

# HEALTH AND HUMAN SERVICES

Resolution HHS-18-04

## A RESOLUTION ENCOURAGING INCREASED SICKLE CELL DISEASE RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT

WHEREAS, Sickle cell disease is an inherited blood disorder affecting approximately 100,000 Americans which causes the destruction and deformation of red blood cells due to the presence of abnormal hemoglobin, resulting in anemia and vaso-occlusive crisis, which essentially means the blocking of blood vessels due to sticky, inflexible, sickled-shaped red blood cells.

WHEREAS, one in every 400 African American newborns has Sickle Cell disease, as does one in every 1,200 newborns of Hispanic descent;

WHEREAS, in 2004, Congress recognized the need to do more to improve the treatment and prevention of sickle cell disease; specifically, as part of the American Jobs Creation Act, a Sickle Cell Disease Prevention and Treatment Demonstration Program was enacted;

WHEREAS, the Sickle Cell Disease Association of America, (SCDAA) a national organization that advocates for sickle cell disease, represents 45-member organizations, 35 affiliate partners, and over 100,000 patients and their families affected with sickle cell disease has initiated this request of legislation as the national advocacy agency for sickle cell disease;

WHEREAS, cogent policies dedicated to expanding, coordinating, and implementing transition services for adolescents with Sickle Cell disease making the transition to adult-focused health care;

WHEREAS, increased surveillance grant programs would allow state Departments of Health to gather data on health outcomes, complications, and treatments related to Sickle Cell disease to develop therapies and strategies;

WHEREAS, SCDAA has been working in partnership with the American Society of Hematology, in support of the reauthorization of the sickle cell disease programs and on other legislative and regulatory initiatives to better meet the needs of this underserved community; and

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

THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL), urges Congress to reauthorize and fund, legislation, to assure program stability and allow for a broader reach into areas of the country where people with sickle cell disease are not being adequately served;

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BE IT FURTHER RESOLVED, that the NBCSL urges medical providers to engage in training to decrease bias and perception of pain management in the face of the opioid crisis; 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 U.S. Congress, and other federal and state officials as appropriate.

**SPONSOR(s): Senator Gladys A. Robinson (NC) and Representative John Richard C. King (SC)**

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

**Certified by Committee Chair(s): Representative John Richard C. King (SC) and Representative Toni Rose (TX)**

**Ratified in Plenary Session: Ratification Date is December 2, 2017**

**Ratification is certified by: Representative Gregory W. Porter (IN), President**