



Resolution

A RESOLUTION ENCOURAGING STATES TO PROVIDE: LUPUS PATIENTS ACCESS TO TREATMENTS PROMPTLY; SUPPORT FOR LUPUS AWARENESS; and INCREASES IN FUNDING FOR LUPUS RESEARCH.

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, 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*; and,

WHEREAS, 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, 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, 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; and

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; and

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

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 formularies, even if such therapies represent significant clinical advancements; and,

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;

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 add any FDA approved therapies indicated for the treatment of lupus or lupus nephritis to their formularies promptly;

BE IT FURTHER RESOLVED, that the NBCSL urges states to not restrict access to lupus or lupus nephritis therapies through restrictive and burdensome processes so that patients may access expeditiously these therapies for which they have waited so long;

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

BE IT FURTHER RESOLVED, that the NBSCL 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 U.S. Congress, and other federal and state officials as appropriate.