

HR 8091

2021

House Resolution

A resolution recognizing September 2021 as "Sickle Cell Disease Awareness Month" in Florida.

WHEREAS, "sickle cell anemia" and "sickle cell disease," used interchangeably, refer to a group of inherited disorders that affect the 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, sickle cell disease is a genetic disorder where 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 1 out of every 13 African Americans and in 1 out of every 100 Latinos in the United States, 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

HR 8091

2021

26 | 16,300 Hispanic-American births, and it is estimated that 8,000
27 | to 14,000 African-Americans in Florida have sickle cell disease,
28 | and

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

32 | WHEREAS, the United States Food and Drug Administration has
33 | granted orphan drug designation to sickle cell therapies to
34 | provide incentives and encourage the development of therapies
35 | for rare diseases, and

36 | WHEREAS, the United States Food and Drug Administration
37 | granted accelerated approval for a new treatment for sickle cell
38 | disease at the end of 2019, and

39 | WHEREAS, sickle cell disease is a chronic condition that
40 | can affect any organ, including the kidneys, lungs, and spleen,
41 | and research indicates that patients experience many severe
42 | complications, including stroke, infections, and pulmonary
43 | embolism, and have a shorter life expectancy than the general
44 | population, and

45 | WHEREAS, vaso-occlusive crises are a common painful
46 | complication of sickle cell disease in adolescents and adults
47 | which may occur several times a year, and these recurrent
48 | episodes induce severe pain; decrease quality of life; can cause
49 | life-threatening complications, including stroke; are the

HR 8091

2021

50 primary cause of hospitalizations in sickle cell disease; and
51 are associated with increased mortality, and

52 WHEREAS, vaso-occlusive crises typically last several days
53 and are the leading cause of hospitalizations of patients with
54 sickle cell disease, and

55 WHEREAS, sickle cell disease can be a life-threatening
56 condition leading to a 25 to 30-year reduction in life
57 expectancy, and access to comprehensive care can be limited by
58 social, economic, cultural, and geographic barriers, and

59 WHEREAS, individuals living with sickle cell disease
60 encounter barriers to obtaining quality care and improving their
61 quality of life, and these barriers include limitations in
62 geographic access to comprehensive care, the varied use of
63 effective treatments, the high reliance on emergency care and on
64 public health programs, and the limited number of health care
65 providers with knowledge and experience to manage and treat
66 sickle cell disease, and

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

71 WHEREAS, one-time, potentially curative therapies for
72 sickle cell disease may offer substantial savings over the
73 patient's lifetime by avoiding the cost of future health
74 services, NOW, THEREFORE,

HR 8091

2021

75

76 Be It Resolved by the House of Representatives of the State of
77 Florida:

78

79 That September 2021 is recognized as "Sickle Cell Disease
80 Awareness Month" in Florida.