

HEALTH AND HUMAN SERVICES

Resolution HHS-18-27

A RESOLUTION CALLING ON FUNDING FOR RESEARCH, TRAINING, AND INCENTIVES FOR THE ESTABLISHMENT OF A SICKLE CELL REGISTRY

WHEREAS, the National Black Caucus of State Legislators (NBCSL) supports initiatives designed to address health care disparities and inequalities that occur throughout communities served by NBCSL legislators;

WHEREAS, the mission of the NBCSL is to develop, conduct, and promote educational, research, and training programs designed to enhance the effectiveness of its members;

WHEREAS, according to the Centers for Disease Control and Prevention (CDC), sickle cell disease (SCD) affects 100,000 Americans and occurs in 1 of every 365 Black or African American birth and about 1 in 13 Black or African American babies is born with sickle cell trait (SCT);

WHEREAS, in 2010, the CDC and the National Heart, Lung, and Blood Institute began a two year effort to collect data on individuals with SCD and thalassemia in the states of California, Florida, Georgia, Michigan, New York, North Carolina, and Pennsylvania, as part of the Sickle Cell Surveillance and Registry Program (SCSR Program), to report on the data collected, and to launch related health prevention and promotion activities;

WHEREAS, the SCSR Program found that the total healthcare costs associated with SCD were more than one billion dollars annually, the total hospital costs for hospitalizations principally for SCD were approximately 488 million dollars, and among those hospital stays, approximately 66 percent were paid by Medicaid and 13 percent were paid by Medicare;

WHEREAS, the SCSR Program also found that current challenges include the unknown prevalence of SCD, a lack of access to specialty and quality care, especially for adults and including management or acute painful episodes, a lack of understanding of risk factors and complications over the lifespan, an absence of a national coordination of services, and a lack of community awareness;

WHEREAS, health care professionals specializing in the treatment of patients with SCD or conducting research relating to SCD or SCT are not compensated as highly as their peers specializing in other areas of medicine, which undermines the retention of qualified health care professionals willing to provide these services;

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WHEREAS, medical and nursing schools and licensing boards do not require sufficient education or training about the symptoms, treatment, and management of SCD;

WHEREAS, legislation to establish new federal sickle cell disease research, surveillance, prevention, and treatment programs, including through the award of grants to collect data on the prevalence and demographics of SCD and SCT has been introduced in Congress;

WHEREAS, sickle cell patient registries would facilitate the collection of data nationwide about the incidence and nature of SCD and SCT, which could be used to educate primary, specialty, and emergency care physicians and other health care practitioners, inform policy discussions, and raise public awareness;

WHEREAS, a sickle cell patient registry through which a physician may register patients with SCD or SCT could help coordinate and improve access to care, especially for patients who seek acute care, and improve the services provided to help patients manage symptoms;

WHEREAS, improved access to care should include access to effective management of painful acute episodes, including through the prescription of appropriate medication as determined by the treating physician;

WHEREAS, SCD and SCT education and training requirements for physicians, nurses and other healthcare professionals would improve access to quality care; and

WHEREAS, loan forgiveness programs and other financial incentives targeting health care professionals who choose to specialize in diagnosing and treating patients with SCD or SCT would promote the quality of care provided to these patients.

THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL) recognizes that sickle cell disease (SCD) and sickle cell trait (SCT) significantly impact the communities served by NBCSL legislators, there is a need to collect and analyze data on the prevalence of SCD and SCT throughout the nation, and use of voluntary sickle cell registries can be an effective tool to promote data collection and analysis;

BE IT FURTHER RESOLVED, that the NBCSL urges state legislatures and departments of health to take the steps necessary to create and maintain a voluntary sickle cell patient registry to collect and study data on the incidence and nature of SCD and SCT to improve patient care and access to services;

BE IT FURTHER RESOLVED, that the NBCSL urges state legislatures and departments of health in jurisdictions that allow the use of cannabis for medical purposes to include acute painful episodes of SCD as a qualifying condition authorizing the patient to use cannabis to

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control the pain, and to encourage state legislatures in states not yet allowing the use of cannabis for medical purposes to legalize the practice;

BE IT FURTHER RESOVLED, that the NBCSL urges medical providers to engage in training and knowledge on bias as it relates to pain management in the face of the opioid crisis;

BE IT FURTHER RESOLVED, that the NBCSL urges state legislatures, medical and nursing schools, and health care licensing boards to require training and education in SCD symptoms, diagnosis, treatment, and management, especially for adult patients;

BE IT FURTHER RESOLVED, that the NBCSL urges state legislatures and medical and nursing schools to consider loan forgiveness programs and other financial incentives to increase the number of health care practitioners who are appropriately qualified to diagnose and treat SCD and to retain those health care professionals; and

BE IT FINALLY RESOLVED, that the NBCSL send a copy of this resolution to the President of the United States, the Vice President of the United States, members of Congress, and other federal and state government officials as appropriate.

SPONSOR: 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