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(Original Signature of Member)

114TH CONGRESS
1ST SESSION

H. R. _____

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

Mr. BILIRAKIS introduced the following bill; which was referred to the
Committee on _____

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 2015”.

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, acting through
8 the Director of the Centers for Disease Control and Pre-
9 vention, shall—

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

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

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

20 “(b) NATIONAL CONGENITAL HEART DISEASE CO-
21 HORT STUDY.—

22 “(1) IN GENERAL.—The Director of the Cen-
23 ters for Disease Control and Prevention shall plan,
24 develop, implement, and submit one or more reports
25 to the Congress on a cohort study to improve under-
26 standing of the epidemiology of CHD across the life-

1 span, from birth to adulthood, with particular inter-
2 est in the following:

3 “(A) Health care utilization and natural
4 history of those affected by CHD.

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

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

13 “(2) PERMISSIBLE CONSIDERATIONS.—The
14 study under this subsection may—

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

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

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

23 “(3) PUBLIC ACCESS.—Subject to paragraph
24 (4), the data generated from the study under this

1 subsection shall be made available to the public, in-
2 cluding CHD researchers.

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

10 “(c) CONGENITAL HEART DISEASE AWARENESS
11 CAMPAIGN.—

12 “(1) IN GENERAL.—The Director of the Cen-
13 ters for Disease Control and Prevention shall estab-
14 lish and implement an awareness, outreach, and
15 education campaign regarding CHD across the life-
16 span. The information expressed through such cam-
17 paign shall—

18 “(A) emphasize that CHD is the most
19 prevalent birth defect;

20 “(B) identify CHD as a condition that af-
21 fects those diagnosed throughout their lives;
22 and

23 “(C) promote the need for pediatric, ado-
24 lescent, and adult individuals with CHD to seek
25 and maintain lifelong, specialized care.

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

3 “(A) utilize collaborations or partnerships
4 with other agencies, health care professionals,
5 and patient advocacy organizations that spe-
6 cialize in the needs of individuals with CHD;
7 and

8 “(B) include the use of print, film, and
9 electronic materials distributed via television,
10 radio, Internet, and other commercial mar-
11 keting venues.

12 “(d) ELIGIBILITY FOR GRANTS.—To be eligible to re-
13 ceive a grant under subsection (a)(3), an entity shall—

14 “(1) be a public or private nonprofit entity with
15 specialized experience in CHD; and

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

19 “(e) AUTHORIZATION OF APPROPRIATIONS.—To
20 carry out this section, there is authorized to be appro-
21 priated \$4,000,000 for each of fiscal years 2016 through
22 2020.”.

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

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

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

2 “(a) IN GENERAL.—The Director of the Institute
3 may expand, intensify, and coordinate research and re-
4 lated activities of the Institute with respect to congenital
5 heart disease, which may include congenital heart disease
6 research with respect to—

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

9 “(2) long-term outcomes in individuals with
10 congenital heart disease, including infants, children,
11 teenagers, adults, and elderly individuals;

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

13 “(4) studies using longitudinal data and retro-
14 spective analysis to identify effective treatments and
15 outcomes for individuals with congenital heart dis-
16 ease; and

17 “(5) identifying barriers to life-long care for in-
18 dividuals with congenital heart disease.

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

23 “(c) MINORITY AND MEDICALLY UNDERSERVED
24 COMMUNITIES.—In carrying out the activities described in
25 this section, the Director of the Institute shall consider

1 the application of such research and other activities to mi-
2 nority and medically underserved communities.

3 “(d) REPORT FROM NIH.—Not later than 1 year
4 after the date of enactment of the Congenital Heart Fu-
5 tures Reauthorization Act of 2015, the Director of NIH,
6 acting through the Director of the Institute, shall provide
7 a report to Congress—

8 “(1) outlining the ongoing research efforts of
9 the National Institutes of Health regarding con-
10 genital heart disease; and

11 “(2) identifying—

12 “(A) future plans for research regarding
13 congenital heart disease; and

14 “(B) the areas of greatest need for such
15 research.”.