

# STATE OF NEW YORK

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4054

2017-2018 Regular Sessions

## IN SENATE

February 2, 2017

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Introduced by Sens. SANDERS, DILAN, HAMILTON, LATIMER, PARKER, PERKINS,  
PERSAUD -- 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 2017; and  
making an appropriation therefor

The People of the State of New York, represented in Senate and Assem-  
bly, do enact as follows:

1 Section 1. This act shall be known and may be cited as the "sickle  
2 cell treatment act of 2017".

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 is a major health problem in the United States.

7 (2) Approximately 100,000 Americans have SCD with approximately 10% of  
8 SCD patients residing in New York state (NYS). In NYS, 1 in 1,146 live  
9 births have sickle cell disease, with 12% of NYS sickle cell disease  
10 births in the Hispanic population. Higher birth rates for children with  
11 sickle cell disease in NYS occur in mothers born outside of the United  
12 States. Approximately 1,000 American babies are born with the disease  
13 each year. SCD also is a global problem with close to 500,000 babies  
14 born annually with the disease.

15 (3) In the United States, SCD is most common in African-Americans and  
16 in those of Hispanic, Mediterranean, and Middle Eastern ancestry. Among  
17 newborn American infants nationally, SCD occurs in approximately 1 in  
18 500 African-Americans, 1 in 36,000 Hispanics, and 1 in 80,000 Cauca-  
19 sians. In NYS, sickle cell disease occurs in 1 in 230 live births to  
20 non-Hispanic black mothers, 1 in 2,320 births to Hispanic mothers and 1  
21 in 41,647 births to Caucasian mothers.

22 (4) More than 3,000,000 Americans, mostly African-Americans, have the  
23 sickle cell trait. These Americans are carriers of the sickle cell gene

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

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1 who have inherited the normal hemoglobin gene from one parent and the  
2 sickle cell gene from the other parent. A sickle cell trait is not a  
3 disease, but when both parents have the sickle cell trait (SCT), there  
4 is a 1 in 4 chance with each pregnancy that the child will be born with  
5 SCD. However, SCT has its own subtle complications and can also be  
6 deadly.

7 (5) Since SCD is a blood disorder and blood goes to all parts of the  
8 body, people with SCD may exhibit complications in all parts of the  
9 body. This includes, but is not limited to frequent pain episodes,  
10 entrapment of blood within the spleen, severe anemia, acute lung compli-  
11 cations (acute chest syndrome), and priapism. During episodes of severe  
12 pain, spleen enlargement, or acute lung complications, life threatening  
13 complications can develop rapidly. Children with SCD are also at risk  
14 for infections of the blood, meningitis, and stroke. Children with SCD  
15 at highest risk for stroke can be identified and, thus, treated early  
16 with regular blood transfusions for stroke prevention.

17 (6) The most feared complication for children with SCD is a stroke.  
18 Stroke can either be silent (no overt symptoms) or clinical (with symp-  
19 toms) and can affect children as young as 18 months of age. Up to 40% of  
20 children will have had either a silent or clinical stroke by the age of  
21 18. This impacts their ability to learn and/or hold a job. SCD is a  
22 cumulative disease with worsening complications and organ involvement,  
23 including lungs, heart and kidneys, as patients age.

24 (7) Many adults with SCD have acute problems, such as frequent pain  
25 episodes and acute lung complications (acute chest syndrome) that can  
26 result in death. Adults with SCD can also develop chronic problems,  
27 including pulmonary disease, pulmonary hypertension, degenerative chang-  
28 es in the shoulder and hip joints (bone necrosis), poor vision, and  
29 kidney failure.

30 (8) The median life expectancy for SCD is about 45 years. While some  
31 patients can remain without symptoms for years, many others may not  
32 survive infancy or early childhood. Causes of death include bacterial  
33 infection, stroke, and lung, kidney, heart, or liver failure. Bacterial  
34 infections and lung injuries are leading causes of death in children and  
35 adults with SCD.

36 (9) As a complex disorder with multisystem manifestations, SCD  
37 requires specialized comprehensive and continuous care to achieve the  
38 best possible outcome. Newborn screening, genetic counseling, and educa-  
39 tion of patients and family members are critical preventative measures  
40 that decrease morbidity and mortality, delays or prevents complications,  
41 reduces in-patient hospital stays, and decreases overall costs of care.

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

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

47 13. Any inconsistent provision of this chapter or other law notwith-  
48 standing, the department shall be responsible for furnishing medical  
49 assistance for preventative medical strategies, including prophylaxis,  
50 and treatment and services for eligible individuals who have sickle cell  
51 disease. For the purposes of this subdivision, "preventative medical  
52 strategies, treatment and services" shall include, but not be limited to  
53 the following:

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

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

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

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

7 TITLE IV

8 PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM

9 Section 3126. Prevention and treatment of sickle cell disease demon-  
10 stration program.

11 § 3126. Prevention and treatment of sickle cell disease demonstration  
12 program. 1. The commissioner shall establish and conduct a prevention  
13 and treatment of sickle cell disease demonstration program in the city  
14 of New York and for no more than five additional counties, for the  
15 purpose of developing and establishing systemic mechanisms to improve  
16 the prevention and treatment of sickle cell disease, including through:

17 (a) the coordination of service delivery for individuals with sickle  
18 cell disease;

19 (b) genetic counseling and testing;

20 (c) bundling of technical services related to the prevention and  
21 treatment of sickle cell disease;

22 (d) training of health professionals; and

23 (e) identifying and establishing other efforts related to the expan-  
24 sion and coordination of education, treatment, and continuity of care  
25 programs for individuals with sickle cell disease.

26 2. On or before the first of January, two thousand nineteen, the  
27 commissioner shall report to the governor, the speaker of the assembly  
28 and the temporary president of the senate on the impact that the  
29 prevention and treatment of sickle cell disease demonstration program  
30 has had on individuals with sickle cell disease in regards to coordi-  
31 nation of service delivery, genetic counseling and testing, bundling of  
32 technical services related to the prevention and treatment of sickle  
33 cell disease, training of health professionals and the identification  
34 and establishment of other efforts related to the expansion and coordi-  
35 nation of education, treatment, and continuity of care programs for such  
36 individuals.

37 § 5. The sum of one million dollars (\$1,000,000) is hereby appropri-  
38 ated to the department of health out of any moneys in the state treasury  
39 in the general fund to the credit of the state purposes account, not  
40 otherwise appropriated, and made immediately available, for the purpose  
41 of carrying out the provisions of this act. Such moneys shall be payable  
42 on the audit and warrant of the comptroller on vouchers certified or  
43 approved by the commissioner of health in the manner prescribed by law.

44 § 6. This act shall take effect immediately.