

SENATE CONCURRENT RESOLUTION NO. 66

BY SENATOR BARROW

A CONCURRENT RESOLUTION

To urge and request the Louisiana Department of Health to address regulatory barriers that impede patient access to novel therapies for sickle cell disease, and to work to ensure that sickle cell patients in the Louisiana Medicaid program have access to potentially curative therapies.

WHEREAS, sickle cell anemia and sickle cell disease, used interchangeably, refer to a group of inherited disorders that affect the red blood cells; and

WHEREAS, the National Institutes of Health is working on innovative genetic therapies that could someday cure sickle cell disease; and

WHEREAS, the Food and Drug Administration has granted orphan drug designation to sickle cell therapies to provide incentives and encouragement for development, and at the end of 2019, granted accelerated approval for a new treatment for sickle cell disease; and

WHEREAS, sickle cell disease can be a life-threatening condition and access to comprehensive health care may be limited by social, economic, cultural, and geographic barriers; and

WHEREAS, nationwide, more than seventy percent of patients with sickle cell disease are insured under state Medicaid programs; and

WHEREAS, historically and continuing today, the sickle cell disease patient community has been medically underserved, a fact which President Richard Nixon recognized in 1972 when he signed the Sickle Cell Anemia Control Act into law; and

WHEREAS, while there is no widely available cure for sickle cell disease, one-time gene therapies, including gene editing therapeutic approaches, are being developed which may offer potential cures for some patients; and

WHEREAS, the Louisiana Sickle Cell Commission was established within the Louisiana Department of Health and it is appropriate for the department to study the need for equitable access to sickle cell treatment.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby urge and request the Louisiana Department of Health to examine and address the regulatory barriers that impede patient access to novel therapies for sickle cell disease, including one-time, potentially curative therapies.

BE IT FURTHER RESOLVED that the Legislature of Louisiana does hereby urge and request the Louisiana Department of Health to work to ensure that sickle cell patients in the Louisiana Medicaid program have access to potentially curative therapies when those treatments are proven and federally approved.

BE IT FURTHER RESOLVED that the Legislature of Louisiana does hereby urge and request the Louisiana Department of Health to collaborate with other state agencies to take all necessary actions to identify and remove other impediments on patients and their families, such as logistical and financial challenges, including missing work, child care, and other issues, that may prevent or otherwise impede all patients including sickle cell patients from accessing potentially curative therapies.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the secretary of the Louisiana Department of Health.

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PRESIDENT OF THE SENATE

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SPEAKER OF THE HOUSE OF REPRESENTATIVES