

Union Calendar No. 239

115TH CONGRESS
1ST SESSION

H. R. 1222

[Report No. 115–329]

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

SEPTEMBER 25, 2017

Additional sponsors: Mr. ABRAHAM, Mr. SWALWELL of California, Mr. LOEBSACK, Mr. BOST, Mr. SOTO, Mr. POCAN, Mrs. McMORRIS RODGERS, Mrs. MURPHY of Florida, Mr. WEBSTER of Florida, Mr. MULLIN, Mr. EVANS, Mr. STIVERS, Mr. GUTHRIE, Mr. CONNOLLY, Ms. NORTON, Mr. NOLAN, Mr. FITZPATRICK, Mr. COLLINS of New York, Ms. VELÁZQUEZ, Ms. ROS-LEHTINEN, Mr. SESSIONS, Mr. GRIFFITH, Mr. ELLISON, Mr. MOULTON, Mr. CÁRDENAS, Mr. WALBERG, and Mr. MEEHAN

SEPTEMBER 25, 2017

Reported with an amendment, committed to the Committee of the Whole
House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on February 27, 2017]

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”.*

6 **SEC. 2. NATIONAL CONGENITAL HEART DISEASE SURVEIL-**
 7 **LANCE SYSTEM.**

8 *Section 399V–2 of the Public Health Service Act (42*
 9 *U.S.C. 280g–13) is amended to read as follows:*

10 **“SEC. 399V–2. NATIONAL CONGENITAL HEART DISEASE RE-**
 11 **SEARCH, SURVEILLANCE, AND AWARENESS.**

12 *“(a) IN GENERAL.—The Secretary shall—*

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

17 *“(2) award grants to eligible entities to under-*
 18 *take the activities described in this section.*

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

21 *“(1) IN GENERAL.—The Secretary shall plan, de-*
 22 *velop, implement, and submit one or more reports to*
 23 *the Congress on a study to improve understanding of*
 24 *the epidemiology of CHD across the lifespan, from*

1 *birth to adulthood, with particular interest in the fol-*
2 *lowing:*

3 “(A) *Health care utilization of those af-*
4 *ected 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 study*
14 *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, and*
21 *educational outcomes of those affected by CHD.*

22 “(3) *PUBLIC ACCESS.—Data generated from the*
23 *study under this subsection shall be made available—*

24 “(A) *for purposes of CHD research, subject*
25 *to appropriate protections of personal privacy,*

1 *including protections required by paragraph (4);*
 2 *and*

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

6 *“(4) PATIENT PRIVACY.—The Secretary shall en-*
 7 *sure that the study under this subsection is carried*
 8 *out in a manner that complies with the requirements*
 9 *applicable to a covered entity under the regulations*
 10 *promulgated pursuant to section 264(c) of the Health*
 11 *Insurance Portability and Accountability Act of 1996.*

12 *“(c) ELIGIBILITY FOR GRANTS.—To be eligible to re-*
 13 *ceive a grant under subsection (a)(2), 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 *“(d) AUTHORIZATION OF APPROPRIATIONS.—To carry*
 20 *out this section, there is authorized to be appropriated*
 21 *\$4,000,000 for each of fiscal years 2018 through 2022.”.*

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

23 *Section 425 of the Public Health Service Act (42*
 24 *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 may*
 3 *expand, intensify, and coordinate research and related ac-*
 4 *tivities of the Institute with respect to congenital heart dis-*
 5 *ease, which may include congenital heart disease research*
 6 *with respect to—*

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

9 “(2) *long-term outcomes in individuals with con-*
 10 *genital 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 lifelong care for indi-*
 18 *viduals with congenital heart disease.*

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

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

1 cation of such research and other activities to minority and
2 medically underserved communities.

3 “(d) *REPORT FROM NIH.*—Not later than one year
4 after the date of the enactment of the Congenital Heart Fu-
5 tures Reauthorization Act of 2017, the Director of NIH, act-
6 ing through the Director of the Institute, shall provide a
7 report to Congress—

8 “(1) outlining the ongoing research efforts of the
9 National Institutes of Health regarding congenital
10 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 re-
15 search.”.

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