

H. R. 1222

One Hundred Fifteenth Congress of the United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Wednesday,
the third day of January, two thousand and eighteen*

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.

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

This Act may be cited as the “Congenital Heart Futures Reauthorization Act of 2017”.

SEC. 2. NATIONAL CONGENITAL HEART DISEASE RESEARCH, SURVEILLANCE, AND AWARENESS.

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

“SEC. 399V–2. NATIONAL CONGENITAL HEART DISEASE RESEARCH, SURVEILLANCE, AND AWARENESS.

“(a) IN GENERAL.—The Secretary shall, as appropriate—

“(1) enhance and expand research and data collection efforts related to congenital heart disease, including to study and track the epidemiology of congenital heart disease to understand health outcomes for individuals with congenital heart disease across all ages;

“(2) conduct activities to improve public awareness of, and education related to, congenital heart disease, including care of individuals with such disease; and

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

“(b) ACTIVITIES.—

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

“(A) the incidence and prevalence of congenital heart disease in the United States;

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

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

“(D) demographic factors associated with congenital heart disease, such as age, race, ethnicity, sex, and family

history of individuals who are diagnosed with the disease; and

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

“(2) PERMISSIBLE CONSIDERATIONS.—In carrying out the activities under this section, the Secretary may, as appropriate—

“(A) collect data on the health outcomes, including behavioral and mental health outcomes, of a diverse population of individuals of all ages with congenital heart disease, such that analysis of the outcomes will inform evidence-based practices for individuals with congenital heart disease; and

“(B) consider health disparities among individuals with congenital heart disease, which may include the consideration of prenatal exposures.

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

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

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

“(f) ELIGIBILITY FOR GRANTS.—To be eligible to receive a grant under subsection (a)(3), an entity shall—

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

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

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

SEC. 3. REPORT.

Not later than 3 years after the date of enactment of the Congenital Heart Futures Reauthorization Act of 2017, the Secretary of Health and Human Services shall submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives a report summarizing any activities carried out pursuant to section 399V–2 of the Public Health Service Act (as amended by section 2), including planned activities, and a summary of any research findings and ongoing research efforts, gaps, and areas

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of greatest need within the Department of Health and Human
Services regarding congenital heart disease in patients of all ages.

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*