

2023 Regular Session

HOUSE CONCURRENT RESOLUTION NO. 92

BY REPRESENTATIVE HUGHES

HEALTH/LDH: Requests study by Louisiana Department of Health to consider Medicaid coverage of gene therapy

1 A CONCURRENT RESOLUTION

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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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)]

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HCR 92 Reengrossed

2023 Regular Session

Hughes

Requests the La. Dept. 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 treatment via Medicaid.

Summary of Amendments Adopted by House

The House Floor Amendments to the engrossed bill:

1. Add language 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 treatment via Medicaid.
2. Stipulate that there should be no delay in patient access to treatments caused as such treatments become available in the near term.