2022 Regular Session

HOUSE CONCURRENT RESOLUTION NO. 76

BY REPRESENTATIVES PHELPS, ADAMS, BOYD, BRASS, BROWN, BRYANT, CARPENTER, ROBBY CARTER, WILFORD CARTER, CORMIER, COX, DUPLESSIS, FISHER, FREEMAN, GAINES, GLOVER, GREEN, HUGHES, JEFFERSON, JENKINS, TRAVIS JOHNSON, JORDAN, LACOMBE, LAFLEUR, LANDRY, LARVADAIN, LYONS, MARCELLE, DUSTIN MILLER, MOORE, NEWELL, PIERRE, SELDERS, AND WILLARD AND SENATORS BARROW, BOUDREAUX, BOUIE, CARTER, FIELDS, HARRIS, JACKSON, LUNEAU, PRICE, SMITH, AND TARVER

HEALTH/SICKLE CELL ANEM: Expresses support for equitable access to transformative therapies for sickle cell disease

A CONCURRENT RESOLUTION

To express the support of the Legislature of Louisiana for equitable access to transformative therapies for sickle cell disease.

WHEREAS, sickle cell disease is the most common inherited hemoglobin disorder, but despite its high mortality rates and severe economic impact, needs for effective therapies for the disease remain unmet; and

WHEREAS, the United States Centers for Disease Control and Prevention estimates that sickle cell disease affects roughly one hundred thousand Americans; and

WHEREAS, the disease occurs in approximately one out of every three hundred sixty-five African American births and one out of every sixteen thousand three hundred Hispanic American births; and

WHEREAS, sickle cell disease can affect any organ and has particularly harmful effects on the kidneys, lungs, and spleen; vaso-occlusive crises are common among patients, causing recurrent episodes of acute pain and leading to irreversible organ damage, poor quality of life, and stroke; and

WHEREAS, on average, life expectancy among persons who suffer from the disease, tragically, is twenty-five to thirty years less than among those who do not have the disease; and

WHEREAS, according to a 2018 study, sickle cell disease imposes a nearly three billion dollar economic burden on the U.S. healthcare system annually, of which fifty-seven percent is attributed to hospital inpatient costs; and

WHEREAS, the sickle cell disease patient community has long been medically underserved; in 1972, former president Richard Nixon signed the National Sickle Cell Anemia Control Act (Public Law 92-294) and pledged to end neglect of the disease, yet patients still encounter social, economic, cultural, and geographic barriers to quality care today; and

WHEREAS, recognizing the need for dramatic improvements in services and care coordination for sickle cell patients in this state, the legislature passed House Bill No. 260 of the 2015 Regular Session, authored by the late Alfred C. Williams, former state representative for House District 61, and several coauthors; and

WHEREAS, enacted as Act No. 387 of the 2015 Regular Session, this legislation established Louisiana's Sickle Cell Patient Navigator Program; however, while innovative and tremendously promising for sickle cell patients and their families and communities, this program has remained unfunded since its enactment seven years ago; and

WHEREAS, many sickle cell patients receive inconsistent treatments, rely disproportionately on emergency care and public health programs, are unable to participate in clinical trials, and lack access to the limited number of medical providers with the knowledge and experience necessary to provide the highest-quality care; and

WHEREAS, with rapid advancements in technologies such as gene editing, sickle cell disease stakeholders are working diligently to expand availability of the transformative therapies that are currently building clinical momentum; and

WHEREAS, in 2018, the National Institutes of Health launched the Cure Sickle Cell Initiative to accelerate the development of therapies to cure the disease; at the end of the following year, the United States Food and Drug Administration granted accelerated approval for a new treatment, and it has granted orphan drug designation to sickle cell disease therapies in order to encourage scientific innovation; and

WHEREAS, the costs of sickle cell disease are enormous in both human and economic terms, but medical science provides hope for a long-awaited cure.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby express its support for equitable access to transformative therapies for sickle cell disease.

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

DIGEST

HCR 76 Engrossed 2022 Regular Session Phelps

Expresses the support of the legislature for equitable access to transformative therapies for sickle cell disease.