

**Sickle Cell Disease Innovating and Expanding Access to Care**

**Committee: Health Resolution: HEA-21-05**

1. **WHEREAS**, GBT is a biopharmaceutical company dedicated to the discovery,
2. development, and delivery of life changing treatments that provide hope to underserved
3. patient communities.
4. **WHEREAS**, GBT supports SCD policy initiatives consistent with the NOBEL-Women
5. Resolution Sickle Cell Disease Innovating and Expanding Access to Care.
6. **WHEREAS,** NOBEL Women and GBT to provide leadership on a national level to
7. create awareness of the negative impact of sickle cell disease on the health, economic,
8. social, and educational well-being of the individual and his or her family and to create
9. awareness of the requirements for resolution.
10. **WHEREAS**, NOBEL-Women and GBT support initiatives to improve patient access to
11. high-quality care to ensure that SCD patients have comprehensive healthcare coverage
12. **WHEREAS,** states to provide open access to therapies that treat sickle cell disease
13. (SCD), particularly innovative therapies that have been approved in recent years to treat
14. the underlying cause of the disease.
15. **WHEREAS,** SCD treatments have improved over the years and new ones are emerging \
16. from drug company pipelines patients still face serious complications, high rates of \
17. hospitalization and early death compared to the general population. patients are
18. experiencing sub-optimal access due to Medicaid health plans imposing prior
19. authorization and step therapy requirements.
20. **WHEREAS,** to advocate for the ability to improve the quality of health, life and services
21. for individuals, families and communities affected by sickle cell disease and related
22. conditions, while promoting the search for a cure for all people in the world with sickle
23. cell disease."
24. **WHEREAS,** to effectively prevent, or treat hemoglobin disorders, efforts would require
25. the strengthening of existing medical and genetic services, in low-and middle-income
26. communities.
27. **WHEREAS** efforts should focus on the identification and the promotion of affordable
28. interventions. These included among others community education, training of health
29. professionals, newborn screening for early diagnosis sickle cell disease, thus reducing or
30. minimizing morbidity and mortality among patients.
31. **WHEREAS,** involving other potential stakeholders, such as patients/parents’
32. organizations and other national and international health related agencies could
33. significantly contribute towards efforts relating to advocacy, technology transfer and
34. capacity building.
35. **WHEREAS,** the transition from pediatric to adult healthcare is a critical time for SCD
36. patients, and mortality rates and total treatment costs significantly increase during the
37. young adult years.
38. **THEREFORE BE IT RESOLVED,** that the NOBEL-Women urges state and federal
39. policymakers to examine and address when possible the regulatory barriers that have and
40. may continue to impede patient access to novel therapies, including one-time, potentially
41. curative therapies;
42. **BE IT FURTHER RESOLVED,** that state Medicaid programs should work to ensure
43. that sickle cell patients in state Medicaid programs have access to potentially curative
44. therapies when those treatments are proven and federally approved;
45. **BE IT FURTHER RESOLVED,** that state and federal policymakers take all necessary
46. actions to identify and remove other impediments on patients and their families, such as
47. logistical and financial challenges, including missing work, child care, and other issues,
48. that may prevent or otherwise impede all patients including sickle cell patients from
49. accessing potentially curative therapies; and
50. **BE IT FINALLY RESOLVED,** that a copy of this resolution be transmitted to the
51. President of the United States, the Vice President of the United States, members of the
52. United States House of Representatives and the United States Senate, and other federal
53. and state government officials and agencies as appropriate.

**Introduced by the Honorable Sandra Scott**

**And the Representative Gloria Frazier**

**Georgia House of Representatives**