

2024 Regular Session

HOUSE RESOLUTION NO. 261

BY REPRESENTATIVE PHELPS

HEALTH/SICKLE CELL ANEM: Directs the Louisiana Department of Health to meet certain benchmarks to launch the Sickle Cell Disease Registry

1 A RESOLUTION

2 To direct the Louisiana Department of Health to meet certain benchmarks to launch the
3 Sickle Cell Disease Registry.

4 WHEREAS, sickle cell disease is an inherited blood disorder that affects one in three
5 hundred and seventy-five African Americans; and

6 WHEREAS, sickle cell disease affects people across the world of all backgrounds,
7 the greatest number of affected patients in the United States are those with African ancestry;
8 and

9 WHEREAS, sickle cell anemia was the first genetic disease to be examined at the
10 molecular level, and the first article documenting a case of sickle cell anemia was published
11 in 1910; and

12 WHEREAS, despite the history of study and interest in sickle cell anemia, it took
13 over one hundred years for this state to establish the Sickle Cell Commission; and

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

19 WHEREAS, the Legislature of Louisiana has enacted over twenty legislative
20 instruments related to healthcare access, quality, supportive services, and data collection for
21 sickle cell disease to date; and

1 WHEREAS, in 2022, the Legislature of Louisiana enacted Act No. 647, which
2 created the Sickle Cell Disease Registry, the "Skylar-Cooper Database", and tasked the
3 Louisiana Department of Health with collecting patient information from healthcare
4 providers around the state to connect patients with healthcare advocates and associations to
5 assist individuals suffering with sickle cell disease; and

6 WHEREAS, despite efforts by legislators, community leaders, healthcare
7 organizations, and policymakers, the number of patients diagnosed with sickle cell disease
8 in this state remains unknown; and

9 WHEREAS, in 2024, the Sickle Cell Disease Registry remains unenforced by the
10 Louisiana Department of Health and is unable to provide valuable data and information that
11 are needed by state and community leaders, healthcare providers, and sickle cell associations
12 to provide community assistance and to connect individuals with sickle cell disease to the
13 care that they need; and

14 WHEREAS, in 2023, the United States Food and Drug Administration approved a
15 powerful treatment for sickle cell disease utilizing Clustered Regularly Interspaced Short
16 Palindromic Repeats or "CRISPR" gene therapy; and

17 WHEREAS, Children's Hospital in New Orleans is among one of the first hospitals
18 in the nation and the only hospital in this state authorized to provide this life-changing
19 treatment.

20 THEREFORE, BE IT RESOLVED that the House of Representatives of the
21 Legislature of Louisiana does hereby direct the Louisiana Department of Health to meet
22 certain benchmarks to launch the Sickle Cell Disease Registry.

23 BE IT FURTHER RESOLVED that the House of Representatives of the Legislature
24 of Louisiana does hereby direct the Louisiana Department of Health to execute a
25 memorandum of understanding or data use agreement with healthcare providers and sickle
26 cell associations in this state to govern the transfer of patient contact information by July 1,
27 2024.

28 BE IT FURTHER RESOLVED that the House of Representatives of the Legislature
29 of Louisiana does hereby direct the Louisiana Department of Health to submit a report
30 describing the memorandum of understanding or data use agreement and listing the

1 healthcare providers and sickle cell associations that have agreed to the terms of the
2 memorandum of understanding or data use agreement to the House and Senate committees
3 on health and welfare and the Louisiana Sickle Cell Commission by July 15, 2024.

4 BE IT FURTHER RESOLVED that the House of Representatives of the Legislature
5 of Louisiana does hereby direct the Louisiana Department of Health to begin developing the
6 necessary administrative rules to enforce the Sickle Cell Disease Registry by August 1,
7 2024.

8 BE IT FURTHER RESOLVED that the House of Representatives of the Legislature
9 of Louisiana does hereby direct the Louisiana Department of Health to submit a report
10 summarizing the content and purpose of the administrative rules to the House and Senate
11 committees on health and welfare and the Louisiana Sickle Cell Commission by August 15,
12 2024.

13 BE IT FURTHER RESOLVED that the House of Representatives of the Legislature
14 of Louisiana does hereby direct the Louisiana Department of Health to begin analyzing data
15 from existing sources to assess the quality of the data including but not limited to removing
16 duplicate entries and assessing the completeness of geographic information by November
17 1, 2024.

18 BE IT FURTHER RESOLVED that the House of Representatives of the Legislature
19 of Louisiana does hereby direct the Louisiana Department of Health to fully launch the
20 Sickle Cell Disease Registry by December 24, 2024.

21 BE IT FURTHER RESOLVED that a copy of this resolution be transmitted to the
22 secretary of the Louisiana Department of Health and the chairman and vice chairman of the
23 Louisiana Sickle Cell Commission.

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)]

HR 261 Original

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Phelps

Directs the La. Dept. of Health (LDH) to meet certain benchmarks toward establishing the Sickle Cell Disease Registry, including fully launching the registry by Dec. 24, 2024.

Requires LDH to submit a report describing the memorandum of understanding or data use agreement executed by LDH and healthcare providers to facilitate the transfer of information

about patients with sickle cell disease to the House and Senate committees on health and welfare and the La. Sickle Cell Commission by July 15, 2024.

Requires LDH to submit a report summarizing the content and purpose of administrative rules to House and Senate committees on health and welfare and the La. Sickle Cell Commission by Aug. 15, 2024.