

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

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)]

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Phelps

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