Legislation Details (With Text)

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Title: Resolution calling on New York State Legislature to pass, and the Governor to sign, S1839A/A2609 and S1890/A2661, the Sickle Cell Treatment Act.

Sponsors:

Indexes:

Attachments: 1. Res. No. 771, 2. Committee Report 9/20/23, 3. Hearing Testimony 9/20/23, 4. Hearing Transcript 9/20/23, 5. September 14, 2023 - Stated Meeting Agenda, 6. Hearing Transcript - Stated Meeting 9-14-23, 7. Minutes of the Stated Meeting - September 14, 2023

Date	Ver.	Action By	Action	Result
9/14/2023	*	City Council	Introduced by Council	
9/14/2023	*	City Council	Referred to Comm by Council	
9/20/2023	*	Committee on Health	Hearing Held by Committee	
9/20/2023	*	Committee on Health	Laid Over by Committee	
9/20/2023	*	Committee on Hospitals	Hearing Held by Committee	
9/20/2023	*	Committee on Hospitals	Laid Over by Committee	
12/31/2023	*	City Council	Filed (End of Session)	

Res. No. 771

Resolution calling on New York State Legislature to pass, and the Governor to sign, S1839A/A2609 and S1890/A2661, the Sickle Cell Treatment Act.

By Council Members Narcisse, Stevens, Gutiérrez, Louis, Lee, Schulman, Hanif and Brewer

Whereas, Sickle cell disease (SCD) is a group of inherited conditions characterized by abnormal hemoglobin, which could deform or rapture red blood cells leading to chronic pain, stroke, vulnerability to infections, pulmonary hypertension, vision loss, organ damage, and an accumulation of serious health complications including premature death; and

Whereas, SCD affects millions of people throughout the world and disproportionately affects individuals of African, Mediterranean, Middle Eastern, South Asian, and Central and South American descent;

and

Whereas, According to the Centers for Disease Control and Prevention (CDC), SCD affects approximately 100,000 Americans, 10% of whom live in New York State (NYS); and

Whereas, In 2008, the CDC conducted a report on SCD in NYS, and found that SCD occurs among approximately 1 out of every 1,259 births, 1 out of every 260 Black or African-American births, 1 out of every 10,209 white births, and 1 out of every 2,714 Hispanic-American births; and

Whereas, Per the CDC report, approximately 80% of individuals diagnosed with SCD in NYS lived in New York City (NYC) and 76% of newborns with SCD are born in NYC; and

Whereas, Of the 197 babies born with SCD in NYS in 2008, the last time when such data was publicly reported, 80% of these babies were Black or African American, 8% white, 11% Hispanics-Americans, and 3% other or unknown race; and

Whereas, Many suffering from SCD die at an age that is younger than the average lifespan, such as in NYS, where only 14% of individuals diagnosed with SCD lived past the age of 51 years; and

Whereas, Bone marrow or stem cell transplant is the only FDA-approved cure available to individuals suffering from SCD-and it is both an extremely risky and expensive procedure that many cannot afford or qualify for; 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, Both SCT and SCD can be detected before birth or at birth through screening tests and can be

managed with comprehensive care and preventive measures; and

Whereas, However, in NYS, Hospitals only began testing for SCT and SCD in 2006, which means that an entire generation born before this time could be unaware of whether they are an SCD or SCT carrier; and

Whereas, According to the CDC, 1 in 13 Black or African American babies is born with SCT, highlighting the immediate need for early detection and education; and

Whereas, The CDC states that SCD is a major public health concern with life-threatening complications that can develop rapidly and worsen as patients age; and

Whereas, Given the complexity, seriousness, and cost of SCD, patients and physicians often struggle to care for the symptoms and health complications caused by SCD; and

Whereas, SCD requires specialized, comprehensive and continuous care to achieve the best possible outcomes; and

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

Whereas, To address these issues, NYS Senator James Sander Jr. and Assemblywoman Alicia L. Hyndman have introduced S1890/A2661, known as the Sickle Cell Treatment Act, and S1839A/A2609; and

Whereas, S1839A/A2609 aims to establish a sickle cell disease detection and education program within the NYS Department of Health to provide information and resources to individuals with SCD, their families, health care providers, and the general public; and

Whereas, The Sickle Cell Treatment Act, if passed, would establish 5 sickle cells centers of excellence and 10 outpatient treatment centers, staffed by specialists dedicated to serving SCD patients; and

Whereas, Together, these two bills would help increase awareness, knowledge, and understanding of SCD and its complications while improving access to quality prevention, care, and treatment, thereby reducing health disparities, complications, and mortality associated with SCD; now, therefore, be it

Resolved, That the Council of the City of New York calls on New York State Legislature to pass, and

the Governor to sign, S1839A/A2609 and S1890/A2661, the Sickle Cell Treatment Act.

LS # 14158 & 3455
09/08/2023
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