Summary: Gives the Centers for Disease Control and Prevention the ability to establish or award a grant to establish the National Congenital Heart Disease Surveillance System. Also authorizes additional research related to congenital heart disease at the National Heart, Lung, and Blood Institute at the National Institutes of Health.

Next steps: Requires additional appropriations for further actions.

Additional information:
- Centers for Disease Control and Prevention (CDC) background on congenital heart defects, including information on its current state-based birth defects surveillance system in 31 states -- [http://www.cdc.gov/Features/HeartDefects/](http://www.cdc.gov/Features/HeartDefects/)
- CDC's Morbidity and Mortality Weekly Report (MMWR) article regarding racial differences in neonatal deaths attributable to congenital heart defects -- [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5937a3.htm?s_cid=mm5937a3_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5937a3.htm?s_cid=mm5937a3_w)
- National Institutes of Health Quick Links for Congenital Heart Disease -- [http://health.nih.gov/topic/CongenitalHeartDisease](http://health.nih.gov/topic/CongenitalHeartDisease)

Long summary:
Sec. 10411. Programs relating to congenital heart disease.
Allows the Secretary, acting through the Centers for Disease Control and Prevention, to establish or award a grant to establish the National Congenital Heart Disease Surveillance System. This surveillance system would track the epidemiology of congenital heart disease in a nationally-representative, population-based surveillance system. The purpose of this surveillance system would be to facilitate further research into the types of health services patients use and to identify possible areas for educational outreach and prevention. Allows the Director of the National Heart, Lung, and Blood Institute to 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 causation of congenital heart disease, including genetic causes; long-term outcomes in individuals with congenital heart disease, including infants, children, teenagers, adults, and elderly individuals; diagnosis, treatment, and prevention; studies using longitudinal data and retrospective analysis to identify effective treatments and outcomes for individuals with congenital heart disease; and identifying barriers to life-long care for individuals with congenital heart disease.

Authorization of appropriations. Authorizes such sums as may be necessary for each of the fiscal years 2011 through 2015.
Legislative text:

SEC. 10411. PROGRAMS RELATING TO CONGENITAL HEART DISEASE.

(a) SHORT TITLE.—This subtitle may be cited as the "Congenital Heart Futures Act".

(b) PROGRAMS RELATING TO CONGENITAL HEART DISEASE.—

(1) NATIONAL CONGENITAL HEART DISEASE SURVEILLANCE SYSTEM.—Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.), as amended by section 5405, is further amended by adding at the end the following:

"SEC. 399V–2. NATIONAL CONGENITAL HEART DISEASE SURVEILLANCE SYSTEM."

"(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may—

"(1) enhance and expand infrastructure to track the epidemiology of congenital heart disease and to organize such information into a nationally-representative, population-based surveillance system that compiles data concerning actual occurrences of congenital heart disease, to be known as the 'National Congenital Heart Disease Surveillance System'; or

"(2) award a grant to one eligible entity to undertake the activities described in paragraph (1)."

"(b) PURPOSE.—The purpose of the Congenital Heart Disease Surveillance System shall be to facilitate further research into the types of health services patients use and to identify possible areas for educational outreach and prevention in accordance with standard practices of the Centers for Disease Control and Prevention.

"(c) CONTENT.—The Congenital Heart Disease Surveillance System—

"(1) may include information concerning the incidence and prevalence of congenital heart disease in the United States;

"(2) may be used to collect and store data on congenital heart disease, including data concerning—

"(A) demographic factors associated with congenital heart disease, such as age, race, ethnicity, sex, and family history of individuals who are diagnosed with the disease;

"(B) risk factors associated with the disease;

"(C) causation of the disease;

"(D) treatment approaches; and

"(E) outcome measures, such that analysis of the outcome measures will allow derivation of evidence-based best practices and guidelines for congenital heart disease patients; and

"(3) may ensure the collection and analysis of longitudinal data related to individuals of all ages with congenital heart disease, including infants, young children, adolescents, and adults of all ages.

"(d) PUBLIC ACCESS.—The Congenital Heart Disease Surveillance System shall be made available to the public, as appropriate, including congenital heart disease researchers.

"(e) PATIENT PRIVACY.—The Secretary shall ensure that the Congenital Heart Disease Surveillance System is maintained in a manner that complies with the regulations promulgated under section 264 of the Health Insurance Portability and Accountability Act of 1996.

"(f) ELIGIBILITY FOR GRANT.—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 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.”

(2) CONGENITAL HEART DISEASE RESEARCH.—Subpart 2 of part C of title IV of the Public Health Service Act (42 U.S.C. 285b et seq.) is amended by adding at the end the following:

"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) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out the amendments made by this section such sums as may be necessary for each of fiscal years 2011 through 2015.