

2024 Regular Session

SENATE RESOLUTION NO. 134

BY SENATOR BARROW

HEALTH DEPARTMENT. Requests the Louisiana Department of Health to conduct a comprehensive review of current 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 current 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 Louisiana.

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

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

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

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

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

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

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

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

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

22          WHEREAS, the Louisiana Legislature has enacted 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 Louisiana Senate does hereby urge and  
26          request that the Louisiana Department of Health complete a comprehensive review of all  
27          current Louisiana legislation related to sickle cell disease and assessment of clinical quality  
28          outcomes and the current system of care in Louisiana.

29          BE IT FURTHER RESOLVED that the Louisiana Department of Health shall make  
30          recommendations to the governor and legislature to strengthen current statutes related to

1 healthcare access, quality, and supportive services in order to address current demands, align  
 2 with national standards for best practices, and increase accessibility for high-quality care for  
 3 individuals living with sickle cell disease.

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

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

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The original instrument and the following digest, which constitutes no part  
 of the legislative instrument, were prepared by Amanda Trapp.

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SR 134 Original

DIGEST  
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