

Calendar No. 429

118TH CONGRESS
2D SESSION**S. 3757**

To reauthorize the congenital heart disease research, surveillance, and awareness program of the Centers for Disease Control and Prevention, and for other purposes.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 7, 2024

Mr. DURBIN (for himself, Mr. YOUNG, Mr. CASEY, Ms. SMITH, and Mrs. GILLIBRAND) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

JUNE 18, 2024

Reported by Mr. SANDERS, with an amendment

[Strike out all after the enacting clause and insert the part printed in *italic*]

A BILL

To reauthorize the congenital heart disease research, surveillance, and awareness program of the Centers for Disease Control and Prevention, 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,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Congenital Heart Fu-
5 tures Reauthorization Act of 2024”.

1 **SEC. 2. NATIONAL CONGENITAL HEART DISEASE RE-**
 2 **SEARCH, SURVEILLANCE, AND AWARENESS.**

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

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

7 (2) by inserting after subsection (e) the fol-
 8 lowing:

9 “(f) **STAKEHOLDER WORKSHOP.**—

10 “(1) **IN GENERAL.**—Not later than 1 year after
 11 the date of enactment of the Congenital Heart Fu-
 12 tures Reauthorization Act of 2024, the Secretary
 13 shall convene a workshop composed of subject mat-
 14 ter experts, on adult patients living with congenital
 15 heart disease, to—

16 “(A) identify research gaps and opportuni-
 17 ties related to the lifelong needs of congenital
 18 heart disease patients, including long-term
 19 health outcomes, quality of life, mental health,
 20 and health care utilization;

21 “(B) assess the workforce capacity in the
 22 United States of health care providers who
 23 treat adult patients living with congenital heart
 24 disease, and options to address any such short-
 25 ages in such workforce, which may include

1 strategies to expand fellowship training pro-
2 grams and support regional care centers; and

3 ~~“(C) foster collaboration and dissemination~~
4 ~~of information across Federal agencies, health~~
5 ~~care providers, researchers, and patient organi-~~
6 ~~zations.~~

7 ~~“(2) COMPOSITION.—The workshop described~~
8 ~~in paragraph (1) shall be led by the Secretary, and~~
9 ~~shall involve participants that include, as appro-~~
10 ~~priate, stakeholders representing patient organiza-~~
11 ~~tions, health care professionals, research entities,~~
12 ~~health insurance providers, accrediting organiza-~~
13 ~~tions, and relevant Federal agencies, including the~~
14 ~~Centers for Disease Control and Prevention, the Na-~~
15 ~~tional Institutes of Health, and the Health Re-~~
16 ~~sources and Services Administration.~~

17 ~~“(g) REPORT.—Not later than 3 years after the date~~
18 ~~of enactment of the Congenital Heart Futures Reauthor-~~
19 ~~ization Act of 2024, the Secretary shall issue a report to~~
20 ~~the Committee on Health, Education, Labor, and Pen-~~
21 ~~sions of the Senate and the Committee on Energy and~~
22 ~~Commerce of the House of Representatives on findings~~
23 ~~and recommendations of the Secretary with respect to~~
24 ~~strategies to advance research related to the lifelong needs~~
25 ~~of congenital heart disease patients and address workforce~~

1 shortages of providers for adult patients living with con-
 2 genital heart disease, and, as appropriate, progress made
 3 by the Secretary to implement such strategies and a plan
 4 for implementing such recommendations.”; and

5 (3) in subsection (i), as so redesignated, by
 6 striking “2020 through 2024” and inserting “2025
 7 through 2029”.

8 **SECTION 1. SHORT TITLE.**

9 *This Act may be cited as the “Congenital Heart Fu-*
 10 *tures Reauthorization Act of 2024”.*

11 **SEC. 2. NATIONAL CONGENITAL HEART DISEASE RE-**
 12 **SEARCH, SURVEILLANCE, AND AWARENESS.**

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

15 (1) *by redesignating subsections (f) and (g) as*
 16 *subsections (h) and (i), respectively;*

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

18 “(f) **STAKEHOLDER WORKSHOP.**—

19 “(1) **IN GENERAL.**—*Not later than 1 year after*
 20 *the date of enactment of the Congenital Heart Futures*
 21 *Reauthorization Act of 2024, the Secretary shall con-*
 22 *vene a workshop on congenital heart disease, to—*

23 “(A) *identify research gaps and opportuni-*
 24 *ties related to the needs of adults with congenital*
 25 *heart disease, including with respect to long-term*

1 *health outcomes, quality of life, mental health,*
2 *and health care utilization;*

3 “(B) *assess the workforce capacity in the*
4 *United States to treat adults with congenital*
5 *heart disease, and options to address any short-*
6 *ages in such workforce, which may include strat-*
7 *egies related to fellowship training programs;*
8 *and*

9 “(C) *foster collaboration and dissemination*
10 *of information related to congenital heart disease*
11 *among Federal agencies, health care providers,*
12 *researchers, patient advocates, and other relevant*
13 *stakeholders.*

14 “(2) *COMPOSITION.—The workshop described in*
15 *paragraph (1) shall include relevant stakeholders,*
16 *such as patient advocates, health care providers, re-*
17 *searchers, and health insurance issuers, and rep-*
18 *resentatives of relevant Federal agencies, including*
19 *the Centers for Disease Control and Prevention, the*
20 *National Institutes of Health, and the Health Re-*
21 *sources and Services Administration.*

22 “(g) *REPORT.—Not later than 3 years after the date*
23 *of enactment of the Congenital Heart Futures Reauthoriza-*
24 *tion Act of 2024, the Secretary shall issue a report to the*
25 *Committee on Health, Education, Labor, and Pensions of*

1 *the Senate and the Committee on Energy and Commerce*
2 *of the House of Representatives on findings and rec-*
3 *ommendations of the Secretary with respect to strategies to*
4 *advance research related to the needs of individuals of all*
5 *ages with congenital heart disease and address workforce*
6 *shortages of providers for adults with congenital heart dis-*
7 *ease, and, as appropriate, a plan for implementing such*
8 *strategies, including any progress to date.”; and*
9 *(3) in subsection (i), as so redesignated, by strik-*
10 *ing “2020 through 2024” and inserting “2025*
11 *through 2029”.*

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