

115TH CONGRESS
1ST SESSION

H. R. 1222

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 27, 2017

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

A BILL

To amend the Public Health Service Act to coordinate Federal congenital heart disease research 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 SURVEIL-**
2 **LANCE SYSTEM.**

3 Section 399V-2 of the Public Health Service Act (42
4 U.S.C. 280g-13) is amended to read as follows:

5 **“SEC. 399V-2. NATIONAL CONGENITAL HEART DISEASE RE-**
6 **SEARCH, SURVEILLANCE, AND AWARENESS.**

7 “(a) IN GENERAL.—The Secretary shall—

8 “(1) enhance and expand research and surveil-
9 lance infrastructure to study and track the epidemi-
10 ology of congenital heart disease (in this section re-
11 ferred to as ‘CHD’);

12 “(2) plan and implement a public outreach and
13 education campaign regarding CHD across the life-
14 span; and

15 “(3) award grants to eligible entities to under-
16 take the activities described in subsections (b) and
17 (c).

18 “(b) NATIONAL CONGENITAL HEART DISEASE
19 STUDY.—

20 “(1) IN GENERAL.—The Director of the Cen-
21 ters for Disease Control and Prevention shall plan,
22 develop, implement, and submit one or more reports
23 to the Congress on a study to improve under-
24 standing of the epidemiology of CHD across the life-
25 span, from birth to adulthood, with particular inter-
26 est in the following:

1 “(A) Health care utilization of those af-
2 fected by CHD.

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

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

11 “(2) PERMISSIBLE CONSIDERATIONS.—The
12 study under this subsection may—

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

15 “(B) consider health disparities among
16 those affected by CHD, which may include the
17 consideration of prenatal exposures; and

18 “(C) incorporate behavioral, emotional,
19 and educational outcomes of those affected by
20 CHD.

21 “(3) PUBLIC ACCESS.—Data generated from
22 the study under this subsection shall be made avail-
23 able—

24 “(A) for purposes of CHD research, sub-
25 ject to appropriate protections of personal pri-

1 vacy, including protections required by para-
2 graph (4); and

3 “(B) to the public, subject to paragraph
4 (4) and with appropriate exceptions for protec-
5 tion of personal privacy.

6 “(4) PATIENT PRIVACY.—The Secretary shall
7 ensure that the study under this subsection is car-
8 ried out in a manner that complies with the require-
9 ments applicable to a covered entity under the regu-
10 lations promulgated pursuant to section 264(c) of
11 the Health Insurance Portability and Accountability
12 Act of 1996.

13 “(c) CONGENITAL HEART DISEASE AWARENESS
14 CAMPAIGN.—

15 “(1) IN GENERAL.—The Director of the Cen-
16 ters for Disease Control and Prevention shall estab-
17 lish and implement an awareness, outreach, and
18 education campaign regarding CHD across the life-
19 span.

20 “(2) PERMISSIBLE ACTIVITIES.—The campaign
21 under this subsection may—

22 “(A) utilize collaborations or partnerships
23 with other agencies, health care professionals,
24 and patient advocacy organizations that spe-

1 cialize in the needs of individuals with CHD;
 2 and

3 “(B) include the use of print, film, and
 4 electronic materials distributed via television,
 5 radio, Internet, or other commercial marketing
 6 venues.

7 “(d) ELIGIBILITY FOR GRANTS.—To be eligible to re-
 8 ceive a grant under subsection (a)(3), an entity shall—
 9 “(1) be a public or private nonprofit entity with
 10 specialized experience in CHD; and

11 “(2) submit to the Secretary an application at
 12 such time, in such manner, and containing such in-
 13 formation as the Secretary may require.

14 “(e) AUTHORIZATION OF APPROPRIATIONS.—To
 15 carry out this section, there is authorized to be appro-
 16 priated \$4,000,000 for each of fiscal years 2017 through
 17 2021.”.

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

19 Section 425 of the Public Health Service Act (42
 20 U.S.C. 285b–8) is amended to read as follows:

21 **“SEC. 425. CONGENITAL HEART DISEASE.**

22 “(a) IN GENERAL.—The Director of the Institute
 23 may expand, intensify, and coordinate research and re-
 24 lated activities of the Institute with respect to congenital

1 heart disease, which may include congenital heart disease
2 research with respect to—

3 “(1) causation of congenital heart disease, in-
4 cluding genetic causes;

5 “(2) long-term outcomes in individuals with
6 congenital heart disease, including infants, children,
7 teenagers, adults, and elderly individuals;

8 “(3) diagnosis, treatment, and prevention;

9 “(4) studies using longitudinal data and retro-
10 spective analysis to identify effective treatments and
11 outcomes for individuals with congenital heart dis-
12 ease; and

13 “(5) identifying barriers to lifelong care for in-
14 dividuals with congenital heart disease.

15 “(b) COORDINATION OF RESEARCH ACTIVITIES.—
16 The Director of the Institute may coordinate research ef-
17 forts related to congenital heart disease among multiple
18 research institutions and may develop research networks.

19 “(c) MINORITY AND MEDICALLY UNDERSERVED
20 COMMUNITIES.—In carrying out the activities described in
21 this section, the Director of the Institute shall consider
22 the application of such research and other activities to mi-
23 nority and medically underserved communities.

24 “(d) REPORT FROM NIH.—Not later than 1 year
25 after the date of enactment of the Congenital Heart Fu-

1 tures Reauthorization Act of 2017, the Director of NIH,
2 acting through the Director of the Institute, shall provide
3 a report to Congress—

4 “(1) outlining the ongoing research efforts of
5 the National Institutes of Health regarding con-
6 genital heart disease; and

7 “(2) identifying—

8 “(A) future plans for research regarding
9 congenital heart disease; and

10 “(B) the areas of greatest need for such
11 research.”.

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