

115TH CONGRESS  
2D SESSION

# H. R. 1222

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IN THE SENATE OF THE UNITED STATES

FEBRUARY 27, 2018

Received; read twice and referred to the Committee on Health, Education,  
Labor, and Pensions

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## AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

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

4 **SEC. 2. NATIONAL CONGENITAL HEART DISEASE SURVEIL-**  
5 **LANCE SYSTEM.**

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

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

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

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

15 “(2) award grants to eligible entities to under-  
16 take the activities described in this section.

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

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

25 “(A) Health care utilization of those af-  
26 fected by CHD.

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

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

9           “(2) PERMISSIBLE CONSIDERATIONS.—The  
10          study under this subsection may—

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

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

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

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

22           “(A) for purposes of CHD research, sub-  
23           ject to appropriate protections of personal pri-  
24           vacy, including protections required by para-  
25           graph (4); and

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

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

11          “(c) ELIGIBILITY FOR GRANTS.—To be eligible to re-  
12          ceive a grant under subsection (a)(2), an entity shall—

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

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

18          “(d) AUTHORIZATION OF APPROPRIATIONS.—To  
19          carry out this section, there is authorized to be appro-  
20          priated \$4,000,000 for each of fiscal years 2018 through  
21          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  
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 lifelong 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 the enactment of the Congenital Heart  
5 Futures Reauthorization Act of 2017, the Director of  
6 NIH, acting through the Director of the Institute, shall  
7 provide 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.”.

Passed the House of Representatives February 26,  
2018.

Attest:

KAREN L. HAAS,

*Clerk.*