SLS 24RS-4175 **ORIGINAL**

2024 Regular Session

SENATE RESOLUTION NO. 131

BY SENATOR CARTER

DISEASE CONTROL. Requests the Louisiana Department of Health to meet certain benchmarks toward establishing the Sickle Cell Disease Registry.

A RESOLUTION

To request the Louisiana Department of Health to meet certain benchmarks toward establishing the Sickle Cell Disease Registry.

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

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

WHEREAS, sickle cell anemia was the first genetic disease to be examined at the molecular level, and the first documented case of sickle cell anemia was published in 1910; and

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

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 the investment of resources to improve the health and quality of life of individuals living with sickle cell disease; and

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

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

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

WHEREAS, in 2023, the United States Food and Drug Administration approved a powerful treatment for sickle cell disease utilizing CRISPR gene therapy; and

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

WHEREAS, the Sickle Cell Disease Registry is still unable to provide valuable data and information that is needed by state and community leaders, healthcare providers, and sickle cell associations to provide community assistance and to connect individuals with sickle disease to the care that they need.

THEREFORE, BE IT RESOLVED that the Louisiana Senate does hereby urge and request the Louisiana Department of Health to execute a memorandum of understanding or data use agreement with healthcare providers and sickle cell associations in this state to govern the transfer of patient contact information by July 1, 2024.

BE IT FURTHER RESOLVED that the Louisiana Senate does hereby request the Louisiana Department of Health to begin developing the necessary administrative rules to enforce the Sickle Cell Disease Registry by August 1, 2024.

BE IT FURTHER RESOLVED that the Louisiana Senate does hereby request the Louisiana Department of Health to begin analyzing data from existing sources to assess the quality of the data in the database, including but not limited to removing duplicate entries and assessing the completeness of geographic information, by November 1, 2024.

BE IT FURTHER RESOLVED that the Louisiana Senate does hereby request the Louisiana Department of Health to fully launch the Sickle Cell Disease Registry by January 1, 2025.

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

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

DIGEST

SR 131 Original 2024 Regular Session Carter

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