# Committee Print

[SHOWING THE TEXT OF H.R. 1222 AS FORWARDED BY THE SUBCOMMITTEE ON HEALTH ON MAY 18, 2017]

115TH CONGRESS
1ST SESSION

# H. R. 1222

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

---

# 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.

*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 SURVEILLANCE SYSTEM.

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—

“(1) enhance and expand research and surveillance infrastructure to study and track the epidemiology of congenital heart disease (in this section referred to as ‘CHD’); and

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

“(b) NATIONAL CONGENITAL HEART DISEASE STUDY.—

“(1) IN GENERAL.—The Secretary shall plan, develop, implement, and submit one or more reports to the Congress on a study to improve understanding of the epidemiology of CHD across the lifespan, from birth to adulthood, with particular interest in the following:

“(A) Health care utilization of those affected by CHD.

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

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

"(2) PERMISSIBLE CONSIDERATIONS.—The study under this subsection may—

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

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

"(C) incorporate behavioral, emotional, and educational outcomes of those affected by CHD.

"(3) PUBLIC ACCESS.—Data generated from the study under this subsection shall be made available—

"(A) for purposes of CHD research, subject to appropriate protections of personal privacy, including protections required by paragraph (4); and

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

"(4) PATIENT PRIVACY.—The Secretary shall ensure that the study under this subsection is carried out in a manner that complies with the requirements applicable to a covered entity under the regulations promulgated pursuant to section 264(c) of the Health Insurance Portability and Accountability Act of 1996.

"(c) ELIGIBILITY FOR GRANTS.—To be eligible to receive a grant under subsection (a)(2), an entity shall—

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

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

"(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there is authorized to be appropriated $4,000,000 for each of fiscal years 2018 through 2022.".

### SEC. 3. CONGENITAL HEART DISEASE RESEARCH.

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

**"SEC. 425. CONGENITAL HEART DISEASE.**

"(a) IN GENERAL.—The Director of the Institute may expand, intensify, and coordinate research and related activities of the Institute with respect to congenital heart disease, which may include congenital heart disease research with respect to—

"(1) causation of congenital heart disease, including genetic causes;

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

"(3) diagnosis, treatment, and prevention;

"(4) studies using longitudinal data and retrospective analysis to identify effective treatments and outcomes for individuals with congenital heart disease; and

"(5) identifying barriers to lifelong care for individuals with congenital heart disease.

"(b) COORDINATION OF RESEARCH ACTIVITIES.—The Director of the Institute may coordinate research efforts related to congenital heart disease among multiple research institutions and may develop research networks.

"(c) MINORITY AND MEDICALLY UNDERSERVED COMMUNITIES.—In carrying out the activities described in this section, the Director of the Institute shall consider the application of such research and other activities to minority and medically underserved communities.

"(d) REPORT FROM NIH.—Not later than one year after the date of the enactment of the Congenital Heart Futures Reauthorization Act of 2017, the Director of NIH, acting through the Director of the Institute, shall provide a report to Congress—

"(1) outlining the ongoing research efforts of the National Institutes of Health regarding congenital heart disease; and

"(2) identifying—

"(A) future plans for research regarding congenital heart disease; and

"(B) the areas of greatest need for such research.".