By: J. Johnson of Harris H.C.R. No. 86

CONCURRENT RESOLUTION

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

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

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

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

WHEREAS, The sickle cell disease patient community has long been medically underserved; in 1972, then-president Richard Nixon signed the Sickle Cell Anemia Control Act and pledged to end neglect of the disease, but today, patients still encounter social, economic, cultural, and geographic barriers to quality care,

including inconsistent treatments, high reliance on emergency care and public health programs, limited participation in clinical trials, and lack of access to the limited number of medical providers with appropriate knowledge and experience; and

WHEREAS, With rapid advancement in such technologies as gene editing, sickle cell disease stakeholders are working diligently to expand availability of the transformative therapies that are currently building clinical momentum; in 2018, the National Institutes of Health launched the National Heart, Lung, and Blood 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 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 of a long-awaited cure; now, therefore, be it

RESOLVED, That the 87th Legislature of the State of Texas hereby express support for equitable access to transformative therapies for sickle cell disease.