

115TH CONGRESS
2D SESSION

S. 2465

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 SENATE OF THE UNITED STATES

FEBRUARY 28, 2018

Mr. SCOTT (for himself and Mr. BOOKER) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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 2018”.

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. Sense of the Senate.
- Sec. 3. Sickle cell disease surveillance.
- Sec. 4. Sickle cell disease prevention and treatment.
- Sec. 5. Collaboration with community-based entities.

1 SEC. 2. SENSE OF THE SENATE.

2 It is the Sense of the Senate that further research
3 should be undertaken to expand the understanding of the
4 cause of, and to find a cure for, sickle cell disease.

5 SEC. 3. SICKLE CELL DISEASE SURVEILLANCE.

6 Part P of title III of the Public Health Service Act
7 is amended by inserting after section 399V–6 (42 U.S.C.
8 280g–17) the following:

9 **“SEC. 399V–7. NATIONAL SICKLE CELL DISEASE SURVEIL-**
10 **LANCE, PREVENTION, AND TREATMENT PRO-**
11 **GRAM.**

12 **“(a) SURVEILLANCE.—**

13 **“(1) GRANTS.—**The Secretary may, for each
14 fiscal year for which appropriations are available to
15 carry out this subsection, make grants to not more
16 than 20 eligible entities for the following purposes:

17 **“(A)** To conduct surveillance and maintain
18 data on the prevalence and distribution of sickle
19 cell disease and its associated health outcomes,
20 complications, and treatments.

21 **“(B)** To conduct public health initiatives
22 with respect to sickle cell disease, including one
23 or more of the following:

1 “(i) Increasing efforts to improve ac-
2 cess to high-quality sickle cell disease-re-
3 lated health care, including the use of
4 treatments approved under section 505 of
5 the Federal Food, Drug, and Cosmetic Act
6 or licensed under section 351 of this Act.

7 “(ii) Working with partners to im-
8 prove health outcomes of people with sickle
9 cell disease over the lifespan by promoting
10 guidelines for sickle cell disease screening,
11 prevention, and treatment, including man-
12 agement of sickle cell disease complica-
13 tions.

14 “(iii) Providing support to commu-
15 nity-based organizations and State and
16 local health departments in conducting
17 sickle cell disease education and training
18 activities for patients, communities, and
19 health care providers.

20 “(iv) Supporting and training State
21 health departments and regional labora-
22 tories in comprehensive testing to identify
23 specific forms of sickle cell disease in peo-
24 ple of all ages.

1 “(C) To identify and evaluate promising
2 strategies for prevention and treatment of sickle
3 cell disease complications, including through
4 one or more of the following:

5 “(i) Improving estimates of the na-
6 tional incidence and prevalence of sickle
7 cell disease, including estimates about the
8 specific types of sickle cell disease.

9 “(ii) Identifying health disparities re-
10 lated to sickle cell disease.

11 “(iii) Assessing the utilization of
12 therapies and strategies to prevent com-
13 plications related to sickle cell disease.

14 “(iv) Evaluating the impact of ge-
15 netic, environmental, behavioral, and other
16 risk factors that may affect sickle cell dis-
17 ease health outcomes.

18 “(2) POPULATION INCLUDED.—The Secretary
19 shall, to the extent practicable, award grants under
20 this subsection to eligible entities across the United
21 States so as to include data on the majority of the
22 United States population with sickle cell disease.

23 “(3) APPLICATION.—To seek a grant under this
24 subsection, an eligible entity shall submit an applica-
25 tion to the Secretary at such time, in such manner,

1 and containing such information as the Secretary
2 may require.

3 “(4) ELIGIBLE ENTITY.—In this subsection, the
4 term ‘eligible entity’ includes the 50 States, the Dis-
5 trict of Columbia, the Commonwealth of Puerto
6 Rico, the United States Virgin Islands, the Com-
7 monwealth of the Northern Mariana Islands, Amer-
8 ican Samoa, Guam, the Federated States of Micro-
9 nesia, the Republic of Marshall Islands, the Republic
10 of Palau, a State health or public health depart-
11 ment, an institution of higher education, or a non-
12 profit entity.”.

13 **SEC. 4. SICKLE CELL DISEASE PREVENTION AND TREAT-**
14 **MENT.**

15 (a) REAUTHORIZATION.—Section 712(c) of the
16 American Jobs Creation Act of 2004 (Public Law 108–
17 357; 42 U.S.C. 300b–1 note) is amended—

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

20 (2) in paragraph (1)(A), by striking “grants to
21 up to 40 eligible entities for each fiscal year in which
22 the program is conducted under this section for the
23 purpose of developing and establishing systemic
24 mechanisms to improve the prevention and treat-
25 ment of Sickle Cell Disease” and inserting “grants

1 to up to 25 eligible entities for each fiscal year in
 2 which the program is conducted under this section
 3 for the purpose of developing and establishing sys-
 4 temic mechanisms to improve the prevention and
 5 treatment of sickle cell disease in populations with
 6 a high density of sickle cell disease patients”;

7 (3) in paragraph (1)(B)—

8 (A) by striking clause (ii) (relating to pri-
 9 ority); and

10 (B) by striking “GRANT AWARD REQUIRE-
 11 MENTS” and all that follows through “The Ad-
 12 ministrator shall” and inserting “GEOGRAPHIC
 13 DIVERSITY.—The Administrator shall”;

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

16 “(E) To expand, coordinate, and imple-
 17 ment transition services for adolescents with
 18 sickle cell disease making the transition to adult
 19 health care.”; and

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

24 (b) TECHNICAL CHANGES.—Subsection (c) of section
 25 712 of the American Jobs Creation Act of 2004 (Public

1 Law 108–357; 42 U.S.C. 300b–1 note), as amended by
 2 subsection (a), is—

3 (1) transferred to the Public Health Service Act
 4 (42 U.S.C. 201 et seq.);

5 (2) redesignated as subsection (b); and

6 (3) inserted at the end of section 399V–7 of
 7 such Act, as added by section 2 of this Act.

8 **SEC. 5. COLLABORATION WITH COMMUNITY-BASED ENTI-**
 9 **TIES.**

10 Section 399V–7 of the Public Health Service Act, as
 11 amended by section 3, is further amended by adding at
 12 the end the following:

13 “(c) COLLABORATION WITH COMMUNITY-BASED EN-
 14 TITIES.—To be eligible to receive a grant or other assist-
 15 ance under subsection (a) or (b), an eligible entity must
 16 have in effect a collaborative agreement with a commu-
 17 nity-based organization with five or more years of experi-
 18 ence in providing services to sickle cell disease patients.”.

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