

108TH CONGRESS  
1ST SESSION

# H. R. 1736

To amend title XIX of the Social Security Act to include primary and secondary preventative medical strategies for children and adults with Sickle Cell Disease as medical assistance under the Medicaid Program, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

APRIL 10, 2003

Mr. DAVIS of Illinois (for himself, Mr. BURR, Mr. SHIMKUS, and Mr. RUSH) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend title XIX of the Social Security Act to include primary and secondary preventative medical strategies for children and adults with Sickle Cell Disease as medical assistance under the Medicaid Program, and for other purposes.

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.**

4 This Act may be cited as the “Sickle Cell Treatment  
5 Act of 2003”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

1           (1) Sickle Cell Disease (in this section referred  
2 to as “SCD”) is an inherited disease of red blood  
3 cells that is a major health problem in the United  
4 States.

5           (2) Approximately 70,000 Americans have SCD  
6 and approximately 1,800 American babies are born  
7 with the disease each year. SCD also is a global  
8 problem with close to 300,000 babies born annually  
9 with the disease.

10          (3) In the United States, SCD is most common  
11 in African-Americans and in those of Hispanic, Med-  
12 iterranean, and Middle Eastern ancestry. Among  
13 newborn American infants, SCD occurs in approxi-  
14 mately 1 in 300 African-Americans, 1 in 36,000  
15 Hispanics, and 1 in 80,000 Caucasians.

16          (4) More than 2,500,000 Americans, mostly Af-  
17 rican-Americans, have the sickle cell trait. These  
18 Americans are healthy carriers of the sickle cell gene  
19 who have inherited the normal hemoglobin gene  
20 from 1 parent and the sickle gene from the other  
21 parent. A sickle cell trait is not a disease, but when  
22 both parents have the sickle cell trait, there is a 1  
23 in 4 chance with each pregnancy that the child will  
24 be born with SCD.

1           (5) Children with SCD may exhibit frequent  
2 pain episodes, entrapment of blood within the spleen,  
3 severe anemia, acute lung complications, and  
4 priapism. During episodes of severe pain, spleen en-  
5 largement, or acute lung complications, life threat-  
6 ening complications can develop rapidly. Children  
7 with SCD are also at risk for septicemia, meningitis,  
8 and stroke. Children with SCD at highest risk for  
9 stroke can be identified and, thus, treated early with  
10 regular blood transfusions for stroke prevention.

11           (6) The most feared complication for children  
12 with SCD is a stroke (either overt or silent) occur-  
13 ring in 30 percent of the children with sickle cell  
14 anemia prior to their 18th birthday and occurring in  
15 infants as young as 18 months of age. Students with  
16 SCD and silent strokes may not have any physical  
17 signs of such disease or strokes but may have a  
18 lower educational attainment when compared to chil-  
19 dren with SCD and no strokes. Approximately 60  
20 percent of students with silent strokes have difficulty  
21 in school, require special education, or both.

22           (7) Many adults with SCD have acute prob-  
23 lems, such as frequent pain episodes and acute lung  
24 complications that can result in death. Adults with  
25 SCD can also develop chronic problems, including

1 pulmonary disease, pulmonary hypertension, degener-  
2 erative changes in the shoulder and hip joints, poor  
3 vision, and kidney failure.

4 (8) The average life span for an adult with  
5 SCD is the mid-40s. While some patients can re-  
6 main without symptoms for years, many others may  
7 not survive infancy or early childhood. Causes of  
8 death include bacterial infection, stroke, and lung,  
9 kidney, heart, or liver failure. Bacterial infections  
10 and lung injuries are leading causes of death in chil-  
11 dren and adults with SCD.

12 (9) As a complex disorder with multisystem  
13 manifestations, SCD requires specialized comprehen-  
14 sive and continuous care to achieve the best possible  
15 outcome. Newborn screening, genetic counseling, and  
16 education of patients and family members are crit-  
17 ical preventative measures that decrease morbidity  
18 and mortality, delaying or preventing complications,  
19 in-patient hospital stays, and increased overall costs  
20 of care.

21 (10) Stroke in the adult SCD population com-  
22 monly results in both mental and physical disabili-  
23 ties for life.

24 (11) Currently, one of the most effective treat-  
25 ments to prevent or treat an overt stroke or a silent

1 stroke for a child with SCD is at least monthly blood  
2 transfusions throughout childhood for many, and  
3 throughout life for some, requiring removal of sickle  
4 blood and replacement with normal blood.

5 (12) With acute lung complications, trans-  
6 fusions are usually required and are often the only  
7 therapy demonstrated to prevent premature death.

8 **SEC. 3. INCLUSION OF PRIMARY AND SECONDARY PRE-**  
9 **VENTATIVE MEDICAL STRATEGIES FOR CHIL-**  
10 **DREN AND ADULTS WITH SICKLE CELL DIS-**  
11 **EASE AS MEDICAL ASSISTANCE UNDER THE**  
12 **MEDICAID PROGRAM.**

13 (a) IN GENERAL.—Section 1905 of the Social Secu-  
14 rity Act (42 U.S.C. 1396d) is amended—

15 (1) in subsection (a)—

16 (A) by striking “and” at the end of para-  
17 graph (26);

18 (B) by redesignating paragraph (27) as  
19 paragraph (28); and

20 (C) by inserting after paragraph (26), the  
21 following:

22 “(27) subject to subsection (x), primary and  
23 secondary preventative medical strategies, including  
24 prophylaxes, and treatment and services for individ-  
25 uals who have Sickle Cell Disease; and”;

1 (2) by adding at the end the following:

2 “(x) For purposes of subsection (a)(27), the strate-  
3 gies, treatment, and services described in that subsection  
4 include the following:

5 “(1) Chronic blood transfusion (with  
6 deferoxamine chelation) to prevent stroke in individ-  
7 uals with Sickle Cell Disease who have been identi-  
8 fied as being at high risk for stroke.

9 “(2) Genetic counseling and testing for individ-  
10 uals with Sickle Cell Disease or the sickle cell trait.

11 “(3) Other treatment and services to prevent  
12 individuals who have Sickle Cell Disease and who  
13 have had a stroke from having another stroke.”.

14 (b) FEDERAL REIMBURSEMENT FOR EDUCATION  
15 AND OTHER SERVICES RELATED TO THE PREVENTION  
16 AND TREATMENT OF SICKLE CELL DISEASE.—Section  
17 1903(a)(3) of the Social Security Act (42 U.S.C.  
18 1396b(a)(3)) is amended—

19 (1) in subparagraph (D), by striking “plus” at  
20 the end and inserting “and”; and

21 (2) by adding at the end the following:

22 “(E) 50 percent of the sums expended with  
23 respect to costs incurred during such quarter as  
24 are attributable to providing—

1           “(i) services to identify and educate  
2           individuals who have Sickle Cell Disease or  
3           who are carriers of the sickle cell gene, in-  
4           cluding education regarding how to iden-  
5           tify such individuals; or

6           “(ii) education regarding the risks of  
7           stroke and other complications, as well as  
8           the prevention of stroke and other com-  
9           plications, in individuals who have Sickle  
10          Cell Disease; plus”.

11          (c) EFFECTIVE DATE.—The amendments made by  
12 this section take effect on the date of enactment of this  
13 Act and apply to medical assistance and services provided  
14 under title XIX of the Social Security Act (42 U.S.C.  
15 1396 et seq.) on or after that date, without regard to  
16 whether final regulations to carry out such amendments  
17 have been promulgated by such date.

18 **SEC. 4. DEMONSTRATION PROGRAM FOR THE DEVELOP-**  
19 **MENT AND ESTABLISHMENT OF SYSTEMIC**  
20 **MECHANISMS FOR THE PREVENTION AND**  
21 **TREATMENT OF SICKLE CELL DISEASE.**

22          (a) AUTHORITY TO CONDUCT DEMONSTRATION PRO-  
23 GRAM.—

24           (1) IN GENERAL.—The Administrator, through  
25          the Bureau of Primary Health Care and the Mater-

1       nal and Child Health Bureau, shall conduct a dem-  
2       onstration program by making grants to up to 40 el-  
3       igible entities for each fiscal year in which the pro-  
4       gram is conducted under this section for the purpose  
5       of developing and establishing systemic mechanisms  
6       to improve the prevention and treatment of Sickle  
7       Cell Disease, including through—

8               (A) the coordination of service delivery for  
9               individuals with Sickle Cell Disease;

10              (B) genetic counseling and testing;

11              (C) bundling of technical services related  
12              to the prevention and treatment of Sickle Cell  
13              Disease;

14              (D) training of health professionals; and

15              (E) identifying and establishing other ef-  
16              forts related to the expansion and coordination  
17              of education, treatment, and continuity of care  
18              programs for individuals with Sickle Cell Dis-  
19              ease.

20       (2) GRANT AWARD REQUIREMENTS.—

21              (A) GEOGRAPHIC DIVERSITY.—The Ad-  
22              ministrator shall, to the extent practicable,  
23              award grants under this section to eligible enti-  
24              ties located in different regions of the United  
25              States.

1 (B) PRIORITY.—In awarding grants under  
2 this section, the Administrator shall give pri-  
3 ority to awarding grants to eligible entities that  
4 are—

5 (i) Federally-qualified health centers  
6 that have a partnership or other arrange-  
7 ment with a comprehensive Sickle Cell Dis-  
8 ease treatment center that does not receive  
9 funds from the National Institutes of  
10 Health; or

11 (ii) Federally-qualified health centers  
12 that intend to develop a partnership or  
13 other arrangement with a comprehensive  
14 Sickle Cell Disease treatment center that  
15 does not receive funds from the National  
16 Institutes of Health.

17 (b) ADDITIONAL REQUIREMENTS.—An eligible entity  
18 awarded a grant under this section shall use funds made  
19 available under the grant to carry out, in addition to the  
20 activities described in subsection (a)(1), the following ac-  
21 tivities:

22 (1) To facilitate and coordinate the delivery of  
23 education, treatment, and continuity of care for indi-  
24 viduals with Sickle Cell Disease under—

1 (A) the entity's collaborative agreement  
2 with a community-based Sickle Cell Disease or-  
3 ganization or a nonprofit entity that works with  
4 individuals who have Sickle Cell Disease;

5 (B) the Sickle Cell Disease newborn  
6 screening program for the State in which the  
7 entity is located; and

8 (C) the maternal and child health program  
9 under title V of the Social Security Act (42  
10 U.S.C. 701 et seq.) for the State in which the  
11 entity is located.

12 (2) To train nursing and other health staff who  
13 specialize in pediatrics, obstetrics, internal medicine,  
14 or family practice to provide health care and genetic  
15 counseling for individuals with the sickle cell trait.

16 (3) To enter into a partnership with adult or  
17 pediatric hematologists in the region and other re-  
18 gional experts in Sickle Cell Disease at tertiary and  
19 academic health centers and State and county health  
20 offices.

21 (4) To identify and secure resources for ensur-  
22 ing reimbursement under the medicaid program,  
23 State children's health insurance program, and other  
24 health programs for the prevention and treatment of  
25 Sickle Cell Disease, including the genetic testing of

1 parents or other appropriate relatives of children  
2 with Sickle Cell Disease and of adults with Sickle  
3 Cell Disease.

4 (c) NATIONAL COORDINATING CENTER.—

5 (1) ESTABLISHMENT.—The Administrator shall  
6 enter into a contract with an entity to serve as the  
7 National Coordinating Center for the demonstration  
8 program conducted under this section.

9 (2) ACTIVITIES DESCRIBED.—The National Co-  
10 ordinating Center shall—

11 (A) collect, coordinate, monitor, and dis-  
12 tribute data, best practices, and findings re-  
13 garding the activities funded under grants made  
14 to eligible entities under the demonstration pro-  
15 gram;

16 (B) develop a model protocol for eligible  
17 entities with respect to the prevention and  
18 treatment of Sickle Cell Disease;

19 (C) develop educational materials regard-  
20 ing the prevention and treatment of Sickle Cell  
21 Disease; and

22 (D) prepare and submit to Congress a  
23 final report that includes recommendations re-  
24 garding the effectiveness of the demonstration

1 program conducted under this section and such  
2 direct outcome measures as—

3 (i) the number and type of health care  
4 resources utilized (such as emergency room  
5 visits, hospital visits, length of stay, and  
6 physician visits for individuals with Sickle  
7 Cell Disease); and

8 (ii) the number of individuals that  
9 were tested and subsequently received ge-  
10 netic counseling for the sickle cell trait.

11 (d) APPLICATION.—An eligible entity desiring a  
12 grant under this section shall submit an application to the  
13 Administrator at such time, in such manner, and con-  
14 taining such information as the Administrator may re-  
15 quire.

16 (e) DEFINITIONS.—In this section:

17 (1) ADMINISTRATOR.—The term “Adminis-  
18 trator” means the Administrator of the Health Re-  
19 sources and Services Administration.

20 (2) ELIGIBLE ENTITY.—The term “eligible enti-  
21 ty” means a Federally-qualified health center, a non-  
22 profit hospital or clinic, or a university health center  
23 that provides primary health care, that—

24 (A) has a collaborative agreement with a  
25 community-based Sickle Cell Disease organiza-

1           tion or a nonprofit entity with experience in  
2           working with individuals who have Sickle Cell  
3           Disease; and

4                   (B) demonstrates to the Administrator  
5           that either the Federally-qualified health center,  
6           the nonprofit hospital or clinic, the university  
7           health center, the organization or entity de-  
8           scribed in subparagraph (A), or the experts de-  
9           scribed in subsection (b)(3), has at least 5  
10          years of experience in working with individuals  
11          who have Sickle Cell Disease.

12           (3) **FEDERALLY-QUALIFIED HEALTH CEN-**  
13          **TER.**—The term “Federally-qualified health center”  
14          has the meaning given that term in section  
15          1905(l)(2)(B) of the Social Security Act (42 U.S.C.  
16          1396d(l)(2)(B)).

17          (f) **AUTHORIZATION OF APPROPRIATIONS.**—There is  
18          authorized to be appropriated to carry out this section,  
19          \$10,000,000 for each of fiscal years 2004 through 2009.

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