

2023 Regular Session

HOUSE CONCURRENT RESOLUTION NO. 92

BY REPRESENTATIVE HUGHES

A CONCURRENT RESOLUTION

To urge and request the Louisiana Department of Health to ensure timely access to gene therapy to the extent necessary to study the feasibility of funding gene therapy for all sickle cell patients via Medicaid.

WHEREAS, sickle cell anemia is a genetic disease that, according to the Centers for Disease Control and Prevention, affects approximately one in every three hundred sixty-five African American babies; and

WHEREAS, the state of Louisiana, through its recent efforts to create a statewide registry of sickle cell patients, estimates that there are thousands of Louisiana residents with sickle cell anemia; and

WHEREAS, in 2020, over one thousand four hundred individuals in Louisiana were hospitalized for symptoms related to sickle cell anemia with an average hospital stay of thirty days; and

WHEREAS, research shows that one in every ten children with sickle cell anemia will have a symptomatic stroke by the age of twenty; and

WHEREAS, until recently, the only means of a cure for sickle cell anemia was a bone marrow transplant; however, statistics show that very few patients are medically eligible for such a procedure; and

WHEREAS, recent breakthroughs in medical research have led to new gene therapy treatments that could save the lives of sickle cell patients; and

WHEREAS, such medical advancements could soon be approved by the United States Food and Drug Administration by the end of the 2023 calendar year; and

WHEREAS, while gene therapy is believed to cure sickle cell disease and the symptoms resulting therefrom, such therapy is predicted to be costly; and

WHEREAS, a financing mechanism to provide this care is needed as the projected cost of the treatment is over one million dollars per patient; and

WHEREAS, the state has used innovative financing models to provide critical access for other high cost medications, such as those needed for patients with hepatitis C; and

WHEREAS, the state's financing models for such services could serve as a model for financing similar arrangements for patients with sickle cell anemia; and

WHEREAS, implementation of this potentially life-saving treatment could lead to a substantially improved quality of life for thousands of Louisiana residents.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby urge and request the Louisiana Department of Health to ensure timely patient access to gene therapies utilizing any and all available, innovative payment arrangements and methodologies for the Medicaid program to study the feasibility of funding gene therapy for all sickle cell patients via Medicaid without causing any delay in patient access to treatments that may become available in the near term.

BE IT FURTHER RESOLVED that the Louisiana Department of Health shall develop findings and recommendations concerning this topic and submit its findings in the form of a written report to the House Committee on Health and Welfare, Senate Committee on Health and Welfare, and the David R. Poynter Legislative Research Library no later than thirty days prior to the convening of the 2024 Regular Session.

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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SPEAKER OF THE HOUSE OF REPRESENTATIVES

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PRESIDENT OF THE SENATE