

STATE OF NEW YORK

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IN ASSEMBLY

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Introduced by M. of A. HYNDMAN, JEAN-PIERRE, BLAKE, BARRON, PERRY, WRIGHT, JOYNER, TAYLOR, PICHARDO, DICKENS, BICHOTTE, MOSLEY, NIOU, DAVILA, PEOPLES-STOKES, DE LA ROSA, BARNWELL, RA, GALEF -- Multi-Sponsored by -- M. of A. COOK, PRETLOW, SIMON, SIMOTAS -- read once and referred to the Committee on Health

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:

1 Section 1. This act shall be known and may be cited as the "Sickle
2 Cell Treatment Act of 2019".

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

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

10 (2) Sickle cell disease affects approximately 100,000 Americans and is
11 most common in African-Americans as well as those of Hispanic, Mediter-
12 ranean and Middle Eastern ancestry. Nationally, SCD occurs in approxi-
13 mately 1:500 African-Americans, 1:36,000 Hispanics and 1:80,000 Cauca-
14 sians. However, in NYS (New York State) SCD occurs in 1:230 live births
15 to non-Hispanic black mothers, 1:2,320 births to Hispanic mothers and
16 1:41,647 Caucasian mothers.

17 (3) Approximately 10% of SCD patients reside in NYS. In NYS, 1:1,146
18 live births have sickle cell disease, with 12% of NYS sickle cell
19 disease births in the Hispanic population. Higher birth rates for SCD
20 occur in mothers who were born outside of the US. In NYS, approximately
21 80% of sickle cell disease patients live in the NYC area.

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

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(4) Sickle cell disease is the most costly disease per patient to NYS Medicaid, costing \$15,000/year/patient. Despite this, NYS only spends 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 subspecialties in order to provide the comprehensive care that patients need. As well, insurance companies need to

1 understand that these patients require complicated medical care to stay
2 healthy and provide the correct and adequate financial support to allow
3 the hiring of appropriate support staff as well as adequately compensate
4 the medical staff for the increased hours it takes to manage these
5 complex patients.

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

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

14 § 3. Section 365 of the social services law is amended by adding a new
15 subdivision 13 to read as follows:

16 13. Any inconsistent provision of this chapter or other law notwith-
17 standing, the department shall be responsible for furnishing medical
18 assistance for preventative medical strategies, including prophylaxis,
19 treatment and services for eligible individuals who have sickle cell
20 disease. For the purposes of this subdivision, "preventative medical
21 strategies, treatment and services" shall include, but not be limited to
22 the following:

23 (a) chronic blood transfusion (with deferoxamine chelation) to prevent
24 stroke in individuals with sickle cell disease who have been identified
25 as being at high risk for stroke;

26 (b) genetic counseling and testing for individuals with sickle cell
27 disease or the sickle cell trait; or

28 (c) other treatment and services to prevent individuals who have sick-
29 le cell disease and who have had a stroke from having another stroke.

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

32 TITLE IV

33 PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM
34 Section 3126. Prevention and treatment of sickle cell disease demon-
35 stration program.

36 § 3126. Prevention and treatment of sickle cell disease demonstration
37 program. 1. The commissioner shall create prevention and treatment of
38 sickle cell disease demonstration programs throughout the state to
39 implement care for sickle cell disease patients based on common problems
40 faced throughout the state as well as regional or local issues that
41 affect the sickle cell disease patient population. These programs would
42 not only evaluate impact of care and quality of life on their sickle
43 cell disease patients, but also track the costs and cost savings occur-
44 ring with implemented changes.

45 2. The purpose of the prevention and treatment of sickle cell disease
46 demonstration programs would be to develop and establish systemic mech-
47 anisms to improve the prevention and treatment of sickle cell disease
48 and sickle cell trait in New York state.

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

53 (b) The regional programs shall be established based on sickle cell
54 disease demographics in the state of New York, to serve individuals in
55 downstate cities, including New York city, and upstate cities, including

1 Buffalo, Rochester, and Albany. Where a higher concentration of programs
2 will be in the New York city area.

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

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

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

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

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

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

20 (v) establish outreach to the community for sickle cell disease, with
21 each program providing fifty thousand dollars to community based organ-
22 izations, where available, or for other community outreach;

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

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

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

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

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

38 (e) The commissioner shall create one statewide coordinating center
39 for the program for five years with funding at one million dollars for
40 the first year, and five hundred thousand dollars for each year there-
41 after.

42 (i) This coordinating center would work with the prevention and treat-
43 ment of sickle cell demonstration programs to establish statewide goals
44 for standard of care for sickle cell disease patients and those with
45 sickle cell trait for all programs to achieve.

46 (ii) This coordinating center would work with the regional and commu-
47 nity hospital programs to establish goals to evaluate specific chal-
48 lenges that are specific to that region and community hospital.

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

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

1 (v) It will conduct and pay for a minimum of two face to face meetings
2 of program staff, including physicians, nurses, social workers and
3 patient representatives and hospital administration (at a minimum), each
4 year.

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

8 § 5. On or before the first of January, after the first full year of
9 funding being awarded and thereafter each first of January until the
10 completion of the grant cycle, the commissioner of health shall report
11 to the governor, the speaker of the assembly and the temporary president
12 of the senate on the impact that the prevention and treatment of sickle
13 cell disease demonstration programs have had on, but not limited to, the
14 cost of care, mental health, quality of life and identification and
15 establishment of other efforts related to the expansion and coordination
16 of education, treatment, and continuity of care programs for sickle cell
17 disease patients and those with sickle cell trait.

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

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

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

41 § 9. This act shall take effect immediately.