

115TH CONGRESS 2D SESSION

H.R. 1222

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,

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

- "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
- "(2) award grants to eligible entities to under-15 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:
- "(A) Health care utilization of those af-25 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:

"SEC. 425. CONGENITAL HEART DISEASE.

2	"(a) IN	GENERAL	.—The	Director	of th	ie Instit	tute
3	may expand,	intensify,	and co	ordinate	resear	ch 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;
- "(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
- 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 minority and medically underserved communities. 3 "(d) REPORT FROM NIH.—Not later than 1 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 8 9 the National Institutes of Health regarding congenital heart disease; and 10 "(2) identifying— 11 "(A) future plans for research regarding 12 13 congenital heart disease; and "(B) the areas of greatest need for such 14

Passed the House of Representatives February 26, 2018.

Attest:

research.".

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Clerk.

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