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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, Deutsch, 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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