1-1 By: J. Johnson of Harris (Senate Sponsor - Miles) H.C.R. No. 86 1-2 (In the Senate - Received from the House May 19, 2021; 1-3 May 19, 2021, read first time and referred to Committee on Health & 1-4 Human Services; May 21, 2021, reported favorably by the following 1-5 vote: Yeas 9, Nays 0; May 21, 2021, sent to printer.)

1-6

COMMITTEE VOTE

1-7		Yea	Nay	Absent	PNV
1-8	Kolkhorst	Х			
1-9	Perry	Х			
L - 10	Blanco	Х			
L - 11	Buckingham	Х			
L - 12	Campbell	Х			
L - 13	Hall	Х			
L - 14	Miles	Х			
L - 15	Powell	Х			
L - 16	Seliger	Х			

1-17

HOUSE CONCURRENT RESOLUTION

1-18 WHEREAS, Sickle cell disease is the most common inherited 1-19 hemoglobin disorder, but despite its high mortality rates and 1-20 severe economic impact, the need for effective therapies remains 1-21 unmet; and

1-22 WHEREAS, The U.S. Centers for Disease Control and Prevention 1-23 estimates that sickle cell disease affects approximately 100,000 1-24 Americans, occurring among about 1 in every 365 African American 1-25 births and 1 out of every 16,300 Hispanic American births; and

1-26 WHEREAS, Sickle cell disease can affect any organ, including 1-27 the kidneys, lungs, and spleen; vaso-occlusive crises are common 1-28 among patients, causing recurrent episodes of acute pain and 1-29 leading to irreversible end-organ damage, poor quality of life, and 1-30 stroke; the life expectancy among sufferers is reduced, tragically, 1-31 by some 25 to 30 years; and

1-32 WHEREAS, According to a 2018 study, sickle cell disease 1-33 imposes a nearly \$3 billion economic burden on the U.S. healthcare 1-34 system each year, of which 57 percent is attributed to hospital 1-35 inpatient costs; more than 70 percent of patients are insured under 1-36 state Medicaid programs; and

1-37 WHEREAS, The sickle cell disease patient community has long 1-38 been medically underserved; in 1972, then-president Richard Nixon 1-39 signed the Sickle Cell Anemia Control Act and pledged to end neglect 1-40 of the disease, but today, patients still encounter social, 1-41 economic, cultural, and geographic barriers to quality care, 1-42 including inconsistent treatments, high reliance on emergency care 1-43 and public health programs, limited participation in clinical 1-44 trials, and lack of access to the limited number of medical 1-45 providers with appropriate knowledge and experience; and

WHEREAS, With rapid advancement in such technologies as gene 1-46 editing, sickle cell disease stakeholders are working diligently to 1-47 expand availability of the transformative therapies that are currently building clinical momentum; in 2018, the National 1-48 1-49 1-50 Institutes of Health launched the National Heart, Lung, and Blood 1-51 Institute Cure Sickle Cell Initiative to accelerate the development of therapies to cure the disease; at the end of the following year, the Food and Drug Administration granted accelerated approval for a 1-52 1-53 1-54 new treatment, and it has granted Orphan Drug designation to sickle 1-55 cell disease therapies in order to encourage scientific innovation; 1-56 and

1-57 WHEREAS, The costs of sickle cell disease are enormous in 1-58 both human and economic terms, but medical science provides hope of 1-59 a long-awaited cure; now, therefore, be it

1-60 RESOLVED, That the 87th Legislature of the State of Texas 1-61 hereby express support for equitable access to transformative

H.C.R. No. 86

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