118TH CONGRESS
2d Session
HOUSE OF REPRESENTATIVES
REPORT
118–517

CONGENITAL HEART FUTURES REAUTHORIZATION ACT OF 2024

MAY 22, 2024.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mrs. RODGERS of Washington, from the Committee on Energy and Commerce, submitted the following

R E P O R T

[To accompany H.R. 7189]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 7189) to amend the Public Health Service Act to reauthorize a national congenital heart disease research, surveillance, and awareness program, and for other purposes, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

CONTENTS

The amendment is as follows:
Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "Congenital Heart Futures Reauthorization Act of 2024".

SEC. 2. REAUTHORIZATION OF NATIONAL CONGENITAL HEART DISEASE RESEARCH, SURVEILLANCE, AND AWARENESS PROGRAM.

Section 399V–2 of the Public Health Service Act (42 U.S.C. 280g–13) is amended—

(1) by redesignating subsections (f) and (g) as subsections (g) and (h), respectively;

(2) by inserting after subsection (e) the following:

"(f) REPORT AND STRATEGY.—

"(1) REPORT.—Not later than 2 years after the date of enactment of the Congenital Heart Futures Reauthorization Act of 2024, the Secretary shall issue a report to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate including the following:

"(A) A description of past and present activities of the Department of Health and Human Services to increase awareness and knowledge of the public with respect to congenital heart disease, including efforts to address the lifelong needs of congenital heart disease patients.

"(B) An assessment of past and present activities of the Department of Health and Human Services to increase education and training of health care providers with respect to congenital heart disease, including efforts to address the lifelong needs of congenital heart disease patients.

"(C) A description of the current workforce capacity in the United States of health care providers who treat adult patients living with congenital heart disease.

"(2) STRATEGY.—

"(A) DEVELOPMENT; SUBMISSION TO CONGRESS.—Not later than 1 year after submitting the report required by paragraph (1), the Secretary shall develop and submit to Congress a strategy for improving efforts to increase awareness and knowledge of the public and education and training of health care providers with respect to congenital heart disease. Such strategy shall include findings and recommendations to—

"(i) address any public awareness and research gaps and opportunities related to the lifelong needs of congenital heart disease patients, including long-term health outcomes, quality of life, mental health, and health care utilization;

"(ii) address any shortages in the current workforce of health care providers who treat adult patients living with congenital heart disease, which may include strategies to enhance fellowship training programs or other continuing education programs; and

"(iii) foster collaboration and dissemination of information across Federal agencies, health care providers, researchers, and patient organizations.

"(B) CONSULTATION.—In developing the strategy under subparagraph (A), the Secretary shall, as appropriate, consult with qualified stakeholder groups, including patient organizations, health care professionals, research entities, health insurance providers, accrediting organizations, and relevant Federal agencies, including the Centers for Disease Control and Prevention, the National Institutes of Health, and the Health Resources and Services Administration."; and

(3) in subsection (h), as so redesignated, by striking "2020 through 2024" and inserting "2025 through 2029".

PURPOSE AND SUMMARY

H.R. 7189 reauthorizes the national congenital heart disease research, surveillance, and awareness program at the Centers for Disease Control and Prevention (CDC). The bill also requires the Secretary to issue a report and strategy for improvement to Congress on activities related to congenital heart disease for both the public and health care providers, as well as the current workforce capacity of health care providers who treat adult patients living with congenital heart disease (CHD). The bill reauthorizes the program for five fiscal years from 2025 through 2029.

BACKGROUND AND NEED FOR LEGISLATION

The National Congenital Heart Disease Research, Surveillance, and Awareness Program supports the scientific understanding of congenital heart disease and the impact of heart defects at every stage of life through epidemiology, education for CHD patients and communities, and a workshop on research gaps and workforce. The information gained through this program is intended to develop lifelong, specialized care for patients with congenital heart defects. Heart defects are the most common type of birth defect, about 40,000 babies are born with a heart defect each year in the United States.[1] As medical care and treatments have advanced, people with heart defects are living longer and healthier lives; currently, it is estimated that more than 2 million people in the United States are living with a heart defect.[2]

COMMITTEE ACTION

On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 7189. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:

- Andy Shih, PhD, Chief Science Officer, Autism Speaks;
- Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
- Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
- Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;
- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

On March 12, 2024, the Subcommittee on Health met in open markup session and forwarded H.R. 7189, as amended, to the full Committee by a record vote of 24 yeas and 0 nays.

On March 20, 2024, the full Committee on Energy and Commerce met in open markup session and ordered H.R. 7189, as amended, favorably reported to the House by a record vote of 43 yeas and 0 nays.

COMMITTEE VOTES

Clause 3(b) of rule XIII requires the Committee to list the record votes on the motion to report legislation and amendments thereto. The following reflects the record votes taken during the Committee consideration:

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[1] Centers for Disease Control and Prevention, "Five Things To Know About Heart Defects", 2021. https://www.cdc.gov/ncbddd/heartdefects/materials/5-things-to-know.html#:~:text=Five%20Things%20To%20Know%20About%20Heart%20Defects%201,defects%20need%20lifelong%20specialty%20care%20for%20their%20hearts.

[2] *Id*.

COMMITTEE ON ENERGY AND COMMERCE
118TH CONGRESS
ROLL CALL VOTE # 18

BILL: H.R. 7189, Congenital Heart Futures Reauthorization Act of 2024

AMENDMENT: A motion by Chair Rodgers to order H.R. 7189 favorably reported to the House, as amended. (Final Passage)

DISPOSITION: **AGREED TO**, by a roll call vote of 43 yeas to 0 nays.

REPRESENTATIVE	YEAS	NAYS	PRESENT	REPRESENTATIVE	YEAS	NAYS	PRESENT
Rep. Rodgers	X			Rep. Pallone	X		
Rep. Burgess				Rep. Eshoo	X		
Rep. Latta	X			Rep. DeGette	X		
Rep. Guthrie	X			Rep. Schakowsky	X		
Rep. Griffith	X			Rep. Matsui	X		
Rep. Bilirakis	X			Rep. Castor	X		
Rep. Bucshon	X			Rep. Sarbanes	X		
Rep. Hudson	X			Rep. Tonko	X		
Rep. Walberg	X			Rep. Clarke			
Rep. Carter	X			Rep. Cárdenas	X		
Rep. Duncan	X			Rep. Ruiz	X		
Rep. Palmer				Rep. Peters	X		
Rep. Dunn	X			Rep. Dingell	X		
Rep. Curtis				Rep. Veasey	X		
Rep. Lesko	X			Rep. Kuster			
Rep. Pence	X			Rep. Kelly			
Rep. Crenshaw	X			Rep. Barragán	X		
Rep. Joyce	X			Rep. Blunt Rochester			
Rep. Armstrong				Rep. Soto	X		
Rep. Weber	X			Rep. Craig	X		
Rep. Allen	X			Rep. Schrier	X		
Rep. Balderson	X			Rep. Trahan	X		
Rep. Fulcher	X			Rep. Fletcher	X		
Rep. Pfluger	X						
Rep. Harshbarger	X						
Rep. Miller-Meeks	X						
Rep. Cammack	X						
Rep. Obernolte	X						

03/20/2024

OVERSIGHT FINDINGS AND RECOMMENDATIONS

Pursuant to clause 2(b)(1) of rule X and clause 3(c)(1) of rule XIII, the Committee held a hearing and made findings that are reflected in this report.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Pursuant to clause 3(c)(2) of rule XIII, the Committee finds that H.R. 7189 would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII, at the time this report was filed, the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974 was not available.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to continue to support efforts that improve scientific understanding and public awareness of congenital heart disease.

DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 7189 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111–139 or the most recent Catalog of Federal Domestic Assistance.

RELATED COMMITTEE AND SUBCOMMITTEE HEARINGS

Pursuant to clause 3(c)(6) of rule XIII, the following related hearing was used to develop or consider H.R. 7189:

- On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 7189. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:
  - Andy Shih, PhD, Chief Science Officer, Autism Speaks;
  - Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
  - Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
  - Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein Col-

lege of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;

- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

COMMITTEE COST ESTIMATE

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974. At the time this report was filed, the estimate was not available.

EARMARK, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 7189 contains no earmarks, limited tax benefits, or limited tariff benefits.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 provides that the Act may be cited as the "Congenital Heart Futures Reauthorization Act of 2024".

Section 2. Reauthorization of national congenital heart disease research, surveillance, and awareness program

Section 2 reauthorizes a national congenital heart disease program. This section also requires the Secretary of Health and Human Services (HHS) to issue a report to Congress within two years of the bill's enactment. The report must include a description and assessment of past and present activities at HHS, as well as current CHD workforce capacity needs. In the following year after report submission, a national strategy is required to be submitted to Congress detailing efforts to improve public awareness and train care providers on congenital heart disease must be submitted as well.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics, and existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

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TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

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PART P—ADDITIONAL PROGRAMS

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SEC. 399V–2. NATIONAL CONGENITAL HEART DISEASE RESEARCH, SURVEILLANCE, AND AWARENESS.

(a) IN GENERAL.—The Secretary shall, as appropriate—

(1) enhance and expand research and data collection efforts related to congenital heart disease, including to study and track the epidemiology of congenital heart disease to understand health outcomes for individuals with congenital heart disease across all ages;

(2) conduct activities to improve public awareness of, and education related to, congenital heart disease, including care of individuals with such disease; and

(3) award grants to entities to undertake the activities described in this section.

(b) ACTIVITIES.—

(1) IN GENERAL.—The Secretary shall carry out activities, including, as appropriate, through a national cohort study and a nationally-representative, population-based surveillance system, to improve the understanding of the epidemiology of congenital heart disease in all age groups, with particular attention to—

(A) the incidence and prevalence of congenital heart disease in the United States;

(B) causation and risk factors associated with, and natural history of, congenital heart disease;

(C) health care utilization by individuals with congenital heart disease;

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

(E) evidence-based practices related to care and treatment for individuals with congenital heart disease.

(2) PERMISSIBLE CONSIDERATIONS.—In carrying out the activities under this section, the Secretary may, as appropriate—

(A) collect data on the health outcomes, including behavioral and mental health outcomes, of a diverse population of individuals of all ages with congenital heart disease, such that analysis of the outcomes will inform evidence-based practices for individuals with congenital heart disease; and

(B) consider health disparities among individuals with congenital heart disease, which may include the consideration of prenatal exposures.

(c) AWARENESS CAMPAIGN.—The Secretary may carry out awareness and educational activities related to congenital heart disease in individuals of all ages, which may include information for patients, family members, and health care providers, on topics such as the prevalence of such disease, the effect of such disease on individuals of all ages, and the importance of long-term, specialized care for individuals with such disease.

(d) PUBLIC ACCESS.—The Secretary shall ensure that, subject to subsection (e), information collected under this section is made available, as appropriate, to the public, including researchers.

(e) PATIENT PRIVACY.—The Secretary shall ensure that the data and information collected under this section are made available in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law.

(f) REPORT AND STRATEGY.—

(1) REPORT.—Not later than 2 years after the date of enactment of the Congenital Heart Futures Reauthorization Act of 2024, the Secretary shall issue a report to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate including the following:

(A) A description of past and present activities of the Department of Health and Human Services to increase awareness and knowledge of the public with respect to congenital heart disease, including efforts to address the lifelong needs of congenital heart disease patients.

(B) An assessment of past and present activities of the Department of Health and Human Services to increase education and training of health care providers with respect to congenital heart disease, including efforts to address the lifelong needs of congenital heart disease patients.

(C) A description of the current workforce capacity in the United States of health care providers who treat adult patients living with congenital heart disease.

(2) STRATEGY.—

(A) DEVELOPMENT; SUBMISSION TO CONGRESS.—Not later than 1 year after submitting the report required by paragraph (1), the Secretary shall develop and submit to Congress a strategy for improving efforts to increase awareness and knowledge of the public and education and training of health care providers with respect to congenital heart disease. Such strategy shall include findings and recommendations to—

(i) address any public awareness and research gaps and opportunities related to the lifelong needs of congenital heart disease patients, including long-term

health outcomes, quality of life, mental health, and health care utilization;

(ii) address any shortages in the current workforce of health care providers who treat adult patients living with congenital heart disease, which may include strategies to enhance fellowship training programs or other continuing education programs; and

(iii) foster collaboration and dissemination of information across Federal agencies, health care providers, researchers, and patient organizations.

(B) CONSULTATION.—In developing the strategy under subparagraph (A), the Secretary shall, as appropriate, consult with qualified stakeholder groups, including patient organizations, health care professionals, research entities, health insurance providers, accrediting organizations, and relevant Federal agencies, including the Centers for Disease Control and Prevention, the National Institutes of Health, and the Health Resources and Services Administration.

[(f)**]** *(g)* 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 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.

[(g)**]** *(h)* AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated $10,000,000 for each of fiscal years **[**2020 through 2024**]** *2025 through 2029*.

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