

113<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 5124

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.

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## 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

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## 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 2014”.

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.
- Sec. 6. Authorization of appropriations.

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

2 Part P of title III of the Public Health Service Act  
3 is amended by inserting after section 399V–5 (42 U.S.C.  
4 280g–16) the following:

5 **“SEC. 399V-6. NATIONAL SICKLE CELL DISEASE RESEARCH,**  
6 **SURVEILLANCE, PREVENTION, AND TREAT-**  
7 **MENT PROGRAM.**

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

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

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

15 “(b) SURVEILLANCE.—

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

20 “(A) to conduct surveillance and maintain  
21 data on the prevalence and distribution of sickle

1 cell disease and its associated health outcomes,  
2 complications, and treatments;

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

5 “(i) increasing efforts to improve ac-  
6 cess to, and receipt of, high-quality sickle  
7 cell disease-related health care, including  
8 the use of proven treatments such as  
9 Hydroxyurea;

10 “(ii) working with partners to improve  
11 health outcomes of people with sickle cell  
12 disease over the lifespan by promoting  
13 guidelines for sickle cell disease screening,  
14 prevention, and treatment, including man-  
15 agement of sickle cell disease complica-  
16 tions;

17 “(iii) providing support to community-  
18 based organizations and State and local  
19 health departments in conducting sickle  
20 cell disease education and training activi-  
21 ties for patients, communities, and health  
22 care providers; and

23 “(iv) supporting and training State  
24 health departments and regional labora-  
25 tories in comprehensive testing to identify

1 specific forms of sickle cell disease in peo-  
2 ple of all ages; and

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

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

10 “(ii) identifying health disparities re-  
11 lated to sickle cell disease;

12 “(iii) assessing the utilization of  
13 therapies and strategies to prevent com-  
14 plications related to sickle cell disease; and

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

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

24 “(3) APPLICATION.—To seek a grant under this  
25 subsection, a State shall submit an application to

1 the Secretary at such time, in such manner, and  
2 containing such information as the Secretary may  
3 require.

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

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

9 “(B) The term ‘State’ includes the 50  
10 States, the District of Columbia, the Common-  
11 wealth of Puerto Rico, the United States Virgin  
12 Islands, the Commonwealth of the Northern  
13 Mariana Islands, American Samoa, Guam, the  
14 Federated States of Micronesia, the Republic of  
15 the Marshall Islands, and the Republic of  
16 Palau.”.

17 **SEC. 4. SICKLE CELL DISEASE PREVENTION AND TREAT-**  
18 **MENT.**

19 (a) REAUTHORIZATION.—Section 712(c) of the  
20 American Jobs Creation Act of 2004 (Public Law 108–  
21 357; 42 U.S.C. 300b–1 note) is amended—

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

24 (2) in paragraph (1)(A), by striking “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 “grants  
5 to up to 25 eligible entities for each fiscal year in  
6 which the program is conducted under this section  
7 for the purpose of developing and establishing sys-  
8 temic mechanisms to improve the prevention and  
9 treatment of sickle cell disease in populations with  
10 a high density of sickle cell disease patients”;

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 expand, coordinate, and imple-  
21 ment transition services for adolescents with  
22 sickle cell disease making the transition to adult  
23 health care.”; and

24 (5) by striking paragraph (6).

25 (b) TECHNICAL CHANGES.—

1           (1) Subsection (e) of section 712 of the Amer-  
2           ican Jobs Creation Act of 2004 (Public Law 108–  
3           357; 42 U.S.C. 300b–1 note) is—

4                   (A) transferred to the Public Health Serv-  
5           ice Act (42 U.S.C. 201 et seq.); and

6                   (B) inserted at the end of section 399V–  
7           6 of such Act, as added and amended by sec-  
8           tions 2 and 3 of this Act.

9           (2) The table of contents in section 1(c) of the  
10          American Jobs Creation Act of 2004 (Public Law  
11          108–357) is amended by striking the item relating  
12          to section 712.

13 **SEC. 5. COLLABORATION WITH COMMUNITY-BASED ENTI-**  
14 **TIES.**

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

18          “(c) COLLABORATION WITH COMMUNITY-BASED EN-  
19          TITIES.—To be eligible to receive a grant or other assist-  
20          ance under subsection (a), (b), or (c), an entity must have  
21          in effect a collaborative agreement with a community-  
22          based organization with 5 or more years of experience in  
23          providing services to sickle cell disease patients.”.

1 **SEC. 6. AUTHORIZATION OF APPROPRIATIONS.**

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

5 “(d) AUTHORIZATION OF APPROPRIATIONS.—To  
6 carry out this section, there are authorized to be appro-  
7 priated \$20,000,000 for each of fiscal years 2015 through  
8 2020.”.

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