

3256--B

2015-2016 Regular Sessions

I N S E N A T E

February 4, 2015

Introduced by Sens. SANDERS, DILAN, HAMILTON, HASSELL-THOMPSON, LATIMER, PARKER, PERKINS -- read twice and ordered printed, and when printed to be committed to the Committee on Finance -- recommitted to the Committee on Finance in accordance with Senate Rule 6, sec. 8 -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the social services law and the public health law, in relation to establishing the sickle cell treatment act of 2016; 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 2016".
3 S 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

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

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1 non-Hispanic black mothers, 1 in 2,320 births to Hispanic mothers and 1
2 in 41,647 births to Caucasian mothers.

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

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

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

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

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

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

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

49 S 3. Section 365 of the social services law is amended by adding a new
50 subdivision 13 to read as follows:

51 13. ANY INCONSISTENT PROVISION OF THIS CHAPTER OR OTHER LAW NOTWITH-
52 STANDING, THE DEPARTMENT SHALL BE RESPONSIBLE FOR FURNISHING MEDICAL
53 ASSISTANCE FOR PREVENTATIVE MEDICAL STRATEGIES, INCLUDING PROPHYLAXIS,
54 AND TREATMENT AND SERVICES FOR ELIGIBLE INDIVIDUALS WHO HAVE SICKLE CELL
55 DISEASE. FOR THE PURPOSES OF THIS SUBDIVISION, "PREVENTATIVE MEDICAL

1 STRATEGIES, TREATMENT AND SERVICES" SHALL INCLUDE, BUT NOT BE LIMITED TO
2 THE FOLLOWING:

3 (A) CHRONIC BLOOD TRANSFUSION (WITH DEFEROXAMINE CHELATION) TO PREVENT
4 STROKE IN INDIVIDUALS WITH SICKLE CELL DISEASE WHO HAVE BEEN IDENTIFIED
5 AS BEING AT HIGH RISK FOR STROKE;

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

8 (C) OTHER TREATMENT AND SERVICES TO PREVENT INDIVIDUALS WHO HAVE SICK-
9 LE CELL DISEASE AND WHO HAVE HAD A STROKE FROM HAVING ANOTHER STROKE.

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

12 TITLE IV

13 PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM
14 SECTION 3126. PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMON-
15 STRATION PROGRAM.

16 S 3126. PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION
17 PROGRAM. 1. THE COMMISSIONER SHALL ESTABLISH AND CONDUCT A PREVENTION
18 AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM IN THE CITY
19 OF NEW YORK AND FOR NO MORE THAN FIVE ADDITIONAL COUNTIES, FOR THE
20 PURPOSE OF DEVELOPING AND ESTABLISHING SYSTEMIC MECHANISMS TO IMPROVE
21 THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE, INCLUDING THROUGH:

22 (A) THE COORDINATION OF SERVICE DELIVERY FOR INDIVIDUALS WITH SICKLE
23 CELL DISEASE;

24 (B) GENETIC COUNSELING AND TESTING;

25 (C) BUNDLING OF TECHNICAL SERVICES RELATED TO THE PREVENTION AND
26 TREATMENT OF SICKLE CELL DISEASE;

27 (D) TRAINING OF HEALTH PROFESSIONALS; AND

28 (E) IDENTIFYING AND ESTABLISHING OTHER EFFORTS RELATED TO THE EXPAN-
29 SION AND COORDINATION OF EDUCATION, TREATMENT, AND CONTINUITY OF CARE
30 PROGRAMS FOR INDIVIDUALS WITH SICKLE CELL DISEASE.

31 2. ON OR BEFORE THE FIRST OF JANUARY, TWO THOUSAND EIGHTEEN, THE
32 COMMISSIONER SHALL REPORT TO THE GOVERNOR, THE SPEAKER OF THE ASSEMBLY
33 AND THE TEMPORARY PRESIDENT OF THE SENATE ON THE IMPACT THAT THE
34 PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM
35 HAS HAD ON INDIVIDUALS WITH SICKLE CELL DISEASE IN REGARDS TO COORDI-
36 NATION OF SERVICE DELIVERY, GENETIC COUNSELING AND TESTING, BUNDLING OF
37 TECHNICAL SERVICES RELATED TO THE PREVENTION AND TREATMENT OF SICKLE
38 CELL DISEASE, TRAINING OF HEALTH PROFESSIONALS AND THE IDENTIFICATION
39 AND ESTABLISHMENT OF OTHER EFFORTS RELATED TO THE EXPANSION AND COORDI-
40 NATION OF EDUCATION, TREATMENT, AND CONTINUITY OF CARE PROGRAMS FOR SUCH
41 INDIVIDUALS.

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

49 S 6. This act shall take effect immediately.