

# HEALTH AND HUMAN SERVICES

Resolution HHH-21-17

## A RESOLUTION ON EQUITABLE ACCESS FOR TRANSFORMATIVE THERAPIES FOR SICKLE CELL DISEASE

WHEREAS, sickle cell anemia and sickle cell disease, used interchangeably, refer to a group of inherited disorders that affect the red blood cells;

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;

WHEREAS, 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, sickle cell disease is a genetic disorder where individuals with the disease are born with two sickle cell genes, each inherited from one parent;

WHEREAS, an individual with only one sickle cell gene has a "sickle cell trait," which occurs in one out of every 13 African Americans and in one out of every 100 Latinos in the United States;

WHEREAS, the United States Centers for Disease Control and Prevention estimate that sickle cell disease affects approximately 100,000 Americans, and occurs among about 1 in every 365 Black or African-American births and 1 out of every 16,300 Hispanic-American births;

WHEREAS, the National Institutes of Health is working on innovative genetic therapies that could someday cure sickle cell disease;

WHEREAS, the Food and Drug Administration has granted Orphan Drug designation to sickle cell therapies to provide incentives and encourage the development of therapies for rare diseases;

WHEREAS, the Food and Drug Administration granted accelerated approval for a new treatment for sickle cell disease at the end of 2019;

WHEREAS, sickle cell disease is a chronic condition that can affect any organ, including the kidneys, lungs, and spleen, and research indicates that patients experience many severe complications, including stroke, infections, and pulmonary embolism, and have a shorter life expectancy than the general population;

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WHEREAS, Vaso-occlusive crises are a common painful complication of sickle cell disease in adolescents and adults which may occur several times a year, and these recurrent episodes induce severe pain; decrease quality of life; can cause life-threatening complications, including stroke; are the primary cause of hospitalizations in sickle cell disease; and are associated with increase mortality;

WHEREAS, Vaso-occlusive crises are the leading cause of hospitalizations that last several days;

WHEREAS, sickle cell disease can be a life-threatening condition leading to a 25 to 30-year reduction in life expectancy, and access to comprehensive care can be limited by social, economic, cultural, and geographic barriers;

WHEREAS, according to a 2018 study, the total economic burden on the US healthcare system associated with sickle cell disease was 2.98 billion dollars annually, of which 57% was attributed to hospital inpatient costs;

WHEREAS, the estimated annual medical cost for patients with sickle cell disease range from more than \$34,000 to more than \$286,000;

WHEREAS, nationwide, more than 70% of patients with sickle cell disease are insured under state Medicaid programs;

WHEREAS, individuals living with sickle cell disease encounters 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 high reliance on emergency care and on public health programs, and the limited number of health care providers with knowledge and experience to manage and treat sickle cell disease;

WHEREAS, historically and continuing today, the sickle cell disease patient community has been medically underserved, a fact which President Richard Nixon recognized in 1972 when he signed the Sickle Cell Anemia Control Act into law, pledging that his administration would “reverse the record of neglect of the dreaded disease;”

WHEREAS, while there is no widely available cure for sickle cell disease, one-time gene therapies, including gene editing therapeutic approaches, are being developed which may offer potential cures for some patients;

WHEREAS one-time, potentially curative therapies for sickle cell disease may offer substantial savings over the patient’s lifetime by avoiding future the cost of future health services; and

WHEREAS, The National Black Caucus of State Legislators represents communities and states across the country most affected by sickle cell disease.

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THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators(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, child care, 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 Marilyn Moore (CT) and Representative Gregory Porter (IN)**

**Committee of Jurisdiction: Health and Human Services Policy Committee**

**Certified by Committee Co-Chairs: Representative David J. Mack, III (SC) and Senator Marilyn Moore (CT)**

**Ratified in Plenary Session: Ratification Date is December 3, 2020**

**Ratification is certified by: Representative Gilda Cobb-Hunter (SC), President**