

1 “(1) IN GENERAL.—The Secretary shall plan,
2 develop, implement, and submit one or more reports
3 to the Congress on a study to improve under-
4 standing of the epidemiology of CHD across the life-
5 span, from birth to adulthood, with particular inter-
6 est in the following:

7 “(A) Health care utilization of those af-
8 fected by CHD.

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

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

17 “(2) PERMISSIBLE CONSIDERATIONS.—The
18 study under this subsection may—

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

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

1 “(C) incorporate behavioral, emotional,
2 and educational outcomes of those affected by
3 CHD.

4 “(3) PUBLIC ACCESS.—Data generated from
5 the study under this subsection shall be made avail-
6 able—

7 “(A) for purposes of CHD research, sub-
8 ject to appropriate protections of personal pri-
9 vacy, including protections required by para-
10 graph (4); and

11 “(B) to the public, subject to paragraph
12 (4) and with appropriate exceptions for protec-
13 tion of personal privacy.

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

21 “(c) ELIGIBILITY FOR GRANTS.—To be eligible to re-
22 ceive a grant under subsection (a)(2), an entity shall—

23 “(1) be a public or private nonprofit entity with
24 specialized experience in CHD; 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 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
5 carry out this section, there is authorized to be appro-
6 priated \$4,000,000 for each of fiscal years 2018 through
7 2022.”.

8 **SEC. 3. CONGENITAL HEART DISEASE RESEARCH.**

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

11 **“SEC. 425. CONGENITAL HEART DISEASE.**

12 “(a) IN GENERAL.—The Director of the Institute
13 may expand, intensify, and coordinate research and re-
14 lated activities of the Institute with respect to congenital
15 heart disease, which may include congenital heart disease
16 research with respect to—

17 “(1) causation of congenital heart disease, in-
18 cluding genetic causes;

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

22 “(3) diagnosis, treatment, and prevention;

23 “(4) studies using longitudinal data and retro-
24 spective analysis to identify effective treatments and

1 outcomes for individuals with congenital heart dis-
2 ease; and

3 “(5) identifying barriers to lifelong care for in-
4 dividuals with congenital heart disease.

5 “(b) COORDINATION OF RESEARCH ACTIVITIES.—

6 The Director of the Institute may coordinate research ef-
7 forts related to congenital heart disease among multiple
8 research institutions and may develop research networks.

9 “(c) MINORITY AND MEDICALLY UNDERSERVED
10 COMMUNITIES.—In carrying out the activities described in
11 this section, the Director of the Institute shall consider
12 the application of such research and other activities to mi-
13 nority and medically underserved communities.

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

19 “(1) outlining the ongoing research efforts of
20 the National Institutes of Health regarding con-
21 genital heart disease; and

22 “(2) identifying—

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

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

