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 2017".

§ 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 is a major health problem in the United States.
(2) Approximately 100,000 Americans have SCD with approximately 10% of SCD patients residing in New York state (NYS). In NYS, 1 in 1,146 live births have sickle cell disease, with 12% of NYS sickle cell disease births in the Hispanic population. Higher birth rates for children with sickle cell disease in NYS occur in mothers born outside of the United States. Approximately 1,000 American babies are born with the disease each year. SCD also is a global problem with close to 500,000 babies born annually with the disease.
(3) In the United States, SCD is most common in African-Americans and in those of Hispanic, Mediterranean, and Middle Eastern ancestry. Among newborn American infants nationally, SCD occurs in approximately 1 in 500 African-Americans, 1 in 36,000 Hispanics, and 1 in 80,000 Caucasians. In NYS, sickle cell disease occurs in 1 in 230 live births to non-Hispanic black mothers, 1 in 2,320 births to Hispanic mothers and 1 in 41,647 births to Caucasian mothers.
(4) More than 3,000,000 Americans, mostly African-Americans, have the 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.
who have inherited the normal hemoglobin gene from one parent and the
sickle cell gene from the other parent. A sickle cell trait is not a
disease, but when both parents have the sickle cell trait (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.
(5) Since 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 compli-
cations (acute chest syndrome), and priapism. During episodes of severe
pain, spleen enlargement, or acute lung complications, life threatening
complications can develop rapidly. Children with SCD are also at risk
for infections of the blood, meningitis, and stroke. Children with SCD
at highest risk for stroke can be identified and, thus, treated early
with regular blood transfusions for stroke prevention.
(6) The most feared complication for children with SCD is a stroke.
Stroke can either be silent (no overt symptoms) or clinical (with symp-
toms) 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. This impacts their ability to learn and/or hold a job. SCD is a
cumulative disease with worsening complications and organ involvement,
including lungs, heart and kidneys, as patients age.
(7) Many adults with SCD have acute problems, such as frequent pain
episodes and acute lung complications (acute chest syndrome) that can
result in death. Adults with SCD can also develop chronic problems,
including pulmonary disease, pulmonary hypertension, degenerative chang-
es in the shoulder and hip joints (bone necrosis), poor vision, and
kidney failure.
(8) The median life expectancy for SCD is about 45 years. While some
patients can remain without symptoms for years, many others may not
survive infancy or early childhood. Causes of death include bacterial
infection, stroke, and lung, kidney, heart, or liver failure. Bacterial
infections and lung injuries are leading causes of death in children and
adults with SCD.
(9) As a complex disorder with multisystem manifestations, SCD
requires specialized comprehensive and continuous care to achieve the
best possible outcome. Newborn screening, genetic counseling, and educa-
tion of patients and family members are critical preventative measures
that decrease morbidity and mortality, delays or prevents complications,
and reduces in-patient hospital stays, and decreases overall costs of care.
The legislature declares its intent to develop and establish systemic
mechanisms to improve the prevention and treatment 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 notwith-
standing, the department shall be responsible for furnishing medical
assistance for preventative medical strategies, including prophylaxis,
and 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 IV to read as follows:

TITLE IV
PREVENTION AND TREATMENT OF SICKLE CELL DISEASE DEMONSTRATION PROGRAM
Section 3126. Prevention and treatment of sickle cell disease demon-
stration program.
§ 3126. Prevention and treatment of sickle cell disease demonstration
program. 1. The commissioner shall establish and conduct a prevention
and treatment of sickle cell disease demonstration program in the city
of New York and for no more than five additional counties, for the
purpose of developing and establishing systemic mechanisms to improve
the prevention and treatment of sickle cell disease, including through:
(a) the coordination of service delivery for individuals with sickle
cell disease;
(b) genetic counseling and testing;
(c) bundling of technical services related to the prevention and
treatment of sickle cell disease;
(d) training of health professionals; and
(e) identifying and establishing other efforts related to the expan-
sion and coordination of education, treatment, and continuity of care
programs for individuals with sickle cell disease.
2. On or before the first of January, two thousand nineteen, the
commissioner 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 program
has had on individuals with sickle cell disease in regards to coordi-
nation of service delivery, genetic counseling and testing, bundling of
technical services related to the prevention and treatment of sickle
cell disease, training of health professionals and the identification
and establishment of other efforts related to the expansion and coordi-
nation of education, treatment, and continuity of care programs for such
individuals.
§ 5. The sum of one million dollars ($1,000,000) is hereby appropri-
ated 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, not
otherwise appropriated, 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.
§ 6. This act shall take effect immediately.