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## THE COUNCIL

# COMMITTEE REPORT OF THE HUMAN SERVICES Division

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**COMMITTEE ON HEALTH**

*Hon. Mark Levine, Chair*

#### February 26, 2020

**Proposed Res. No. 335-A:** By Council Members Dromm, Ampry-Samuel, Van Bramer, Miller, Levine, Rivera, Richards, Constantinides, Ayala, Cumbo, Adams, Eugene, Rosenthal, Rodriguez, Grodenchik, Lander, Lancman, Powers, Holden, Maisel, Cornegy, Moya, Koslowitz, Menchaca, Rose, Salamanca, Gibson, Cabrera, Koo, Perkins, Brannan, Vallone, Levin, Torres, Barron, Reynoso, Kallos, Louis, Chin, Ulrich and The Public Advocate (Mr. Williams)

**Title:**  Resolution calling upon the New York State Legislature to pass and fully fund, and the Governor to sign, A.6493/S.2281, legislation that would establish eight demonstration programs throughout New York State and one coordinating center to improve the care of sickle cell disease patients and educate about sickle cell trait

**Res. No. 980:** By Council Members Miller, Barron, Cornegy, Louis, Chin and Holden

**Title:**  Resolution declaring June 19 Sickle Cell Awareness Day in the City of New York

1. **INTRODUCTION**

On February 26, 2020, the Committee on Health, chaired by Council Member Levine, will hold a hearing on Resolution No. 335-A, calling upon the New York State Legislature to pass and fully fund, and the Governor to sign, A.6493/S.2281, legislation that would establish eight demonstration programs throughout New York State and one coordinating center to improve the care of sickle cell disease patients and educate about sickle cell trait, and Resolution No. 980, a resolution declaring June 19 Sickle Cell Awareness Day in the City of New York. These resolutions were originally heard at a hearing of this Committee on September 9, 2019, at which the Committee received testimony from the New York City Department of Health and Mental Hygiene (DOHMH), advocacy groups, and other concerned members of the public.

 **BACKGROUND**

*Sickle Cell Disease*

 Sickle Cell Disease (SCD) occurs when a person has two copies of a gene that cause the blood cells to be inflexible, sticky, and crescent or sickle shaped.[[1]](#footnote-1) The blood frequently gets stuck when trying to flow through blood vessels, causing intense pain and other serious problems, like anemia and stroke.[[2]](#footnote-2) When a person only has one copy of the gene, they have Sickle Cell Trait (SCT).[[3]](#footnote-3) Most individuals with SCT are healthy, yet, in rare instances, some people with SCT will experience pain.[[4]](#footnote-4) When two people with SCT have children, each one of their children has a 25 percent chance of having SCD and a 50 percent chance of having SCT.[[5]](#footnote-5)

In the United States, SCD is the most common inherited blood disorder.[[6]](#footnote-6) About 100,000 people in the U.S. are living with SCD, approximately 10 percent of which live in New York City.[[7]](#footnote-7) SCD is most common in individuals who have ancestors from Sub-Saharan Africa, South America, the Caribbean, Central America, the Middle East, and the Mediterranean.[[8]](#footnote-8) SCD occurs in one out of every 365 Black or African American births and one out of 16,300 Hispanic American births.[[9]](#footnote-9) In 2008, out of the 197 babies born in New York State with SCD, 136 of their births occurred in New York City.[[10]](#footnote-10) Many more people have SCT than SCD.[[11]](#footnote-11) SCT occurs in one out of every 13 Black or African American births.[[12]](#footnote-12)

Currently, the only cure for SCD is an extremely risky bone marrow or stem cell transplant.[[13]](#footnote-13) There are also a few medications to help people, but they mainly treat symptoms of SCD.[[14]](#footnote-14) SCD affects predominately minority communities, and there are many concerns that health officials, researchers, and doctors overlook the patients with SCD and the actual disease itself, likely in part as a result of conscious and unconscious bias.[[15]](#footnote-15) Although treatment can help people with SCD live quality lives, a study found that children who rely on public insurance were more likely to utilize urgent health care settings and delay preventative care and other necessary care for effective treatment.[[16]](#footnote-16) According to a *New York Times* article, about 90 percent of people with SCD are enrolled in Medicaid.[[17]](#footnote-17)

There are also reports that patients feel ignored or judged and do not want to seek medical help.[[18]](#footnote-18) Additionally, officials have shown a lack of interest in funding to help those with SCD.[[19]](#footnote-19) SCD is relatively rare, but other rarer diseases have gotten more attention.[[20]](#footnote-20) For example, in 2011, research for Cystic Fibrosis, which predominately affects white individuals,[[21]](#footnote-21) received 11 times more per-person funding from the National Institutes of Health (NIH) than SCD.[[22]](#footnote-22) The National spending for Cystic Fibrosis was 440 times that for SCD, and Cystic Fibrosis had more than twice as many peer-reviewed publications than SCD.[[23]](#footnote-23) Additionally, in 2011, the Food and Drug Administration (FDA) approved and released five medications for Cystic Fibrosis, while there were no new drugs for SCD.[[24]](#footnote-24) Since the FDA’s first drug approval for SCD in 1998, there have only been two other drug approvals for SCD, both of which occurred in 2017.[[25]](#footnote-25)

NYSDOH’s website has a page dedicated to providing information on health topics. Cystic Fibrosis and ALS (Lou Gehrig’s disease), both diseases that predominately affect white populations,[[26]](#footnote-26) have pages dedicated to providing the public with information and resources.[[27]](#footnote-27) These diseases are even rarer than SCD. About 30,000 people nationwide suffer from Cystic Fibrosis.[[28]](#footnote-28) Another 30,000 people in the U.S. have ALS.[[29]](#footnote-29) Although SCD affects more New Yorkers than these two diseases, there is no informational page for SCD on DOH’s website.[[30]](#footnote-30)

Res. No. 335-A

Resolution calling upon the New York State Legislature to pass and fully fund, and the Governor to sign, A.6493/S.2281, legislation that would establish eight demonstration programs throughout New York State and one coordinating center to improve the care of sickle cell disease patients and educate about sickle cell trait

By Council Members Dromm, Ampry-Samuel, Van Bramer, Miller, Levine, Rivera, Richards, Constantinides, Ayala, Cumbo, Adams, Eugene, Rosenthal, Rodriguez, Grodenchik, Lander, Lancman, Powers, Holden, Maisel, Cornegy, Moya, Koslowitz, Menchaca, Rose, Salamanca, Gibson, Cabrera, Koo, Perkins, Brannan, Vallone, Levin, Torres, Barron, Reynoso, Kallos, Louis, Chin, Ulrich and The Public Advocate (Mr. Williams)

Whereas, Sickle cell disease (SCD) affects approximately 100,000 Americans and is most common in those with African, Hispanic, Mediterranean and Middle Eastern ancestry; and

Whereas, Nationally, SCD occurs in approximately 1:365 Black or African American births, 1:16,300 Hispanic births and 1:80,000 White births, according to the Centers for Disease Control and Prevention (CDC); and

Whereas, In New York State (NYS) SCD occurs in 1:230 live births to non-Hispanic Black mothers, 1:2,320 births to Hispanic mothers and 1:41,647 to non-Hispanic White mothers; and

Whereas, In NYS, 1:1,146 live births have SCD, with 86% of NYS sickle cell disease births among babies with Black mothers and 12% with Hispanic mothers; and

Whereas, Higher birth rates for SCD occur in mothers who were born outside of the US; and

Whereas, In NYS, approximately 70% of all newborns with SCD were born in the NYC area; and

Whereas, 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; and

Whereas, Approximately 3 million Americans have SCT; and

Whereas, When both parents have SCT there is a 1 in 4 chance with each pregnancy that the child will be born with SCD; and

Whereas, Most people with SCT do not have any symptoms of SCD, however, in rare cases, people with SCT might experience complications of SCD; and

Whereas, The CDC states that SCD is a major public health concern; and

Whereas, Those with SCD may exhibit complications in all parts of the body; and

Whereas, This includes, but is not limited to, severe pain episodes, entrapment of blood within the spleen, severe anemia, acute lung complications (acute chest syndrome), stroke, priapism in males and other life-threatening conditions; and

Whereas, These life-threatening complications can develop rapidly, especially stroke and infections of the blood and brain; and

Whereas, Stroke can be either silent (no overt symptoms) or clinical (with symptoms); and

Whereas, Silent strokes occur in up to 35% of children with sickle cell anemia and clinically overt strokes occur in approximately 10% of children with sickle cell anemia, often causing cognitive impairments; and

Whereas, SCD is a cumulative disease with worsening complications and damage of organs, including lungs, heart and kidneys, as patients get older; and

Whereas, In addition, with the toll of the disease on patients, particularly to their brain, mental health issues can significantly impact the SCD patient and family; and

Whereas, As a complex disease with multisystem manifestations, SCD requires specialized, comprehensive and continuous care to achieve the best possible outcomes; and

Whereas, Newborn screening, genetic counseling and education of patients, family members, schools and health care providers are critical preventative measures; and

Whereas, Early detection can decrease morbidity, and holistic care reduces emergency room visits and in-patient hospital stays, decreasing overall costs of care; and

Whereas, Community-based organizations provide a valuable service in educating their communities about sickle cell disease and trait and, because they act as a bridge between the treatment centers and the community, should be included in any program to improve care to the community; and

Whereas, While SCD patients receiving regular care have improved clinical outcomes, many young adults transitioning out of pediatrics struggle to maintain their care; and

Whereas, A.6493/S.2281, sponsored by Senator James Sanders Jr. and Assembly Member Alicia Hyndman, would create eight regional prevention  and  treatment of SCD demonstration programs throughout NYS; and

Whereas, Over five years, the demonstration programs would coordinate service delivery, provide genetic counseling, conduct community outreach, promote mental health services and train health professionals; and

Whereas, A.6493/S.2281 would also create one statewide coordinating center to provide education and assistance to each program, establish statewide goals for standards of care, collect data and monitor progress; and

Whereas, A.6493/S.2281 would improve the quality of care for SCD patients, increase the average life expectancy for SCD patients, decrease the cost of care of sickle cell disease patients and educate communities about SCT and SCD; now, therefore, be it

Resolved, That the Council of the City of New York calls upon the New York State Legislature to pass and fully fund, and the Governor to sign, A.6493/S.2281, legislation that would establish eight demonstration programs throughout New York State and one coordinating center to improve the care of sickle cell disease patients and educate about sickle cell trait.

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Res. No. 980

..Title

Resolution declaring June 19 of each year Sickle Cell Awareness Day in the City of New York.

..Body

By Council Members Miller, Barron, Cornegy, Louis, Chin and Holden

Whereas, Sickle cell disease (SCD) is a group of inherited red blood cell disorders; and

Whereas, Hemoglobin is a protein in red blood cells that carries oxygen throughout the body and people with SCD inherit two abnormal hemoglobin genes, one from each parent; and

Whereas, The abnormal hemoglobin gene can cause red blood cells to become sickle-shaped (crescent-shaped) and have difficulty passing through small blood vessels; and

Whereas, Those who have inherited an abnormal hemoglobin gene from one parent but a normal hemoglobin gene from the other parent have sickle cell trait (SCT); and

Whereas, People with SCT usually do not have any of the signs of the disease, but they can pass the trait on to their children; and

Whereas, According the Centers for Disease Control and Prevention (CDC), SCD is more common among people whose ancestors came from sub-Saharan Africa, Spanish-speaking regions in the Western Hemisphere, Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy; and

Whereas, The National Institutes of Health (NIH) estimates that about 2 million people in the United States have SCT, and the CDC estimates about 100,000 Americans have SCD; and

Whereas, According to the CDC, approximately one out of every 365 Black or African American babies is born with SCD, and about 1 in every 13 Black or African American babies is born with SCT; and

Whereas, According to the CDC, there were approximately 8,374 people with SCD living in New York State in 2004-2008; and

Whereas, In 2008, 197 babies were born with SCD in New York State; and

Whereas, SCD occurred among approximately 1 out of every 1,259 births, and 1 out of every 260 Black or African American births; and

Whereas, Of the 197 babies born with SCR in New York State in 2008, 89 percent were Black or African American; and

Whereas, In 2008, 56 babies were born with SCD in the Bronx, the highest number in the State, followed by 47 in Brooklyn and 23 in Queens; and

Whereas, The severity of SCD can vary widely from person to person; and

Whereas, SCD can cause organ damage and attacks of sudden and severe pain, which often requires a hospital visit; and

Whereas, The only known cure for SCD is bone marrow or stem cell transplant, and is very risky and can have serious side effects, including death; and

Whereas, Early diagnosis and regular medical care can reduce symptoms, prevent complications, and prolong life, thus making awareness of SCD and SCT crucial; and

Whereas, June 19 is recognized by the United Nations as World Sickle Cell Day; now, therefore, be it

Resolved, That the Council of the City of New York declares June 19 of each year Sickle Cell Awareness Day in the City of New York.

EB

LS 10291

03/27/19

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6. *The FDA Encourages New Treatment for Sickle Cell Disease,* FDA, June 6, 2018, available at <https://www.fda.gov/consumers/consumer-updates/fda-encourages-new-treatments-sickle-cell-disease> [↑](#footnote-ref-6)
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