



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

Committee: Health

Resolution: HEA-20-07

1. **WHEREAS**, Lupus is a chronic, autoimmune disease that can damage any part of the
2. body including skin, joints, and internal organs;
3. **WHEREAS**, people with lupus can experience significant symptoms, such as pain,
4. extreme fatigue, hair loss, cognitive issues, and physical impairments that affect every
5. facet of their lives as well as co-morbidity and mortality conditions such as
6. cardiovascular disease and kidney failure;
7. **WHEREAS**, the effects of lupus on a family can be devastating in that it is a chronic,
8. lifelong, and life-threatening disease, and despite its prevalence, it remains one of the
9. least recognizable and most misunderstood diseases labeling lupus as *the cruel mystery*;
10. and,
11. **WHEREAS**, 10% to 15% of people with lupus die prematurely due to related
12. complications;
13. **WHEREAS**, Approximately 1.5 million Americans suffer from lupus and it
14. disproportionately affects young women of color in the U.S.;
15. **WHEREAS**, lupus affects primarily young women in their crucial childbearing years,
16. but it can also affect men and children of all ages; and
17. **WHEREAS**, 63% of Americans surveyed still have never heard of lupus or know little
18. or nothing about this disease, its symptoms, and it's more serious complications such as
19. lupus nephritis;
20. **WHEREAS**, lupus is two to three times more prevalent among women of color as
21. roughly one in 500 young African-American women suffer from Lupus;
22. **WHEREAS**, research and development into diseases that disproportionately impact
23. people of color has historically been grossly underfunded;
24. **WHEREAS**, lupus is a major health issue that has a significant impact on the economy

25. and takes an immeasurable physical, financial, and emotional toll on many families; and
26. **WHEREAS**, this lack of funding has left lupus incurable and has enhanced health
27. disparities;
28. **WHEREAS**, despite lupus research and development being underfunded, a few
29. treatment options that represent clinical advancements in various forms of lupus,
30. including the morbidity-causing complication lupus nephritis, are likely to be approved
31. soon by the FDA;
32. **WHEREAS**, these treatments can greatly improve the lives of those with lupus;
33. **WHEREAS**, people of color have often struggled to gain timely access to new or
34. advanced treatments further widening disparities in health care,
35. **WHEREAS**, to reduce costs, states often attempt to delay adding new therapies to their
36. Medicaid formularies, even if such therapies represent significant clinical advancements;
37. and,
38. **WHEREAS**, even after adding new therapies to their formularies, to cut costs, states
39. often use restrictive and burdensome processes, such as prior approval or “fail-first” step
40. edits, which prevent or delay patients’ access to necessary therapies;
41. **WHEREAS**, there is currently only one FDA-approved medication for lupus and zero
42. FDA-approved medications for lupus nephritis;
43. **THEREFORE, BE IT RESOLVED**, that the National Organization of Black Elected
44. Legislative Women recognizes the impact lupus has on the African-American
45. community;
46. **BE IT FURTHER RESOLVED**, that the NOBEL Women urges all states to add any
47. FDA approved therapies indicated for the treatment of lupus or lupus nephritis to their
48. formularies promptly;
49. **BE IT FURTHER RESOLVED**, that NOBEL Women urges states to not restrict access
50. to lupus or lupus nephritis therapies through restrictive and burdensome processes so that
51. patients may access expeditiously these therapies for which they have waited so long;
52. **BE IT FURTHER RESOLVED**, that NOBEL Women urges federal and state
53. policymakers to increase funding for lupus research;
54. **BE IT FURTHER RESOLVED**, that NOBEL Women urges federal, state, and local
55. policymakers enact policies to raise awareness of lupus; and

56. **BE IT FINALLY RESOLVED**, that a copy of this resolution be transmitted to the
57. President of the United States, the Vice-President of the United States, members of the
58. U.S. Congress, and other federal and state officials as appropriate.

**Introduced by The Honorable Kim Scholfield
Georgia General Assembly**