Recognizing the Need for Improved Access to Care, Education, Data Collection and Innovative Therapies for Sickle Cell Disease including access to fertility preservation.

EXECUTIVE SUMMARY:

This resolution recognizes that sickle cell disease is a life-shortening condition affecting over 100,000 people in the United States. It further acknowledges that sickle cell disease predominantly impacts people of color and has thus received comparatively little attention from the medical research community. The resolution resolves that there is a need for improved data collection on sickle cell disease and policymakers should ensure that sickle cell disease patients have access to quality care and appropriate treatments, including potentially curative gene therapies, and explore innovative reimbursement and coverage approaches to achieve this goal.

ADDRESSING LONGSTANDING MISTREATMENT OF SICKLE CELL PATIENTS IN HEALTHCARE FACILITIES

WHEREAS, Sickle cell disease is a severe, life-shortening inherited disease that affects the red blood cells and impacts predominantly people of color – especially African Americans;

WHEREAS, although 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, comprehensive and coordinated data collection efforts are needed to better understand and quantify the scope and impact of sickle cell disease on patients, communities, states, and the nation;

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, and 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, 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 for decades, 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, and 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;

WHEREAS, evidence-based clinical guidelines developed by the American Society of Hematology and the American College of Emergency Physicians recommend that individuals with sickle cell disease who present in the emergency room with a sickle cell crises be triaged and administered appropriate pain medications within 60 minutes;

WHEREAS, individuals living with sickle cell disease and their caregivers often report having to wait in emergency rooms for hours while experience severe pain crises, and receiving substandard care prior to discharge;

WHEREAS, many facilities do not have adequate clinical pathways and treatment protocols based on evidence based clinical guidelines pertaining to management of sickle cell disease patients, particularly those experiencing pain crises;

WHEREAS, there is currently one curative therapy option for a limited number of individuals living with sickle cell disease, which is a bone marrow transplant from a matched donor, but the treatment may result in fertility issues;

WHEREAS, the vast majority of states do not currently provide fertility preservation programs for Medicaid beneficiaries, including those living with sickle cell disease who receive curative therapies which may result in fertility issues;

WHEREAS, State governments have tools at their disposal to incentivize or require health care providers, facilities, and entities receiving state monies or licensed by the state to encourage the advancement or adoption of policies to improve care, outcomes, and cost effectiveness; and

WHEREAS, The National Organization of Black Elected Legislative Women (NOBEL Women) represents communities and states across the country most affected by sickle cell disease.

THEREFORE, BE IT RESOLVED, that the NOBEL Women 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;

BE IT FURTHER RESOLVED, that state Medicaid programs and/or Departments of Health consider the implementation of requirements or incentives to encourage health care institutions

to adopt and implement clinical pathways and treatment protocols pertaining to the management of sickle cell disease patients, including in the emergency room;

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;

BE IT FURTHER RESOLVED, that state Medicaid programs and/or Departments of Health shall meet with local and regional community-based organizations representing individuals living with sickle cell disease to understand challenges and barriers impacting access to care;

BE IT FURTHER RESOLVED, that the NOBEL Women believes that institutions should provide high quality, evidence-based care for individuals living with sickle cell disease; and potential opportunities to improve care, outcomes, and cost-effectiveness of care;

BE IT FURTHER RESOLVED, that states shall work with stakeholders, including patients, caregivers, healthcare providers, medical licensing boards, medical colleges, and others, to consider the assignment or availability of continuing medical education for healthcare providers regarding sickle cell disease, including regarding the availability of new treatment guidelines and therapies;

BE IT FURTHER RESOLVED, that state legislatures, Medicaid programs and/or Departments of Health evaluate and implement policies requiring insurers, public and private, to provide comprehensive fertility preservation therapy for individuals that could be rendered infertile by medically necessary treatments, including individuals living with sickle cell disease considering potentially curative treatments;

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.