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I N  A S S E M B L Y

(PREFILED)

January 9, 2013

Introduced by M. of A. GIBSON, CRESPO, SCARBOROUGH, SCHIMEL, HOOPER, JAFFEE -- Multi-Sponsored by -- M. of A. DINOWITZ, PERRY, PRETLOW -- read once and referred to the Committee on Health

AN ACT to amend the social services law, in relation to establishing the sickle cell treatment act of 2014

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. This act shall be known and may be cited as the "sickle cell treatment act of 2014".

S 2. Legislative findings. The legislature hereby finds and declares the following:

(1) Sickle cell disease (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 one 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

EXPLANATION--Matter in ITALICS (underscored) is new; matter in brackets [ ] is old law to be omitted.

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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.

The legislature declares its intent to develop and establish systemic mechanisms to improve the prevention and treatment of sickle cell disease.

S 3. Section 365 of the social services law is amended by adding two new subdivisions 13 and 14 to read as follows:

13. ANY INCONSISTENT PROVISION OF THIS CHAPTER OR OTHER LAW NOTWITHSTANDING, THE DEPARTMENT SHALL BE RESPONSIBLE FOR FURNISHING MEDICAL ASSISTANCE FOR PREVENTATIVE MEDICAL STRATEGIES, INCLUDING PROPHYLAXIS, AND TREATMENT AND SERVICES FOR ELIGIBLE INDIVIDUALS WHO HAVE SICKLE CELL DISEASE. FOR THE PURPOSES OF THIS SUBDIVISION, "PREVENTATIVE MEDICAL STRATEGIES, TREATMENT AND SERVICES" SHALL INCLUDE, BUT NOT BE LIMITED TO THE FOLLOWING:

(A) 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;

(B) GENETIC COUNSELING AND TESTING FOR INDIVIDUALS WITH SICKLE CELL DISEASE OR THE SICKLE CELL TRAIT; OR

(C) OTHER TREATMENT AND SERVICES TO PREVENT INDIVIDUALS WHO HAVE SICKLE CELL DISEASE AND WHO HAVE HAD A STROKE FROM HAVING ANOTHER STROKE.

14. ANY INCONSISTENT PROVISION OF THIS CHAPTER OR OTHER LAW NOTWITHSTANDING, THE DEPARTMENT SHALL BE RESPONSIBLE FOR ARRANGING OR PROVIDING FUNDING FOR THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM, AS DESCRIBED IN SECTION THREE HUNDRED SIXTY-THREE-F OF THIS TITLE.

S 4. The social services law is amended by adding a new section 363-f to read as follows:

S 363-F. PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM. 1. THE COMMISSIONER OF HEALTH SHALL ESTABLISH AND CONDUCT A PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM IN THE CITY OF NEW YORK AND FOR NO MORE THAN FIVE COUNTIES, 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 OF 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. ON OR BEFORE THE FIRST OF JANUARY, TWO THOUSAND EIGHTEEN, THE COMMISSIONER OF HEALTH SHALL REPORT TO THE GOVERNOR, THE SPEAKER OF THE ASSEMBLY AND THE TEMPORARY PRESIDENT OF THE SENATE ON THE IMPACT THAT THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM HAS HAD ON INDIVIDUALS WITH SICKLE CELL DISEASE IN REGARDS TO COORDINATION OF SERVICE DELIVERY, GENETIC COUNSELING AND TESTING BUNDLING OF TECHNICAL SERVICES RELATED TO THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE, TRAINING OF HEALTH PROFESSIONALS AND THE IDENTIFICATION AND ESTABLISHMENT OF OTHER EFFORTS RELATED TO THE EXPANSION AND COORDINATION OF EDUCATION, TREATMENT, AND CONTINUITY OF CARE PROGRAMS FOR SUCH INDIVIDUALS.

S 5. This act shall take effect immediately.