STATE OF NEW YORK

2281

2019-2020 Regular Sessions

IN SENATE

January 23, 2019

Introduced by Sens. SANDERS, BAILEY, KRUEGER, PARKER, PERSAUD, SEPULVEDA, STAVISKY -- read twice and ordered printed, and when printed to be committed to the Committee on Finance

AN ACT to amend the social services law and the public health law, in relation to establishing the sickle cell treatment act of 2019; and making an appropriation therefor

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 2019".

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

(1) Sickle cell disease (SCD) is an inherited disease of red blood cells and the CDC (Centers for Disease Control) states that SCD is a major public health concern. Approximately 1,000 American babies are born with the disease each year, while globally 500,000 babies are born annually with the disease.

(2) Sickle cell disease affects approximately 100,000 Americans and is most common in African-Americans as well as those of Hispanic, Mediterranean and Middle Eastern ancestry. Nationally, SCD occurs in approximately 1:500 African-Americans, 1:36,000 Hispanics and 1:80,000 Caucasians. However, in NYS (New York State) SCD occurs in 1:230 live births to non-Hispanic black mothers, 1:2,320 births to Hispanic mothers and 1:41,647 Caucasian mothers.

(3) Approximately 10% of SCD patients reside in NYS. In NYS, 1:1,146 live births have sickle cell disease, with 12% of NYS sickle cell disease births in the Hispanic population. Higher birth rates for SCD occur in mothers who were born outside of the US. In NYS, approximately 80% of sickle cell disease patients live in the NYC area.

(4) Sickle cell disease is the most costly disease per patient to NYS Medicaid, costing $15,000/year/patient. Despite this, NYS only spends

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

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about $250,000/year to help improve care and decrease the costs of care. This has decreased from approximately $500,000 in 2001. Most adult patients are either not in care with a hematologist or not receiving appropriate disease modifying medications - despite the medical literature which shows costs can be decreased while increasing quality of life for sickle cell disease patients when in care. With a minimal decrease in cost of care/patient of approximately 3%, NYS Medicaid could achieve approximately $4-5,000,000 in savings. This would more than compensate for the cost of the program ($3,000,000).

(5) Persons with sickle cell trait (SCT) are carriers of the sickle cell gene who have inherited the normal hemoglobin gene from one parent and the sickle cell gene from the other parent. More than 3,000,000 Americans, mostly African-Americans, have SCT. Sickle cell trait is not a disease, but when both parents have SCT there is a 1 in 4 chance with each pregnancy that the child will be born with SCD. However, SCT has its own subtle complications, and can also be deadly.

(6) Because SCD is a blood disorder and blood goes to all parts of the body, people with SCD may exhibit complications in all parts of the body. This includes, but is not limited to, frequent pain episodes, entrapment of blood within the spleen, severe anemia, acute lung complications (acute chest syndrome), priapism in males and other life-threatening conditions. These life-threatening complications can develop rapidly, including infections of the blood (sepsis), meningitis and stroke. Stroke can be either silent (no overt symptoms) or clinical (with symptoms) and can affect children as young as 18 months of age. Up to 40% of children will have had either a silent or clinical stroke by the age of 18 years. This impacts their ability to learn and/or hold a job.

(7) Sickle cell disease is a cumulative disease with worsening complications and organ damage, including lungs, heart and kidneys, as patients age. In addition, with the toll of the disease on patients, particularly their brain, mental health issues are extremely important to the sickle cell disease patient and family. The median life expectancy for SCD is about 45 years. While some patients can remain without symptoms for years, many others may not survive childhood or the early adult years.

(8) As a complex disease with multisystem manifestations, SCD requires specialized comprehensive and continuous care to achieve the best possible outcomes. Newborn screening, genetic counseling with education of patients, family members, schools and health care providers are critical preventative measures. These decrease morbidity and mortality, delay or prevent complications, reduce emergency room visits and in-patient hospital stays, and decrease overall costs of care.

(9) Day hospitals, where patients can seek treatment as an outpatient avoiding overburdened emergency rooms and hospitalizations, for as long as 8 hours have consistently proven in peer reviewed publications to improve care and decrease costs in both the pediatric and adult sickle cell population. Yet despite this evidence, few day hospitals exist for adult sickle cell disease patients.

(10) In addition to specialized care and support from medical staff, hospital administrations need to understand the importance of their support of the medical staff and need for the medical and support staff in multiple medical subspecialities in order to provide the comprehensive care that patients need. As well, insurance companies need to understand that these patients require complicated medical care to stay healthy and provide the correct and adequate financial support to allow

the hiring of appropriate support staff as well as adequately compensate the medical staff for the increased hours it takes to manage these complex patients.

(11) Community based organizations provide a valuable service in educating their communities about sickle cell disease and trait, and because they act as a bridge between the treatment centers and the community should be included whenever possible in any program to improve care to the community.

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

§ 3. Section 365 of the social services law is amended by adding a new subdivision 13 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, 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.

§ 4. Article 31 of the public health law is amended by adding a new title 4 to read as follows:

TITLE IV

PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM

Section 3126. Prevention and treatment of sickle cell disease demonstration program.

§ 3126. Prevention and treatment of sickle cell disease demonstration program. 1. The commissioner shall create prevention and treatment of sickle cell disease demonstration programs throughout the state to implement care for sickle cell disease patients based on common problems faced throughout the state as well as regional or local issues that affect the sickle cell disease patient population. These programs would not only evaluate impact of care and quality of life on their sickle cell disease patients, but also track the costs and cost savings occurring with implemented changes.

2. The purpose of the prevention and treatment of sickle cell disease demonstration programs would be to develop and establish systemic mechanisms to improve the prevention and treatment of sickle cell disease and sickle cell trait in New York state.

(a) The commissioner shall create and conduct eight regional prevention and treatment of sickle cell disease demonstration programs for both pediatric and adult care and sickle cell trait education for five years.

(b) The regional programs shall be established based on sickle cell disease demographics in the state of New York, to serve individuals in downstate cities, including New York city, and upstate cities, including Buffalo, Rochester, and Albany. Where a higher concentration of programs will be in the New York city area.

(c) Since many of the sickle cell disease patients in the New York city area are treated in community hospitals, at least two of the New York city area programs will be in community hospitals.

(d) These prevention and treatment of sickle cell demonstration programs will develop and establish systemic mechanisms to improve the prevention and treatment of sickle cell disease and sickle cell trait. These mechanisms shall:

(i) coordinate the service delivery for individuals with sickle cell disease, including the establishment of day hospitals for the adult sickle cell disease population;

(ii) provide genetic counseling for sickle cell disease and sickle cell trait;

(iii) provide bundling of technical services related to the prevention and treatment of sickle cell disease;

(iv) identify and establish other efforts related to the expansion and coordination of education, treatment, and continuity of care programs for individuals with sickle cell disease and sickle cell trait;

(v) establish outreach to the community for sickle cell disease, with each program providing fifty thousand dollars to community based organizations, where available, or for other community outreach;

(vi) provide coordination, treatment and education of mental health services for sickle cell disease patients and their families;

(vii) provide training of health professionals and lay community;

(viii) work on at least two projects designated and agreed by all the programs to be common to all sickle cell patients throughout the state and two projects identified by each program to be important to sickle cell disease patients in that region in conjunction with the department and the coordinating center;

(ix) include any other provision as the program may deem necessary; and

(x) each program is encouraged to consider having the hospital administration sign off on support of the program and having a plan of action on how the hospital administration will support the program and outreach to the community. Hospital administration is also encouraged to have a plan for enhanced care, including support staff, for this program.

(e) The commissioner shall create one statewide coordinating center for the program for five years with funding at one million dollars for the first year, and five hundred thousand dollars for each year thereafter.

(i) This coordinating center would work with the prevention and treatment of sickle cell demonstration programs to establish statewide goals for standard of care for sickle cell disease patients and those with sickle cell trait for all programs to achieve.

(ii) This coordinating center would work with the regional and community hospital programs to establish goals to evaluate specific challenges that are specific to that region and community hospital.

(iii) The coordinating center would provide education and assistance to each program to carry out these goals.

(iv) It will collect data and monitor progress from each program to include in a single report to the state due on the first of January. This report will not only include progress on the care, including mental health, and quality of life for sickle cell disease patients, but also on cost of care, highlighting decreases in cost compared to at the baseline year before the programs are initiated.

(v) It will conduct and pay for a minimum of two face to face meetings of program staff, including physicians, nurses, social workers and

patient representatives and hospital administration (at a minimum), each year.

(f) In order to make sure that the majority of the money appropriated to these programs goes to program activities, indirect costs will be limited to ten percent of the funding programs receive.

§ 5. On or before the first of January, after the first full year of funding being awarded and thereafter each first of January until the completion of the grant cycle, 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 programs have had on, but not limited to, the cost of care, mental health, quality of life and identification and establishment of other efforts related to the expansion and coordination of education, treatment, and continuity of care programs for sickle cell disease patients and those with sickle cell trait.

§ 6. Because sickle cell disease is the most costly disease per patient to the NYS Medicaid program, and so significant savings to the NYS Medicaid program can be achieved through sickle cell disease demonstration programs, the sum of three million dollars ($3,000,000) per year for five years will be appropriated ($1 million for the coordinating center with the rest evenly divided between the eight prevention and treatment of sickle cell disease demonstration programs in year one; for each year thereafter, $500,000 will go to the coordinating center with the rest evenly divided between 8 programs).

§ 7. Sickle cell disease demonstration programs shall be established throughout the state of New York and one statewide coordinating center for the prevention and treatment of sickle cell disease demonstration program shall be created to collect data and monitor the progress of each demonstration project. The sum of one million dollars ($1,000,000) will be appropriated for the first year; for each year thereafter, five hundred thousand dollars ($500,000) shall be appropriated.

§ 8. The money would be appropriated to the department of health out of any moneys in the state treasury in the general fund to the credit of the state purposes account and made immediately available, for the purpose of carrying out the provisions of this act. Such moneys shall be payable on the audit and warrant of the comptroller on vouchers certified or approved by the commissioner of health in the manner prescribed by law.

§ 9. This act shall take effect immediately.