HLS 24RS-4852 **ORIGINAL**

2024 Regular Session

HOUSE RESOLUTION NO. 320

BY REPRESENTATIVE PHELPS

HEALTH/SICKLE CELL ANEM: Recognizes gene editing as a significant advancement in the treatment of sickle cell disease

A RESOLUTION

To recognize gene editing as a significant and profound medical and scientific accomplishment in the treatment of sickle cell disease.

WHEREAS, sickle cell disease is a genetic blood disorder that deforms the shape of hemoglobin, the protein that carries oxygen throughout the body, thus decreasing the red blood cell's affinity for oxygen; 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 disease was the first genetic disease to be examined at the molecular level, and the first article documenting a case of sickle cell disease was published in 1910; and

WHEREAS, sickle cell disease causes pain and increases the likelihood of serious medical complications affecting all the major organs; and

WHEREAS, sickle cell disease most commonly occurs when a person inherits two abnormal copies of the β-globin gene that is responsible for assembling hemoglobin; and

WHEREAS, in 2015, it was estimated that nearly four and a half million people have sickle cell disease, while an additional forty-three million are genetic carriers of the sickle cell trait; and

WHEREAS, individuals with sickle cell disease typically begin experiencing complications between five to six months old, and the condition often gets worse as the individual ages with an average life expectancy of forty to sixty years; and

WHEREAS, a pain attack in individuals with sickle cell disease can be triggered by temperature changes, stress, dehydration, or high altitude; and

WHEREAS, prior to 2023, treating sickle cell disease focused mainly on preventative measures and treating the symptoms and side-effects of sickle cell disease; and

WHEREAS, for decades the only effective, permanent treatment for sickle cell disease was a bone marrow transplant, which is proven to be effective in children; and

WHEREAS, bone marrow transplants are difficult to obtain due to extensive genetic compatibility requirements between donor and donee; and

WHEREAS, in 2023, the United States Food and Drug Administration (FDA) approved two milestone treatments, Casgevy and Lyfgenia, representing the first cell-based gene therapies for the treatment of sickle cell disease in patients twelve years and older; and

WHEREAS, Casgevy is the first FDA-approved therapy utilizing CRISPR/Cas9, a type of gene editing technology, to treat sickle cell disease; and

WHEREAS, CRISPR/Cas9 can be directed to cut and edit DNA in targeted areas thus allowing an individual's own bone marrow cells to be modified to produce healthy blood cells; and

WHEREAS, Children's Hospital in New Orleans is among one of the first hospitals in the country authorized to treat sickle cell disease with Casgevy.

THEREFORE, BE IT RESOLVED that the House of Representatives of the Legislature of Louisiana does hereby recognize gene editing technology as a significant and profound medical and scientific accomplishment in the treatment of sickle cell disease.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the executive director of the Sickle Cell Association of South Louisiana, executive director of Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc., the executive director of the Northwest Louisiana Chapter of the Sickle Cell Disease Association of America, Inc., the executive director of the Sickle Cell Anemia Research Foundation, Alexandria, the executive director of the Southwest Louisiana Sickle Cell Anemia, Inc., the

chairman of the Sickle Cell Commission, the senior director of patient care services of the hematology department of Children's Hospital New Orleans, and the administrative director Tulane Sickle Cell Center of Southern Louisiana.

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 320 Original 2024 Regular Session Phelps

Recognizes gene editing as a significant and profound medical and scientific accomplishment in the treatment of sickle cell disease.