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H.C.R. No. 86

## CONCURRENT RESOLUTION

- 1 WHEREAS, Sickle cell disease is the most common inherited
- 2 hemoglobin disorder, but despite its high mortality rates and
- 3 severe economic impact, the need for effective therapies remains
- 4 unmet; and
- 5 WHEREAS, The U.S. Centers for Disease Control and Prevention
- 6 estimates that sickle cell disease affects approximately 100,000
- 7 Americans, occurring among about 1 in every 365 African American
- 8 births and 1 out of every 16,300 Hispanic American births; and
- 9 WHEREAS, Sickle cell disease can affect any organ, including
- 10 the kidneys, lungs, and spleen; vaso-occlusive crises are common
- 11 among patients, causing recurrent episodes of acute pain and
- 12 leading to irreversible end-organ damage, poor quality of life, and
- 13 stroke; the life expectancy among sufferers is reduced, tragically,
- 14 by some 25 to 30 years; and
- WHEREAS, According to a 2018 study, sickle cell disease
- 16 imposes a nearly \$3 billion economic burden on the U.S. healthcare
- 17 system each year, of which 57 percent is attributed to hospital
- 18 inpatient costs; more than 70 percent of patients are insured under
- 19 state Medicaid programs; and
- 20 WHEREAS, The sickle cell disease patient community has long
- 21 been medically underserved; in 1972, then-president Richard Nixon
- 22 signed the Sickle Cell Anemia Control Act and pledged to end neglect
- 23 of the disease, but today, patients still encounter social,
- 24 economic, cultural, and geographic barriers to quality care,

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- 1 including inconsistent treatments, high reliance on emergency care
- 2 and public health programs, limited participation in clinical
- 3 trials, and lack of access to the limited number of medical
- 4 providers with appropriate knowledge and experience; and
- 5 WHEREAS, With rapid advancement in such technologies as gene
- 6 editing, sickle cell disease stakeholders are working diligently to
- 7 expand availability of the transformative therapies that are
- 8 currently building clinical momentum; in 2018, the National
- 9 Institutes of Health launched the National Heart, Lung, and Blood
- 10 Institute Cure Sickle Cell Initiative to accelerate the development
- 11 of therapies to cure the disease; at the end of the following year,
- 12 the Food and Drug Administration granted accelerated approval for a
- 13 new treatment, and it has granted Orphan Drug designation to sickle
- 14 cell disease therapies in order to encourage scientific innovation;
- 15 and
- WHEREAS, The costs of sickle cell disease are enormous in
- 17 both human and economic terms, but medical science provides hope of
- 18 a long-awaited cure; now, therefore, be it
- 19 RESOLVED, That the 87th Legislature of the State of Texas
- 20 hereby express support for equitable access to transformative
- 21 therapies for sickle cell disease.