



February 24, 2023

Re: New York Senate Bill 1839 and Assembly Bill 6430 – Sickle Cell Disease Detection and Education Program

For Your Consideration,

Sickle cell is a hereditary and life-threatening disease that afflicts an estimated 100,000 people in the United States. New York State has one of the largest populations of sickle cell patients who suffer from the painful effects of the disease every day, leading to long-term damage to the heart, kidneys, brain, and eyes.

We thank you for your continued support of rare, life-threatening, diseases and urge you to continue to use your position to advocate for those who need a strong voice in Albany.

The undersigned organizations strongly support Senate Bill **S1839** (Sanders) and Assembly Bill **A6430** (Hyndman). This legislation will create the sickle cell disease detection and education program, an important step in the educating those with sickle cell and health care professionals. This legislation passed in 2022 but was unfortunately vetoed by the Governor who cited cost with this and several other bills that created educational programs.

The bill would allow the Commissioner to make grants available to approved organizations and community-based organizations, establish an advisory council and require the Commissioner to submit an annual report. A Sickle cell disease detection and education program is crucial to protecting parents and children who are carriers of the trait. There are generations of affected people who are not aware that they are carriers of Sickle Cell Trait and could pass it on to their children. Education and screening to under-served populations is necessary to protect future generations of children in the United States. If approved, a portion of the funds will be allocated to community-based organizations like SCTPN to help educate and spread awareness to SCD community and those who love and care for them – an essential part of our mission.

Sickle cell disease disproportionately impacts historically underserved communities. The actual numbers of sickle patients are unknown as the disease has been historically ignored by the health care system and the medical research community since its discovery over 100 years ago. Patients with SCD suffer from painful crises that often send them to the Emergency Department as well as long-term damage to the heart, kidneys, brain, and eyes. Despite some medical advances in treating SCD, most patients require lifelong treatment, significant use of healthcare resources, and ultimately result in reduced life expectancy.

Now more than ever we must address the needs of our communities of color. The chronic nature of sickle cell disease combined with the fact that these patients belong to an already underserved population means these they do not have the resources needed to access care. Systemic racism, unconscious bias, and the stigma associated with the diagnosis further drive health inequities within the sickle cell disease community.

To continue this important work, we ask for \$750,000 under S1839/A6430 to support our educational programs and, more importantly, our patients and their families.

Please do not hesitate to contact me at gdavis@sctpn.net or by phone at (347) 385-8549 with any questions or comments.

Respectfully,
Teresa Ginger Davis
President
Sickle Cell/Thalassemia Patient Network

The Sickle Cell Thalassemia Patient Network (SCTPN) is a federally approved 501(c) 3, local non-profit organization dedicated to improving the quality of life for individuals and families living with sickle cell disease, thalassemia and other inherited blood disorders through education, advocacy and support interactions. Our goal is to provide those living with SCD a chance to live healthier and more productive lives by diminishing the negative social, psychological, and economic impact these debilitating disorders have on our community.

Co-Signers

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