PUBLIC LAW 115–327—DEC. 18, 2018

SICKLE CELL DISEASE AND OTHER HERITABLE BLOOD DISORDERS RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT ACT OF 2018

Public Law 115–327
115th Congress

An Act

Dec. 18, 2018
[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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018.
42 USC 201 note.

SECTION 1. SHORT TITLE.

This Act may be cited as the “Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018”.

SEC. 2. DATA COLLECTION ON CERTAIN BLOOD DISORDERS.

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

42 USC 300b–5.

“SEC. 1106. SICKLE CELL DISEASE AND OTHER HERITABLE BLOOD DISORDERS RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT.

“(a) GRANTS.—

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

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

“(i) improving national incidence and prevalence data;

“(ii) identifying health disparities, including the geographic distribution, related to such diseases and conditions;

Assessment.

“(iii) assessing the utilization of therapies and strategies to prevent complications; and

Evaluation.

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

“(B) To conduct public health activities with respect to such conditions, which may include—

Strategies.

“(i) developing strategies to improve health outcomes and access to quality health care for the screening for, and treatment and management of, such diseases and conditions, including through public-private partnerships;

"(ii) providing support to community-based organizations and State and local health departments in conducting education and training activities for patients, communities, and health care providers 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

Evaluation.

"(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 with a community-based organization that has experience in, or is capable of, providing services to individuals with heritable blood disorders, including sickle cell disease.

Definition.

"(5) ELIGIBLE ENTITY.—In this subsection, the term 'eligible entity' includes the 50 States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, the Commonwealth of the Northern Mariana Islands, American Samoa, Guam, the Federated States of Micronesia, the Republic of Marshall Islands, the Republic of Palau, Indian tribes, a State or local health department, an institution of higher education, or a nonprofit entity with appropriate experience to conduct the activities under this subsection.".

SEC. 3. SICKLE CELL DISEASE PREVENTION AND TREATMENT.

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

(1) by striking "Sickle Cell Disease" each place it appears and inserting "sickle cell disease";

(2) in paragraph (1)(A), by striking "shall conduct a demonstration program by making grants to up to 40 eligible entities for each fiscal year in which the program is conducted under this section for the purpose of developing and establishing systemic mechanisms to improve the prevention and treatment of Sickle Cell Disease" and inserting "shall continue efforts, including by awarding grants, to develop or establish mechanisms to improve the treatment of sickle cell disease, and to improve the prevention and treatment of complications of sickle cell disease, in populations with a high proportion of individuals with sickle cell disease";

(3) in paragraph (1)(B)—

(A) by striking clause (ii) (relating to priority); and

(B) by striking "GRANT AWARD REQUIREMENTS" and all that follows through "The Administrator shall" and inserting "GEOGRAPHIC DIVERSITY.—The Administrator shall";

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

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

(5) in paragraph (6), by striking "$10,000,000 for each of fiscal years 2005 through 2009" and inserting "$4,455,000 for each of fiscal years 2019 through 2023".

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

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

(2) redesignated as subsection (b); and

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

SEC. 4. SENSE OF THE SENATE.

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

Approved December 18, 2018.

LEGISLATIVE HISTORY—S. 2465 (H.R. 2410):

HOUSE REPORTS: No. 115–354 (Comm. on Energy and Commerce) accompanying H.R. 2410.

CONGRESSIONAL RECORD, Vol. 164 (2018):

Oct. 11, considered and passed Senate.

Dec. 11, considered and passed House.

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