

2024 Regular Session

HOUSE RESOLUTION NO. 275

BY REPRESENTATIVE MILLER

A RESOLUTION

To urge and request the Louisiana Department of Health to conduct a comprehensive review of all 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 this state.

WHEREAS, sickle cell disease is recognized by national health organizations such as the Centers for Disease Control and Prevention, the United States Department of Health and Human Services, the Health Resources and Services Administration, and the American Society of Hematology as a condition long overdue for an 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 announced actions to increase access to sickle cell disease treatments with a focus on the Cell and Gene Therapy Access Model; and

WHEREAS, the American Society of Hematology developed clinical practice guidelines for 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 health care for individuals living with sickle cell disease in this state and, in response, established statewide sickle cell clinics and local programs; and

WHEREAS, in more recent decades, legislators and advocates established the Louisiana Sickle Cell Commission and a 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 recommendations for treatment have evolved since the introduction of legislation; and

WHEREAS, a review of legislation regarding sickle cell disease is essential to ensure that current policies adequately meet the needs of individuals with sickle cell disease; and

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

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

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

THEREFORE, BE IT RESOLVED that the House of Representatives of the Legislature of Louisiana does hereby urge and request the Louisiana Department of Health to conduct a comprehensive review of all 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 this state.

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

BE IT FURTHER RESOLVED that in conducting the review requested in this Resolution, the Louisiana Department of Health shall collaborate with the Louisiana Sickle Cell Commission, individuals living with sickle cell disease, other state agencies, as well as non-governmental entities and professionals who work with individuals living with sickle cell disease.

BE IT FURTHER RESOLVED that the Louisiana Department of Health shall submit a written report of recommendations no later than February 14, 2025, to 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 requested in this Resolution.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the secretary of the Louisiana Department of Health and the chairman of the Louisiana Sickle Cell Commission.

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SPEAKER OF THE HOUSE OF REPRESENTATIVES