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

JULY 16, 2014

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

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.

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

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) Short Title.—This Act may be cited as the “Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2014”.

(b) Table of Contents.—The table of contents of 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.
Sec. 6. Authorization of appropriations.

SEC. 2. SICKLE CELL DISEASE RESEARCH.

Part P of title III of the Public Health Service Act is amended by inserting after section 399V–5 (42 U.S.C. 280g–16) the following:

“SEC. 399V–6. NATIONAL SICKLE CELL DISEASE RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT PROGRAM.

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

SEC. 3. SICKLE CELL DISEASE SURVEILLANCE.

Section 399V–6 of the Public Health Service Act, as added by section 2, is amended by adding at the end the following:

“(b) SURVEILLANCE.—

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

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

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

“(i) increasing efforts to improve access to, and receipt of, high-quality sickle cell disease-related health care, including the use of proven treatments such as Hydroxyurea;

“(ii) working with partners to improve health outcomes of people with sickle cell disease over the lifespan by promoting guidelines for sickle cell disease screening, prevention, and treatment, including management of sickle cell disease complications;

“(iii) providing support to community-based organizations and State and local health departments in conducting sickle cell disease education and training activities for patients, communities, and health care providers; and

“(iv) supporting and training State health departments and regional laboratories in comprehensive testing to identify
specific forms of sickle cell disease in people of all ages; and

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

“(i) improving estimates of the national incidence and prevalence of sickle cell disease, including estimates about the specific types of sickle cell disease;

“(ii) identifying health disparities related to sickle cell disease;

“(iii) assessing the utilization of therapies and strategies to prevent complications related to sickle cell disease; and

“(iv) evaluating the impact of genetic, environmental, behavioral, and other risk factors that may affect sickle cell disease health outcomes.

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

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

“(4) DEFINITIONS.—In this subsection:

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

“(B) The term ‘State’ 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 the Marshall Islands, and the Republic of Palau.”.

SEC. 4. 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 “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 “grants to up to 25 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 in populations with a high density of sickle cell disease patients”; (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 expand, coordinate, and implement transition services for adolescents with sickle cell disease making the transition to adult health care.”; and
(5) by striking paragraph (6).
(b) TECHNICAL CHANGES.—
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(1) Subsection (c) of section 712 of the American Jobs Creation Act of 2004 (Public Law 108–357; 42 U.S.C. 300b–1 note) is—

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

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

(2) The table of contents in section 1(c) of the American Jobs Creation Act of 2004 (Public Law 108–357) is amended by striking the item relating to section 712.

SEC. 5. COLLABORATION WITH COMMUNITY-BASED ENTITIES.

Section 399V–6 of the Public Health Service Act, as amended by section 3, is further amended by adding at the end the following:

“(c) COLLABORATION WITH COMMUNITY-BASED ENTITIES.—To be eligible to receive a grant or other assistance under subsection (a), (b), or (c), an entity must have in effect a collaborative agreement with a community-based organization with 5 or more years of experience in providing services to sickle cell disease patients.”.
SEC. 6. AUTHORIZATION OF APPROPRIATIONS.

Section 399V–6 of the Public Health Service Act, as amended by section 5, is further amended by adding at the end the following:

“(d) Authorization of Appropriations.—To carry out this section, there are authorized to be appropriated $20,000,000 for each of fiscal years 2015 through 2020.”.