HEALTH AND HUMAN SERVICES (HHS)

Resolution **HHS-22-33**

SUPPORTING INNOVATIVE THERAPIES FOR SICKLE CELL DISEASE

WHEREAS, the National Black Caucus of State Legislators (NBCSL) has a long commitment to combating sickle cell disease and has passed and adopted Resolution HHS-21-17 A RESOLUTION ON EQUITABLE ACCESS FOR TRANSFORMATIVE THERAPIES FOR SICKLE CELL DISEASE.

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;

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 that do not last as long as normal round red blood cells, which leads 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;

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;

WHEREAS, the Centers for Disease Control and Prevention estimates that sickle cell disease affects more than 100,000 people in the United States, the exact number of people with sickle cell disease is unknown, there is a need for comprehensive and coordinated data collection efforts to better understand and quantify the scope and impact of sickle cell disease on patients, communities, states, and the nation;

WHEREAS, according for the Centers for Medicare and Medicaid Services more than 40% of sickle cell disease patients are covered by Medicaid;

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;

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 labelled "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;

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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;

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, such therapies have the potential to revolutionize the practice of medicine and transform the lives of individuals living with sickle cell disease;

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;

WHEREAS, at present, gaps of care exist within sickle cell disease and are most glaring within the Medicaid system, but exist for Medicare beneficiaries and patients enrolled in private coverage as well;

WHEREAS, the NBCSL represents communities and states across the country most affected by sickle cell disease;

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;

WHEREAS, SCD treatments have improved over the years and new ones are emerging from drug company pipelines patients still face serious complications, high rates of hospitalization and early death compared to the general population. patients are experiencing sub-optimal access due to Medicaid health plans imposing prior authorization and step therapy requirements;

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 with sickle cell disease;

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;

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 sickle cell disease;

WHEREAS, involving other potential stakeholders, such as patients/parents' organizations and other national and international health related agencies would significantly contribute towards efforts relating to advocacy, technology transfer and capacity building; and

WHEREAS, the transition from pediatric to adult healthcare is a critical time for SCD patients, and mortality rates and total treatment costs significantly increase during the young adult years.

THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL) urges state and federal policymakers to ensure that individuals with sickle cell disease have access to all medications and forms of treatment for sickle cell disease, and services for enrollees with a diagnosis of sickle cell disease, that are eligible for coverage under Medicare and Medicaid programs and work to include new and effective treatments;

BE IT FURTHER RESOLVED, that state Medicaid programs should conduct an annual review to determine if the available covered medications, treatments, and services are adequate to meet the needs of enrollees with a diagnosis of sickle cell disease, and whether Medicaid should seek to add additional medications, treatments, or services;

BE IT FURTHER RESOLVED, that when conducting the annual review, the state Medicaid program and/or the appropriate state agency shall solicit and consider input from the general public, with specific emphasis on attempting to receive input from persons or groups with knowledge and experience in the area of sickle cell disease treatment, including, but not limited to, patients, caregivers, patient advocacy organizations, and hematologists/treating physicians, and other healthcare professionals;

BE IT FURTHER RESOLVED, that, when conducting the annual review, the state Medicaid program and/or the appropriate state agency such as the Department of Health shall identify opportunities where disease education, sickle cell disease services, access to care, access to information and resources for sickle cell disease patients can all be improved;

BE IT FURTHER RESOLVED, that state Medicaid programs should proactively explore innovative reimbursement, coverage and access approaches which may facilitate equitable and appropriate access to potential curative one-time therapies for eligible patients, which may include separate payments from inpatient bundling, outcomes-based arrangements, and other innovative approaches;

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BE IT FURTHER RESOLVED, that state Medicaid programs and other state officials should convene a multi-stakeholder dialogue, including patients, caregivers, physicians, and hospital administrators, to inform and begin working toward policies that will support equitable and appropriate access to innovative sickle cell disease therapies;

BE IT FURTHER RESOLVED, that states and the Federal government should explore enhanced and expanded data collection efforts to determine how many people live with sickle cell disease in the United States, how sickle cell disease affects their health, and how researchers can improve medical treatments to extend and improve the lives of people with sickle cell disease, as well as to better inform policies that impact the sickle cell disease patient community;

BE IT FURTHER RESOLVED, that the NBCSL urges state and federal policymakers to examine and address, when possible, the regulatory barriers that have and may continue to impede patient access to novel therapies, including one-time, potentially curative therapies;

BE IT FURTHER RESOLVED, that state Medicaid programs should work to ensure that sickle cell patients in state Medicaid programs have access to potentially curative therapies when those treatments are proven and federally approved;

BE IT FURTHER RESOLVED, that state and federal policymakers take all necessary actions to identify and remove other impediments on patients and their families, such as logistical and financial challenges, including missing work, childcare, and other issues, that may prevent or otherwise impede all patients including sickle cell patients from accessing potentially curative therapies; and

BE IT FINALLY RESOLVED, that a copy of this resolution be transmitted to the President of the United States, the Vice President of the United States, members of the United States House of Representatives and the United States Senate, and other federal and state government officials and agencies as appropriate.

SPONSOR(S): Senator Raumesh Akbari, Representative Billy Mitchell (GA), Representative Harold Love (TN), and Representative Karen Camper (TN)
Committee of Jurisdiction: Health and Human Services (HHS) Policy Committee
Ratified in Plenary Session: December 2, 2021
Ratification certified by: Representative Billy Mitchell (GA), NBCSL President