

HR 8073

2023

House Resolution

A resolution recognizing June 19, 2023, as "World Sickle Cell Awareness Day" in Florida.

WHEREAS, sickle cell disease refers to a group of inherited disorders that affect red blood cells, and

WHEREAS, sickle cell disease is a disease in which a person's body produces abnormally shaped red blood cells that resemble a crescent or sickle and that do not last as long as normal, round red blood cells, which leads to anemia, and

WHEREAS, the sickle cells also get stuck in blood vessels and block blood flow, resulting in vaso-occlusive crises, which can cause pain and organ damage, and

WHEREAS, one common type of sickle cell disease is sickle cell anemia, in which individuals with the disease are born with two sickle cell genes, each inherited from one parent, and

WHEREAS, an individual with only one sickle cell gene has a "sickle cell trait," which occurs in about 1 out of every 12 African Americans and 1 out of every 100 Hispanic Americans, and

WHEREAS, the United States Centers for Disease Control and Prevention estimates that sickle cell disease affects approximately 100,000 Americans, and occurs among about 1 in every 365 Black or African-American births and 1 out of every 16,300 Hispanic-American births, and

25 WHEREAS, more than 8,000 Floridians have sickle cell
 26 disease, and

27 WHEREAS, the National Institutes of Health is working on
 28 innovative genetic therapies that could someday cure sickle cell
 29 disease, and

30 WHEREAS, the United States Food and Drug Administration has
 31 granted orphan drug designation to sickle cell therapies a
 32 designation that provides incentives and encourages the
 33 development of therapies for rare diseases, and

34 WHEREAS, sickle cell disease is a chronic condition that
 35 can affect any organ, including the kidneys, lungs, and spleen,
 36 and research indicates that patients experience many severe
 37 complications, including stroke, infections, and pulmonary
 38 embolism, and have a shorter life expectancy than the general
 39 population, and

40 WHEREAS, vaso-occlusive crises are a common, painful
 41 complication of sickle cell disease in adolescents and adults
 42 which may occur several times a year; and these recurrent
 43 episodes induce severe pain, decrease quality of life, cause
 44 life-threatening complications such as stroke, and are
 45 associated with increased mortality, and

46 WHEREAS, vaso-occlusive crises can cause intense pain that
 47 lasts anywhere from a few hours to a few weeks, and

48 WHEREAS, sickle cell disease can be a life-threatening
 49 condition leading to a 20 to 30-year reduction in life
 50 expectancy, and

51 WHEREAS, individuals living with sickle cell disease
 52 encounter barriers to obtaining quality care and improving their
 53 quality of life, and these barriers include limitations in
 54 geographic access to comprehensive care, the varied use of
 55 effective treatments, lack of insurance, and the limited number
 56 of health care providers with knowledge and experience to manage
 57 and treat sickle cell disease, and

58 WHEREAS, while there is no widely available cure for sickle
 59 cell disease, one-time gene therapies, including gene editing
 60 therapeutic approaches, are being developed and may offer
 61 potential cures for some patients, and

62 WHEREAS, curative therapies for sickle cell disease may
 63 offer substantial savings over the patient's lifetime by
 64 avoiding the cost of future health services, NOW, THEREFORE,

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 66 Be It Resolved by the House of Representatives of the State of
 67 Florida:

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 69 That June 19, 2023, is recognized as "World Sickle Cell
 70 Awareness Day" in Florida.