

2024 Regular Session

HOUSE RESOLUTION NO. 275

BY REPRESENTATIVE MILLER

HEALTH/SICKLE CELL ANEM: Requests that the Louisiana Department of Health review sickle cell disease legislation

1 A RESOLUTION

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

6 WHEREAS, sickle cell disease is recognized by national health organizations such  
7 as the Centers for Disease Control and Prevention, the United States Department of Health  
8 and Human Services, the Health Resources and Services Administration, and the American  
9 Society of Hematology as a condition long overdue for an investment of resources to  
10 improve the health and quality of life of individuals living with sickle cell disease; and

11 WHEREAS, the Centers for Medicare and Medicaid Services announced actions to  
12 increase access to sickle cell disease treatments with a focus on the Cell and Gene Therapy  
13 Access Model; and

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

18 WHEREAS, since the 1970s, legislators and advocates in Louisiana have recognized  
19 barriers to accessible and high-quality health care for individuals living with sickle cell  
20 disease in this state and, in response, established statewide sickle cell clinics and local  
21 programs; and

1           WHEREAS, in more recent decades, legislators and advocates established the  
2 Louisiana Sickle Cell Commission and a statewide sickle cell disease registry known as the  
3 "Skylar-Cooper Database"; and

4           WHEREAS, the barriers to accessing care affecting individuals with sickle cell  
5 disease and recommendations for treatment have evolved since the introduction of  
6 legislation; and

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

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

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

16           WHEREAS, people living with sickle cell disease are frequently stigmatized,  
17 resulting in socioeconomic effects on education, employment, and psychosocial  
18 development; and

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

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

25           THEREFORE, BE IT RESOLVED that the House of Representatives of the  
26 Legislature of Louisiana does hereby urge and request the Louisiana Department of Health  
27 to conduct a comprehensive review of all Louisiana legislation pertaining to sickle cell  
28 disease to evaluate if the legislation aligns with current conditions and meets the demands  
29 of service delivery and systems of care in this state.

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

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

11 BE IT FURTHER RESOLVED that the Louisiana Department of Health shall submit  
12 a written report of recommendations no later than February 14, 2025, to the governor, the  
13 members of the Louisiana Sickle Cell Commission, and the House and Senate committees  
14 on health and welfare summarizing the findings and recommendations of the comprehensive  
15 review requested in this Resolution.

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

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DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

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HR 275 Original

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Miller

Requests the La. Dept. 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.

Requires the La. Dept. of Health to make recommendations to the governor and legislature to strengthen state law related to sickle cell disease.

Requires the La. Dept. of Health to submit a written report of recommendations no later than Feb. 14, 2025, on how to improve sickle cell disease legislation in this state.