2024 Regular Session **ENROLLED**

SENATE RESOLUTION NO. 134

BY SENATOR BARROW

A RESOLUTION

To urge and request the Louisiana Department of Health to conduct a comprehensive review of all current Louisiana legislation pertaining to sickle cell disease to evaluate if the legislation aligns with current conditions and meets the demands of service delivery and systems of care in Louisiana.

WHEREAS, sickle cell disease is recognized by national health organizations such as the Centers for Disease Control and Prevention, the U.S. Department of Health and Human Services, the Health Resources and Services Administration (HRSA), and the American Society of Hematology as a condition long overdue for the investment of resources to improve the health and quality of life of individuals living with sickle cell disease; and

WHEREAS, the Centers for Medicare and Medicaid Services has announced the federal administration's actions to increase access to sickle cell disease treatments focusing on the Cell and Gene Therapy Access Model; and

WHEREAS, the American Society of Hematology has developed clinical practice guidelines on sickle cell disease that are reviewed annually and outline risks, complications, and evidence-based best practices for treating individuals impacted by sickle cell disease; and

WHEREAS, since the 1970s, legislators and advocates in Louisiana have recognized barriers to accessible and high-quality healthcare for individuals living with sickle cell disease in the state and, in response, established statewide sickle cell clinics and local programs, and in more recent decades, established the Louisiana Sickle Cell Commission and the statewide sickle cell disease registry, known as the "Skylar-Cooper Database"; and

WHEREAS, the barriers to accessing care affecting individuals with sickle cell disease and the treatment recommendations have evolved since the original introduction of the legislation, therefore a continuing review of the legislation is essential to ensure that current policies adequately meet the needs of individuals with sickle cell disease; and

WHEREAS, the implementation of legislation addressing service delivery and the well-being of individuals living with sickle cell disease indicated that the progressions of treatment and comprehensive care come with a high unmet clinical need, underfunded programs, and lack of insurance coverage for medical treatment, resulting in the financial burden of many living with sickle cell disease; and

WHEREAS, adequately trained healthcare clinicians and specialized healthcare services are limited; and

WHEREAS, people living with sickle cell disease are frequently stigmatized, resulting in negative effects on education, work, and psychosocial development; and

WHEREAS, co-management of services and partnerships are necessary for coordination of care, including but not limited to education, clinical specialties, and social support; and

WHEREAS, the Louisiana Legislature has enacted over twenty legislative instruments related to healthcare access, quality, and supportive services for sickle cell disease to date.

THEREFORE, BE IT RESOLVED that the Senate of the Legislature of Louisiana does hereby urge and request that the Louisiana Department of Health complete a comprehensive review of all current Louisiana legislation related to sickle cell disease and assessment of clinical quality outcomes and the current system of care in Louisiana.

BE IT FURTHER RESOLVED that the Louisiana Department of Health shall make recommendations to the governor and legislature to strengthen current statutes related to healthcare access, quality, and supportive services in order to address current demands, align with national standards for best practices, and increase accessibility for high-quality care for individuals living with sickle cell disease.

BE IT FURTHER RESOLVED that in conducting the review, the Louisiana Department of Health shall collaborate with the Louisiana Sickle Cell Commission, individuals with sickle cell disease, other state agencies, as well as nongovernmental entities and professionals that work with individuals living with sickle cell disease to review current Louisiana legislation related to sickle cell disease and obtain recommendations.

BE IT FURTHER RESOLVED that the Louisiana Department of Health shall submit a written report to the secretary of the Louisiana Department of Health, the governor, the members of the Louisiana Sickle Cell Commission, and the House and Senate committees on Health and Welfare summarizing the findings and recommendations of the comprehensive review.

PRESIDENT OF THE SENATE