 Control and Prevention, shall plan, develop, imple-
4 ment, and submit annual reports to the Congress on
5 research and surveillance activities of the Centers
6 for Disease Control and Prevention, including a co-
7 hort study to improve understanding of the epidemi-
8 ology of CHD across the lifespan, from birth to
9 adulthood, with particular interest in the following:

10 “(A) Health care utilization and natural
11 history of individuals affected by CHD.

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

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

20 “(2) PERMISSIBLE CONSIDERATIONS.—The
21 study under this subsection may—

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

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

4 “(C) incorporate behavioral, emotional,
5 and educational outcomes of those affected by
6 CHD.

7 “(3) PUBLIC ACCESS.—Subject to appropriate
8 protections of personal information, including pro-
9 tections required under paragraph (4), data gen-
10 erated from the study under this subsection and
11 through the Congenital Heart Disease Surveillance
12 System under subsection (b) shall be made available
13 for purposes of CHD research and to the public.

14 “(4) PATIENT PRIVACY.—The Secretary shall
15 ensure that the study under this subsection and the
16 Congenital Heart Disease Surveillance System under
17 subsection (b) are carried out in a manner that com-
18 plies with the requirements applicable to a covered
19 entity under the regulations promulgated pursuant
20 to section 264(c) of the Health Insurance Portability
21 and Accountability Act of 1996.

22 “(d) CONGENITAL HEART DISEASE AWARENESS
23 CAMPAIGN.—

24 “(1) IN GENERAL.—The Secretary, acting
25 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:

1 “(f) AUTHORIZATION OF APPROPRIATIONS.—To
 2 carry out this section, there are authorized to be appro-
 3 priated such sums as may be necessary for each of fiscal
 4 years 2017 through 2021.”.

5 **SEC. 3. CONGENITAL HEART DISEASE RESEARCH.**

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

9 “(d) REPORT FROM NIH.—Not later than 1 year
 10 after the date of enactment of the Congenital Heart Fu-
 11 tures Reauthorization Act of 2017, the Director of NIH,
 12 acting through the Director of the Institute, shall provide
 13 a report to Congress—

14 “(1) outlining the ongoing research efforts of
 15 the National Institutes of Health regarding con-
 16 genital heart disease; and

17 “(2) identifying—

18 “(A) future plans for research regarding
 19 congenital heart disease; and

20 “(B) the areas of greatest need for such
 21 research.”.

○