114TH CONGRESS  
1ST SESSION  

H. R.  

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  

Mr. BILIRAKIS introduced the following bill; which was referred to the Committee on ____________________________  

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.

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

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SECTION 1. SHORT TITLE. 

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This Act may be cited as the “Congenital Heart Futures Reauthorization Act of 2015”.

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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, acting through the Director of the Centers for Disease Control and Prevention, 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’);

"(2) plan and implement a public outreach and education campaign regarding CHD across the lifespan; and

"(3) award grants to eligible entities to undertake the activities described in subsections (b) and (c).

"(b) NATIONAL CONGENITAL HEART DISEASE COHORT STUDY.—

"(1) IN GENERAL.—The Director of the Centers for Disease Control and Prevention shall plan, develop, implement, and submit one or more reports to the Congress on a cohort study to improve understanding of the epidemiology of CHD across the life-
span, from birth to adulthood, with particular interest in the following:

“(A) Health care utilization and natural history 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.—Subject to paragraph (4), the data generated from the study under this
subsection shall be made available to the public, in-
cluding CHD researchers.

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

“(c) CONGENITAL HEART DISEASE AWARENESS
CAMPAIGN.—

“(1) IN GENERAL.—The Director of the Cen-
ters for Disease Control and Prevention shall estab-
lish and implement an awareness, outreach, and
education campaign regarding CHD across the life-
span. The information expressed through such cam-
paign shall—

“(A) emphasize that CHD is the most
prevalent birth defect;

“(B) identify CHD as a condition that af-
flicts those diagnosed throughout their lives;

“(C) promote the need for pediatric, ado-
lescent, and adult individuals with CHD to seek
and maintain lifelong, specialized care.
“(2) PERMISSIBLE ACTIVITIES.—The campaign under this subsection may—

“(A) utilize collaborations or partnerships with other agencies, health care professionals, and patient advocacy organizations that specialize in the needs of individuals with CHD; and

“(B) include the use of print, film, and electronic materials distributed via television, radio, Internet, and other commercial marketing venues.

“(d) 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 CHD; and

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

“(e) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there is authorized to be appropriated $4,000,000 for each of fiscal years 2016 through 2020.”.

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 life-long 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 mi-
nority and medically underserved communities.

“(d) REPORT FROM NIH.—Not later than 1 year
after the date of enactment of the Congenital Heart Fu-
tures Reauthorization Act of 2015, 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 con-
genital heart disease; and

“(2) identifying—

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

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