

HEALTH AND HUMAN SERVICES

Resolution HHH-21-29

A RESOLUTION ON LUPUS AWARENESS

WHEREAS, the National Black Caucus of State Legislators (NBCSL) supports initiatives designed to address health care disparities and inequalities;

WHEREAS, lupus is a chronic, autoimmune disease that can damage any part of the body including skin, joints, and internal organs;

WHEREAS, people with lupus can experience significant symptoms, such as pain, extreme fatigue, hair loss, cognitive issues, and physical impairments that affect every facet of their lives as well as co-morbidity and mortality conditions such as cardiovascular disease and kidney failure;

WHEREAS, the effects of lupus on a family can be devastating in that it is a chronic, lifelong, and life-threatening disease, and despite its prevalence, it remains one of the least recognizable and most misunderstood diseases labeling lupus as the cruel mystery;

WHEREAS, according to the Lupus Foundation of America, 10% to 15% of people with lupus die prematurely due to related complications;

WHEREAS, approximately 1.5 million Americans suffer from lupus and it disproportionately affects young women of color in the U.S.;

WHEREAS, according to the Lupus Foundation of America, 63% of Americans surveyed still have never heard of lupus or know little or nothing about this disease, its symptoms, and its more serious complications such as lupus nephritis;

WHEREAS, additionally, lupus is two to three times more prevalent among women of color as roughly one in 500 young African American women suffer from Lupus;

WHEREAS, lupus affects primarily young women in their crucial childbearing years, but it can also affect men and children of all ages;

WHEREAS, research and development into diseases that disproportionately impact people of color has historically been grossly underfunded;

WHEREAS, lupus related research and development is still underfunded;

WHEREAS, lupus is a major health issue that has a significant impact on the economy and takes an immeasurable physical, financial, and emotional toll on many families;

WHEREAS, this lack of funding has left lupus incurable and has enhanced health disparities;

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WHEREAS, despite lupus research and development being underfunded, a few treatment options that represent clinical advancements in various forms of lupus, including the morbidity-causing complication lupus nephritis, are likely to be approved soon by the FDA;

WHEREAS, these treatments can greatly improve the lives of those with lupus;

WHEREAS, people of color have often struggled to gain timely access to new or advanced treatments further widening disparities in health care,

WHEREAS, to reduce costs, states often attempt to delay adding new therapies to their Medicaid Drug Formularies, even if such therapies represent significant clinical advancements;

WHEREAS, even after adding new therapies to their formularies, to cut costs, states often use restrictive and burdensome processes, such as prior approval or “fail-first” step edits, which prevent or delay patients’ access to necessary therapies; and

WHEREAS, there is currently only one FDA-approved medication for lupus and zero FDA-approved medications for lupus nephritis.

THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL) recognizes the impact lupus has on the African American community;

BE IT FURTHER RESOLVED, that the NBCSL urges all states to work to quickly add any FDA approved and effective therapies indicated for the treatment of lupus or lupus nephritis to their formularies;

BE IT FURTHER RESOLVED, that the NBCSL urges states to expedite access to safe and proven access to lupus or lupus nephritis therapies through restrictive and burdensome processes so that patients may access these therapies for which they have waited so long;

BE IT FURTHER RESOLVED, that the NBSCSL urges federal and state policymakers to increase funding for lupus research;

BE IT FURTHER RESOLVED, that the NBSCSL urges federal, state, and local policymakers enact policies to raise awareness of lupus; 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.

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SPONSOR(S): Representative Kim Schofield (GA), Representative Karen Camper (TN), and Representative Debra Bazemore (GA)

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