

115TH CONGRESS
2D SESSION

S. 2465

AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Sickle Cell Disease
3 and Other Heritable Blood Disorders Research, Surveil-
4 lance, Prevention, and Treatment Act of 2018”.

5 **SEC. 2. DATA COLLECTION ON CERTAIN BLOOD DIS-**
6 **ORDERS.**

7 Part A of title XI of the Public Health Service Act
8 is amended by inserting after section 1105 (42 U.S.C.
9 300b–4) the following:

10 **“SEC. 1106. SICKLE CELL DISEASE AND OTHER HERITABLE**
11 **BLOOD DISORDERS RESEARCH, SURVEIL-**
12 **LANCE, PREVENTION, AND TREATMENT.**

13 “(a) GRANTS.—

14 “(1) IN GENERAL.—The Secretary may award
15 grants related to heritable blood disorders, including
16 sickle cell disease, for one or more of the following
17 purposes:

18 “(A) To collect and maintain data on such
19 diseases and conditions, including subtypes as
20 applicable, and their associated health outcomes
21 and complications, including for the purpose
22 of—

23 “(i) improving national incidence and
24 prevalence data;

1 “(ii) identifying health disparities, in-
2 cluding the geographic distribution, related
3 to such diseases and conditions;

4 “(iii) assessing the utilization of
5 therapies and strategies to prevent com-
6 plications; and

7 “(iv) evaluating the effects of genetic,
8 environmental, behavioral, and other risk
9 factors that may affect such individuals.

10 “(B) To conduct public health activities
11 with respect to such conditions, which may in-
12 clude—

13 “(i) developing strategies to improve
14 health outcomes and access to quality
15 health care for the screening for, and
16 treatment and management of, such dis-
17 eases and conditions, including through
18 public-private partnerships;

19 “(ii) providing support to community-
20 based organizations and State and local
21 health departments in conducting edu-
22 cation and training activities for patients,
23 communities, and health care providers
24 concerning such diseases and conditions;

“(iii) supporting State health departments and regional laboratories, including through training, in testing to identify such diseases and conditions, including specific forms of sickle cell disease, in individuals of all ages; and

“(iv) the identification and evaluation of best practices for treatment of such diseases and conditions, and prevention and management of their related complications.

“(2) POPULATION INCLUDED.—The Secretary shall, to the extent practicable, award grants under this subsection to eligible entities across the United States to improve data on the incidence and prevalence of heritable blood disorders, including sickle cell disease, and the geographic distribution of such diseases and conditions.

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

“(4) PRIORITY.—In awarding grants under this subsection, the Secretary may give priority, as appropriate, to eligible entities that have a relationship

1 with a community-based organization that has expe-
 2 rience in, or is capable of, providing services to indi-
 3 viduals with heritable blood disorders, including sick-
 4 le cell disease.

5 “(5) ELIGIBLE ENTITY.—In this subsection, the
 6 term ‘eligible entity’ includes the 50 States, the Dis-
 7 trict of Columbia, the Commonwealth of Puerto
 8 Rico, the United States Virgin Islands, the Com-
 9 monwealth of the Northern Mariana Islands, Amer-
 10 ican Samoa, Guam, the Federated States of Micro-
 11 nesia, the Republic of Marshall Islands, the Republic
 12 of Palau, Indian tribes, a State or local health de-
 13 partment, an institution of higher education, or a
 14 nonprofit entity with appropriate experience to con-
 15 duct the activities under this subsection.”.

16 **SEC. 3. SICKLE CELL DISEASE PREVENTION AND TREAT-**
 17 **MENT.**

18 (a) REAUTHORIZATION.—Section 712(c) of the
 19 American Jobs Creation Act of 2004 (Public Law 108–
 20 357; 42 U.S.C. 300b–1 note) is amended—

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

23 (2) in paragraph (1)(A), by striking “shall con-
 24 duct a demonstration program by making grants to
 25 up to 40 eligible entities for each fiscal year in which

1 the program is conducted under this section for the
2 purpose of developing and establishing systemic
3 mechanisms to improve the prevention and treat-
4 ment of Sickle Cell Disease” and inserting “shall
5 continue efforts, including by awarding grants, to
6 develop or establish mechanisms to improve the
7 treatment of sickle cell disease, and to improve the
8 prevention and treatment of complications of sickle
9 cell disease, in populations with a high proportion of
10 individuals with sickle cell disease”;

11 (3) in paragraph (1)(B)—

12 (A) by striking clause (ii) (relating to pri-
13 ority); and

14 (B) by striking “GRANT AWARD REQUIRE-
15 MENTS” and all that follows through “The Ad-
16 ministrator shall” and inserting “GEOGRAPHIC
17 DIVERSITY.—The Administrator shall”;

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

20 “(E) To provide or coordinate services for
21 adolescents with sickle cell disease making the
22 transition to adult health care.”; and

23 (5) in paragraph (6), by striking “\$10,000,000
24 for each of fiscal years 2005 through 2009” and in-

1 serting “\$4,455,000 for each of fiscal years 2019
2 through 2023”.

3 (b) TECHNICAL CHANGES.—Subsection (c) of section
4 712 of the American Jobs Creation Act of 2004 (Public
5 Law 108–357; 42 U.S.C. 300b–1 note), as amended by
6 subsection (a), is—

7 (1) transferred to the Public Health Service Act
8 (42 U.S.C. 201 et seq.);

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

10 (3) inserted at the end of section 1106 of such
11 Act, as added by section 2 of this Act.

12 **SEC. 4. SENSE OF THE SENATE.**

13 It is the Sense of the Senate that further research
14 should be undertaken to expand the understanding of the
15 causes of, and to find cures for, heritable blood disorders,
16 including sickle cell disease.

Passed the Senate October 11, 2018.

Attest:

Secretary.

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