I

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.

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

---

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.

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

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Sickle Cell Treatment Act of 2003''.

SEC. 2. FINDINGS.

Congress makes the following findings:

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

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

(3) In the United States, SCD is most common in African-Americans and in those of Hispanic, Mediterranean, and Middle Eastern ancestry. Among newborn American infants, SCD occurs in approximately 1 in 300 African-Americans, 1 in 36,000 Hispanics, and 1 in 80,000 Caucasians.

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

(5) Children with SCD may exhibit frequent pain episodes, entrapment of blood within the spleen, severe anemia, acute lung complications, and priapism. During episodes of severe pain, spleen enlargement, or acute lung complications, life threatening complications can develop rapidly. Children with SCD are also at risk for septicemia, meningitis, and stroke. Children with SCD at highest risk for stroke can be identified and, thus, treated early with regular blood transfusions for stroke prevention.

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

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

pulmonary disease, pulmonary hypertension, degenerative changes in the shoulder and hip joints, poor vision, and kidney failure.

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

(9) As a complex disorder with multisystem manifestations, SCD requires specialized comprehensive and continuous care to achieve the best possible outcome. Newborn screening, genetic counseling, and education of patients and family members are critical preventative measures that decrease morbidity and mortality, delaying or preventing complications, in-patient hospital stays, and increased overall costs of care.

(10) Stroke in the adult SCD population commonly results in both mental and physical disabilities for life.

(11) Currently, one of the most effective treatments to prevent or treat an overt stroke or a silent

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

(12) With acute lung complications, transfusions are usually required and are often the only therapy demonstrated to prevent premature death.

SEC. 3. INCLUSION OF PRIMARY AND SECONDARY PREVENTATIVE MEDICAL STRATEGIES FOR CHILDREN AND ADULTS WITH SICKLE CELL DISEASE AS MEDICAL ASSISTANCE UNDER THE MEDICAID PROGRAM.

(a) IN GENERAL.—Section 1905 of the Social Security Act (42 U.S.C. 1396d) is amended—

(1) in subsection (a)—

(A) by striking ''and'' at the end of paragraph (26);

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

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

''(27) subject to subsection (x), primary and secondary preventative medical strategies, including prophylaxes, and treatment and services for individuals who have Sickle Cell Disease; and''; and

(2) by adding at the end the following:

''(x) For purposes of subsection (a)(27), the strategies, treatment, and services described in that subsection include the following:

''(1) Chronic blood transfusion (with deferoxamine chelation) to prevent stroke in individuals with Sickle Cell Disease who have been identified as being at high risk for stroke.

''(2) Genetic counseling and testing for individuals with Sickle Cell Disease or the sickle cell trait.

''(3) Other treatment and services to prevent individuals who have Sickle Cell Disease and who have had a stroke from having another stroke.''.

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

(1) in subparagraph (D), by striking ''plus'' at the end and inserting ''and''; and

(2) by adding at the end the following:

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

''(i) services to identify and educate individuals who have Sickle Cell Disease or who are carriers of the sickle cell gene, including education regarding how to identify such individuals; or

''(ii) education regarding the risks of stroke and other complications, as well as the prevention of stroke and other complications, in individuals who have Sickle Cell Disease; plus''.

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

SEC. 4. DEMONSTRATION PROGRAM FOR THE DEVELOPMENT AND ESTABLISHMENT OF SYSTEMIC MECHANISMS FOR THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE.

(a) AUTHORITY TO CONDUCT DEMONSTRATION PROGRAM.—

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

nal and Child Health Bureau, 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, including through—

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

(B) genetic counseling and testing;

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

(D) training of health professionals; and

(E) identifying and establishing other efforts related to the expansion and coordination of education, treatment, and continuity of care programs for individuals with Sickle Cell Disease.

(2) GRANT AWARD REQUIREMENTS.—

(A) GEOGRAPHIC DIVERSITY.—The Administrator shall, to the extent practicable, award grants under this section to eligible entities located in different regions of the United States.

(B) PRIORITY.—In awarding grants under this section, the Administrator shall give priority to awarding grants to eligible entities that are—

(i) Federally-qualified health centers that have a partnership or other arrangement with a comprehensive Sickle Cell Disease treatment center that does not receive funds from the National Institutes of Health; or

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

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

(1) To facilitate and coordinate the delivery of education, treatment, and continuity of care for individuals with Sickle Cell Disease under—

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

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

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

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

(3) To enter into a partnership with adult or pediatric hematologists in the region and other regional experts in Sickle Cell Disease at tertiary and academic health centers and State and county health offices.

(4) To identify and secure resources for ensuring reimbursement under the medicaid program, State children's health insurance program, and other health programs for the prevention and treatment of Sickle Cell Disease, including the genetic testing of

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

(c) NATIONAL COORDINATING CENTER.—

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

(2) ACTIVITIES DESCRIBED.—The National Coordinating Center shall—

(A) collect, coordinate, monitor, and distribute data, best practices, and findings regarding the activities funded under grants made to eligible entities under the demonstration program;

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

(C) develop educational materials regarding the prevention and treatment of Sickle Cell Disease; and

(D) prepare and submit to Congress a final report that includes recommendations regarding the effectiveness of the demonstration

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

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

(ii) the number of individuals that were tested and subsequently received genetic counseling for the sickle cell trait.

(d) APPLICATION.—An eligible entity desiring a grant under this section shall submit an application to the Administrator at such time, in such manner, and containing such information as the Administrator may require.

(e) DEFINITIONS.—In this section:

(1) ADMINISTRATOR.—The term ''Administrator'' means the Administrator of the Health Resources and Services Administration.

(2) ELIGIBLE ENTITY.—The term ''eligible entity'' means a Federally-qualified health center, a nonprofit hospital or clinic, or a university health center that provides primary health care, that—

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

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

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

(3) FEDERALLY-QUALIFIED HEALTH CENTER.—The term ''Federally-qualified health center'' has the meaning given that term in section 1905(l)(2)(B) of the Social Security Act (42 U.S.C. 1396d(l)(2)(B)).

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

○