HLS 22RS-2138 **ORIGINAL**

2022 Regular Session

1

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

2	To express the support of the Legislature of Louisiana for equitable access to transformative
3	therapies for sickle cell disease.
4	WHEREAS, sickle cell disease is the most common inherited hemoglobin disorder,
5	but despite its high mortality rates and severe economic impact, needs for effective therapies
6	for the disease remain unmet; and
7	WHEREAS, the United States Centers for Disease Control and Prevention estimates
8	that sickle cell disease affects roughly one hundred thousand Americans; and
9	WHEREAS, the disease occurs in approximately one out of every three hundred
10	sixty-five African American births and one out of every sixteen thousand three hundred
11	Hispanic American births; and
12	WHEREAS, sickle cell disease can affect any organ and has particularly harmful
13	effects on the kidneys, lungs, and spleen; vaso-occlusive crises are common among patients,
14	causing recurrent episodes of acute pain and leading to irreversible organ damage, poor
15	quality of life, and stroke; and

1	WHEREAS, on average, life expectancy among persons who suffer from the disease,
2	tragically, is twenty-five to thirty years less than among those who do not have the disease;
3	and
4	WHEREAS, according to a 2018 study, sickle cell disease imposes a nearly three
5	billion dollar economic burden on the U.S. healthcare system annually, of which fifty-seven
6	percent is attributed to hospital inpatient costs; and
7	WHEREAS, the sickle cell disease patient community has long been medically
8	underserved; in 1972, former president Richard Nixon signed the National Sickle Cell
9	Anemia Control Act (Public Law 92-294) and pledged to end neglect of the disease, yet
10	patients still encounter social, economic, cultural, and geographic barriers to quality care
11	today; and
12	WHEREAS, recognizing the need for dramatic improvements in services and care
13	coordination for sickle cell patients in this state, the legislature passed House Bill No. 260
14	of the 2015 Regular Session, authored by the late Alfred C. Williams, former state
15	representative for House District 61, and several coauthors; and
16	WHEREAS, enacted as Act No. 387 of the 2015 Regular Session, this legislation
17	established Louisiana's Sickle Cell Patient Navigator Program; however, while innovative
18	and tremendously promising for sickle cell patients and their families and communities, this
19	program has remained unfunded since its enactment seven years ago; and
20	WHEREAS, many sickle cell patients receive inconsistent treatments, rely
21	disproportionately on emergency care and public health programs, are unable to participate
22	in clinical trials, and lack access to the limited number of medical providers with the
23	knowledge and experience necessary to provide the highest-quality care; and
24	WHEREAS, with rapid advancements in technologies such as gene editing, sickle
25	cell disease stakeholders are working diligently to expand availability of the transformative
26	therapies that are currently building clinical momentum; and
27	WHEREAS, in 2018, the National Institutes of Health launched the Cure Sickle Cell
28	Initiative to accelerate the development of therapies to cure the disease; at the end of the
29	following year, the United States Food and Drug Administration granted accelerated

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- 1 approval for a new treatment, and it has granted orphan drug designation to sickle cell
- 2 disease therapies in order to encourage scientific innovation; and
- 3 WHEREAS, the costs of sickle cell disease are enormous in both human and
- 4 economic terms, but medical science provides hope for a long-awaited cure.
- 5 THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby
- 6 express its support for equitable access to transformative therapies for sickle cell disease.
- 7 BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the
- 8 chairman of the Louisiana Sickle Cell Commission.

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)]

HCR 76 Original

2022 Regular Session

Phelps

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