

Union Calendar No. 258

115TH CONGRESS
1ST SESSION

H. R. 2410

[Report No. 115-354]

To amend the Public Health Service Act to reauthorize a sickle cell disease prevention and treatment demonstration program and to provide for sickle cell disease research, surveillance, prevention, and treatment.

IN THE HOUSE OF REPRESENTATIVES

MAY 11, 2017

Mr. DANNY K. DAVIS of Illinois (for himself and Mr. BURGESS) introduced the following bill; which was referred to the Committee on Energy and Commerce

OCTOBER 19, 2017

Additional sponsor: Mr. BUTTERFIELD

OCTOBER 19, 2017

Committed to the Committee of the Whole House on the State of the Union
and ordered to be printed

A BILL

To amend the Public Health Service Act to reauthorize a sickle cell disease prevention and treatment demonstration program and to provide for sickle cell disease research, surveillance, prevention, and treatment.

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; TABLE OF CONTENTS.**

4 (a) **SHORT TITLE.**—This Act may be cited as the
 5 “Sickle Cell Disease Research, Surveillance, Prevention,
 6 and Treatment Act of 2017”.

7 (b) **TABLE OF CONTENTS.**—The table of contents of
 8 this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Sickle cell disease research.
- Sec. 3. Sickle cell disease surveillance.
- Sec. 4. Sickle cell disease prevention and treatment.
- Sec. 5. Collaboration with community-based entities.

9 **SEC. 2. SICKLE CELL DISEASE RESEARCH.**

10 Part P of title III of the Public Health Service Act
 11 is amended by inserting after section 399V–6 (42 U.S.C.
 12 280g–17) the following:

13 **“SEC. 399V-7. NATIONAL SICKLE CELL DISEASE RESEARCH,**
 14 **SURVEILLANCE, PREVENTION, AND TREAT-**
 15 **MENT PROGRAM.**

16 “(a) **RESEARCH.**—The Secretary may conduct or
 17 support research to expand the understanding of the cause
 18 of, and to find a cure for, sickle cell disease.”.

19 **SEC. 3. SICKLE CELL DISEASE SURVEILLANCE.**

20 Section 399V–7 of the Public Health Service Act, as
 21 added by section 2, is amended by adding at the end the
 22 following:

23 “(b) **SURVEILLANCE.**—

1 “(1) GRANTS.—The Secretary may, for each
2 fiscal year for which appropriations are available to
3 carry out this subsection, make grants to not more
4 than 20 States—

5 “(A) to conduct surveillance and maintain
6 data on the prevalence and distribution of sickle
7 cell disease and its associated health outcomes,
8 complications, and treatments;

9 “(B) to conduct public health initiatives
10 with respect to sickle cell disease, including—

11 “(i) increasing efforts to improve ac-
12 cess to, and receipt of, high-quality sickle
13 cell disease-related health care, including
14 the use of treatments approved under sec-
15 tion 505 of the Federal Food, Drug, and
16 Cosmetic Act or licensed under section 351
17 of this Act;

18 “(ii) working with partners to improve
19 health outcomes of people with sickle cell
20 disease over the lifespan by promoting
21 guidelines for sickle cell disease screening,
22 prevention, and treatment, including man-
23 agement of sickle cell disease complica-
24 tions;

1 “(iii) providing support to community-
2 based organizations and State and local
3 health departments in conducting sickle
4 cell disease education and training activi-
5 ties for patients, communities, and health
6 care providers; and

7 “(iv) supporting and training State
8 health departments and regional labora-
9 tories in comprehensive testing to identify
10 specific forms of sickle cell disease in peo-
11 ple of all ages; and

12 “(C) to identify and evaluate promising
13 strategies for prevention and treatment of sickle
14 cell disease complications, including through—

15 “(i) improving estimates of the na-
16 tional incidence and prevalence of sickle
17 cell disease, including estimates about the
18 specific types of sickle cell disease;

19 “(ii) identifying health disparities re-
20 lated to sickle cell disease;

21 “(iii) assessing the utilization of
22 therapies and strategies to prevent com-
23 plications related to sickle cell disease; and

24 “(iv) evaluating the impact of genetic,
25 environmental, behavioral, and other risk

1 factors that may affect sickle cell disease
2 health outcomes.

3 “(2) POPULATION INCLUDED.—The Secretary
4 shall, to the extent practicable, award grants under
5 this subsection to States across the United States so
6 as to include data on the majority of the United
7 States population with sickle cell disease.

8 “(3) APPLICATION.—To seek a grant under this
9 subsection, a State shall submit an application to
10 the Secretary at such time, in such manner, and
11 containing such information as the Secretary may
12 require.

13 “(4) DEFINITIONS.—In this subsection:

14 “(A) The term ‘Secretary’ means the Sec-
15 retary of Health and Human Services, acting
16 through the Director of the National Center on
17 Birth Defects and Developmental Disabilities.

18 “(B) The term ‘State’ includes the 50
19 States, the District of Columbia, the Common-
20 wealth of Puerto Rico, the United States Virgin
21 Islands, the Commonwealth of the Northern
22 Mariana Islands, American Samoa, Guam, the
23 Federated States of Micronesia, the Republic of
24 the Marshall Islands, and the Republic of
25 Palau.”.

1 **SEC. 4. SICKLE CELL DISEASE PREVENTION AND TREAT-**
2 **MENT.**

3 (a) REAUTHORIZATION.—Section 712(c) of the
4 American Jobs Creation Act of 2004 (Public Law 108–
5 357; 42 U.S.C. 300b–1 note) is amended—

6 (1) by striking “Sickle Cell Disease” each place
7 it appears and inserting “sickle cell disease”;

8 (2) in paragraph (1)(A), by striking “grants to
9 up to 40 eligible entities for each fiscal year in which
10 the program is conducted under this section for the
11 purpose of developing and establishing systemic
12 mechanisms to improve the prevention and treat-
13 ment of Sickle Cell Disease” and inserting “grants
14 to up to 25 eligible entities for each fiscal year in
15 which the program is conducted under this section
16 for the purpose of developing and establishing sys-
17 temic mechanisms to improve the prevention and
18 treatment of sickle cell disease in populations with
19 a high density of sickle cell disease patients”;

20 (3) in paragraph (1)(B)—

21 (A) by striking clause (ii) (relating to pri-
22 ority); and

23 (B) by striking “GRANT AWARD REQUIRE-
24 MENTS” and all that follows through “The Ad-
25 ministrator shall” and inserting “GEOGRAPHIC
26 DIVERSITY.—The Administrator shall”;

1 (4) in paragraph (2), by adding the following
2 new subparagraph at the end:

3 “(E) To expand, coordinate, and imple-
4 ment transition services for adolescents with
5 sickle cell disease making the transition to adult
6 health care.”; and

7 (5) in paragraph (6), by striking “\$10,000,000
8 for each of fiscal years 2005 through 2009” and in-
9 serting “\$4,455,000 for each of fiscal years 2018
10 through 2022”.

11 (b) TECHNICAL CHANGES.—Subsection (e) of section
12 712 of the American Jobs Creation Act of 2004 (Public
13 Law 108–357; 42 U.S.C. 300b–1 note), as amended by
14 subsection (a), is—

15 (1) transferred to the Public Health Service Act
16 (42 U.S.C. 201 et seq.); and

17 (2) inserted at the end of section 399V–7 of
18 such Act, as added and amended by sections 2 and
19 3 of this Act.

20 **SEC. 5. COLLABORATION WITH COMMUNITY-BASED ENTI-**
21 **TIES.**

22 Section 399V–7 of the Public Health Service Act, as
23 amended by section 4, is further amended by adding at
24 the end the following:

1 “(d) COLLABORATION WITH COMMUNITY-BASED EN-
2 TITIES.—To be eligible to receive a grant or other assist-
3 ance under subsection (b) or (c), an entity must have in
4 effect a collaborative agreement with a community-based
5 organization with 5 or more years of experience in pro-
6 viding services to sickle cell disease patients.”.

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