

In the Senate of the United States,

December 12, 2018.

Resolved, That the bill from the House of Representatives (H.R. 1222) entitled “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.”, do pass with the following

AMENDMENT:

Strike all after the enacting clause and insert the following:

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 RE-***
5 ***SEARCH, SURVEILLANCE, AND AWARENESS.***

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

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

3 “(a) *IN GENERAL.*—*The Secretary shall, as appro-*
4 *priate—*

5 “(1) *enhance and expand research and data col-*
6 *lection efforts related to congenital heart disease, in-*
7 *cluding to study and track the epidemiology of con-*
8 *genital heart disease to understand health outcomes*
9 *for individuals with congenital heart disease across*
10 *all ages;*

11 “(2) *conduct activities to improve public aware-*
12 *ness of, and education related to, congenital heart dis-*
13 *ease, including care of individuals with such disease;*
14 *and*

15 “(3) *award grants to entities to undertake the*
16 *activities described in this section.*

17 “(b) *ACTIVITIES.*—

18 “(1) *IN GENERAL.*—*The Secretary shall carry*
19 *out activities, including, as appropriate, through a*
20 *national cohort study and a nationally-representative,*
21 *population-based surveillance system, to improve the*
22 *understanding of the epidemiology of congenital heart*
23 *disease in all age groups, with particular attention*
24 *to—*

25 “(A) *the incidence and prevalence of con-*
26 *genital heart disease in the United States;*

1 “(B) causation and risk factors associated
2 with, and natural history of, congenital heart
3 disease;

4 “(C) health care utilization by individuals
5 with congenital heart disease;

6 “(D) demographic factors associated with
7 congenital heart disease, such as age, race, eth-
8 nicity, sex, and family history of individuals
9 who are diagnosed with the disease; and

10 “(E) evidence-based practices related to care
11 and treatment for individuals with congenital
12 heart disease.

13 “(2) *PERMISSIBLE CONSIDERATIONS.*—In car-
14 rying out the activities under this section, the Sec-
15 retary may, as appropriate—

16 “(A) collect data on the health outcomes, in-
17 cluding behavioral and mental health outcomes,
18 of a diverse population of individuals of all ages
19 with congenital heart disease, such that analysis
20 of the outcomes will inform evidence-based prac-
21 tices for individuals with congenital heart dis-
22 ease; and

23 “(B) consider health disparities among in-
24 dividuals with congenital heart disease, which

1 *may include the consideration of prenatal expo-*
2 *sure.*

3 “(c) *AWARENESS CAMPAIGN.—The Secretary may*
4 *carry out awareness and educational activities related to*
5 *congenital heart disease in individuals of all ages, which*
6 *may include information for patients, family members, and*
7 *health care providers, on topics such as the prevalence of*
8 *such disease, the effect of such disease on individuals of all*
9 *ages, and the importance of long-term, specialized care for*
10 *individuals with such disease.*

11 “(d) *PUBLIC ACCESS.—The Secretary shall ensure*
12 *that, subject to subsection (e), information collected under*
13 *this section is made available, as appropriate, to the public,*
14 *including researchers.*

15 “(e) *PATIENT PRIVACY.—The Secretary shall ensure*
16 *that the data and information collected under this section*
17 *are made available in a manner that, at a minimum, pro-*
18 *TECTS personal privacy to the extent required by applicable*
19 *Federal and State law.*

20 “(f) *ELIGIBILITY FOR GRANTS.—To be eligible to re-*
21 *ceive a grant under subsection (a)(3), an entity shall—*

22 “(1) *be a public or private nonprofit entity with*
23 *specialized experience in congenital heart disease; and*

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

4 “(g) *AUTHORIZATION OF APPROPRIATIONS.*—To carry
 5 out this section, there are authorized to be appropriated
 6 \$10,000,000 for each of fiscal years 2020 through 2024.”.

7 **SEC. 3. REPORT.**

8 Not later than 3 years after the date of enactment of
 9 the Congenital Heart Futures Reauthorization Act of 2017,
 10 the Secretary of Health and Human Services shall submit
 11 to the Committee on Health, Education, Labor, and Pen-
 12 sions of the Senate and the Committee on Energy and Com-
 13 merce of the House of Representatives a report summarizing
 14 any activities carried out pursuant to section 399V–2 of
 15 the Public Health Service Act (as amended by section 2),
 16 including planned activities, and a summary of any re-
 17 search findings and ongoing research efforts, gaps, and
 18 areas of greatest need within the Department of Health and
 19 Human Services regarding congenital heart disease in pa-
 20 tients of all ages.

Attest:

Secretary.

115TH CONGRESS
2^D SESSION

H.R. 1222

AMENDMENT