

# STATE OF NEW YORK

6493

2019-2020 Regular Sessions

## IN ASSEMBLY

March 8, 2019

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.

LBD05436-01-9

1 (4) Sickle cell disease is the most costly disease per patient to NYS  
2 Medicaid, costing \$15,000/year/patient. Despite this, NYS only spends  
3 about \$250,000/year to help improve care and decrease the costs of care.  
4 This has decreased from approximately \$500,000 in 2001. Most adult  
5 patients are either not in care with a hematologist or not receiving  
6 appropriate disease modifying medications - despite the medical litera-  
7 ture which shows costs can be decreased while increasing quality of life  
8 for sickle cell disease patients when in care. With a minimal decrease  
9 in cost of care/patient of approximately 3%, NYS Medicaid could achieve  
10 approximately \$4-5,000,000 in savings. This would more than compensate  
11 for the cost of the program (\$3,000,000).

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

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

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

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

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

52 (10) In addition to specialized care and support from medical staff,  
53 hospital administrations need to understand the importance of their  
54 support of the medical staff and need for the medical and support staff  
55 in multiple medical subspecialties in order to provide the comprehen-  
56 sive 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.