PRINTER'S NO. 3511

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 230 Session of 2022

INTRODUCED BY KINSEY, BULLOCK, HOHENSTEIN, HILL-EVANS, McNEILL, SAPPEY, HENNESSEY, MILLARD, SANCHEZ, SCHLOSSBERG, WARREN, MADDEN, PARKER, DELLOSO, BRADFORD AND MALAGARI, SEPTEMBER 21, 2022

REFERRED TO COMMITTEE ON HEALTH, SEPTEMBER 21, 2022

A RESOLUTION

Ensuring greater access to sickle cell disease treatments and designating the Department of Health to conduct a comprehensive and coordinated data collection effort to better understand and quantify the scope and impact of sickle cell disease on patients, communities and states throughout the United States.

WHEREAS, Sickle cell disease is a severe, life-shortening and inherited blood disorder that predominantly impacts 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

WHEREAS, Sickle cell disease typically first appears in children around six months of age; and

WHEREAS, Symptoms of sickle cell disease may include anemia, pain, swelling of hands and feet, frequent infections, delayed growth or puberty and vision problems; and

WHEREAS, According to the Department of Health, an estimated 3,870 Pennsylvanians were reported living with sickle cell

disease in 2019-2020; and

WHEREAS, The exact number of people with sickle cell disease nationwide is still unknown, though the Centers for Disease Control and Prevention estimates that sickle cell disease affects more than 100,000 Americans; and

WHEREAS, Sickle cell disease occurs in approximately 1 out of every 365 Black or African-American births nationwide; and

WHEREAS, Individuals living with sickle cell disease encounter barriers to obtaining quality care, such as limited geographic access, financial and socioeconomic barriers, specialist availability, transportation needs, translation services and social factors, such as stigma, bias and lack of public awareness; and

WHEREAS, Due to new treatments, individuals with sickle cell disease now have a longer life expectancy, improved quality of life and survival rates past 50 years of age; and

WHEREAS, However, there is a need for more comprehensive and coordinated data collection efforts to better understand and quantify the scope and impact of sickle cell disease; and

WHEREAS, Further, there is a need for states to provide open access to therapies that treat sickle cell disease, particularly innovative therapies that have been approved in recent years to treat the underlying cause of the 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, Efforts should focus on the identification and the promotion of affordable interventions, including community education, training of health professionals and newborn

screening for early diagnosis of sickle cell disease; and

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

RESOLVED, That the House of Representatives ensure greater access to sickle cell disease treatments and designate the Department of Health to conduct a comprehensive and coordinated data collection effort to better understand and quantify the scope and impact of sickle cell disease on patients, communities and states throughout the United States; and be it further

RESOLVED, That the House of Representatives and members of the Legislative Black Caucus urge Federal policymakers to ensure that individuals with sickle cell disease have access to all medications and forms of treatment for the disease, including services for enrollees who are diagnosed with the disease and who are eligible for covered services under Medicare and Medicaid programs, and to ensure that new and effective treatments are developed for sickle cell disease.