City Council
Chief Clerk's Office
402 City Hall
Philadelphia, PA 19107

Legislation Text

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Urging federal policymakers to ensure that individuals with Sickle Cell Disease have access to all medications and forms of treatment for Sickle Cell Disease, no matter their form of health care insurance.

WHEREAS, Sickle Cell Disease (SCD) is a severe, life-shortening inherited disease that affects the red blood cells and impacts predominantly people of color -particularly African Americans; and

WHEREAS, Sickle Cell Disease is a disease in which a person's body produces abnormally shaped red blood cells that resemble a crescent or sickle and do not last as long as normal round red blood cells, leading to anemia. The sickle cells also get stuck in blood vessels and block blood flow, resulting in vaso-occlusive crises, which can cause pain and organ damage; and

WHEREAS, Individuals living with Sickle Cell Disease experience severe pain, anemia, organ failure, stroke, and infection; and in one recent study, more than 30% of those diagnosed experienced premature death, and another recent study estimates that the life expectancy for individuals with sickle cell disease is 54 years; and

WHEREAS, According to the Pennsylvania Department of Health, an estimated 3,870 Pennsylvanians were reported to be living with Sickle Cell Disease. However, the exact number of people with sickle cell disease is unknown. There is a need for comprehensive and coordinated data collection efforts to further understand and quantify the scope and impact of Sickle Cell Disease on patients, communities, states, and the nation; and

WHEREAS, Penn Medicine Comprehensive Sickle Cell Program provides world-renowned care for Sickle Cell adults and offers a multidisciplinary approach to care; and

WHEREAS, In the more than 100 years since the underlying cause of Sickle Cell Disease was discovered, the sickle cell patient community has received relatively little attention and few resources, and these individuals have suffered due to racial discrimination in the health care system in addition to life-threatening disease burden; and

WHEREAS, Individuals living with Sickle Cell Disease encounter barriers to obtaining quality care and improving their quality of life, these barriers include limitations in geographic access to comprehensive care, the varied use of effective treatments, the discrimination of being labeled "drug seekers" when seeking care during a crisis, the high reliance on emergency care, and the limited number of health care providers with knowledge and experience to manage and treat Sickle Cell Disease; and

WHEREAS, After decades of relatively little progress being made in therapeutic innovations for Sickle Cell Disease, several therapies for Sickle Cell Disease have been approved in the last few years, providing patients and their physicians with new therapeutic options to manage and treat their condition; and

WHEREAS, With several rapidly progressing one-time genetic therapies in clinical development, we are now on the verge of a potential cure for some patients living with Sickle Cell Disease. These investigational approaches are still being evaluated in clinical trials, and such therapies have the potential to revolutionize the

practice of medicine and transform the lives of individuals living with Sickle Cell Disease; and

WHEREAS, Scientific and medical research advances need to be coupled with health care delivery and payment policies to ensure universal access to innovative pipeline products, particularly for Medicaid beneficiaries; and

WHEREAS, At present, gaps exist within Sickle Cell Disease care and are most glaring within the Medicaid system, but exists for Medicare beneficiaries and patients enrolled in private coverage as well; and

WHEREAS, The Philadelphia City Council represents communities in Philadelphia most affected by Sickle Cell Disease; and

WHEREAS, There is a need for states to provide open access to therapies that treat SCD, particularly innovative therapies that have been approved in recent years to treat the underlying cause of the disease; and

WHEREAS, There is a need to advocate for the ability to improve the quality of health, life, and services for individuals, families, and communities affected by Sickle Cell Disease and related conditions while promoting the search for a cure for all people in the world and the Commonwealth with Sickle Cell Disease; and

WHEREAS, To effectively prevent or treat hemoglobin disorders, efforts would require the strengthening of existing medical and genetic services in low-and middle-income communities; and

WHEREAS, Efforts should focus on the identification and the promotion of affordable interventions, including but not limited to community education, training of health professionals, newborn screening for early diagnosis of Sickle Cell Disease; and

WHEREAS, Involving other potential stakeholders, such as patient and parents' organizations and other national and international health-related-agencies would significantly contribute towards efforts relating to advocacy, technology transfer, and capacity building; now, therefore, be it

RESOLVED, THAT THE COUNCIL OF THE CITY OF PHILADELPHIA, Hereby urges federal policymakers to ensure that individuals with Sickle Cell Disease have access to all medications and forms of treatment for Sickle Cell Disease, no matter their form of health care insurance.