

117TH CONGRESS  
1ST SESSION

# H. RES. 494

Expressing support for the designation of September 2021 as “Sickle Cell Disease Awareness Month” in order to educate communities across the United States about sickle cell disease and the need for research, early detection methods, effective treatments, and preventative care programs with respect to complications from sickle cell disease and conditions related to sickle cell disease.

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## IN THE HOUSE OF REPRESENTATIVES

JUNE 23, 2021

Mr. DANNY K. DAVIS of Illinois (for himself, Mr. BURGESS, and Ms. LEE of California) submitted the following resolution; which was referred to the Committee on Energy and Commerce

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## RESOLUTION

Expressing support for the designation of September 2021 as “Sickle Cell Disease Awareness Month” in order to educate communities across the United States about sickle cell disease and the need for research, early detection methods, effective treatments, and preventative care programs with respect to complications from sickle cell disease and conditions related to sickle cell disease.

Whereas sickle cell disease (referred to in this preamble as “SCD”) is an inherited blood disorder that is a major health problem in the United States and worldwide;

Whereas SCD causes the rapid destruction of sickle cells, which results in multiple medical complications, including

anemia, jaundice, gallstones, strokes, restricted blood flow, damaged tissue in the liver, spleen, and kidneys, and death;

Whereas SCD causes episodes of considerable pain in the arms, legs, chest, and abdomen of an individual, which often result in lengthy hospital stays;

Whereas SCD affects an estimated 100,000 individuals in the United States;

Whereas approximately 1,000 babies are born with SCD each year in the United States, with the disease occurring in approximately 1 in 365 newborn African-American infants and 1 in 16,300 newborn Hispanic-American infants, and SCD can be found in individuals of Mediterranean, Middle Eastern, Asian, and Indian origin;

Whereas more than 3,000,000 individuals in the United States have the sickle cell trait, and 1 in 13 African Americans carries the trait;

Whereas there is a 1 in 4 chance that a child born to parents who both have the sickle cell trait will have the disease;

Whereas the life expectancy of an individual with SCD in the United States is often severely limited to an average of 42 years for a woman and 38 years for a man;

Whereas, according to a 2018 study, the total economic burden on the United States health care system associated with SCD was \$2,980,000,000 annually, of which 57 percent was attributed to hospital inpatient costs;

Whereas, in 2020, the National Academies of Sciences, Engineering, and Medicine developed a comprehensive Strategic Plan and Blueprint for Action to Address Sickle Cell Disease, which cited the need for new innovative

therapies as well as to address barriers that may impact delivery and access to approved treatments;

Whereas there are emerging genetic therapy technologies, including gene editing, that can modify a patient's own hematopoietic stem cells with the goal of the patient being able to generate healthy red blood cells to prevent sickle cell crisis;

Whereas while hematopoietic stem cell transplantation is currently the only cure for SCD and advances in treating the associated complications of SCD have occurred, more research is needed to find widely available treatments and cures to help individuals with SCD; and

Whereas September 2021 has been designated as Sickle Cell Disease Awareness Month in order to educate communities across the United States about SCD, including early detection methods, effective treatments, and preventative care programs with respect to complications from SCD and conditions related to SCD: Now, therefore, be it

1       *Resolved*, That the House of Representatives—

2               (1) supports the goals and ideals of Sickle Cell  
3       Disease Awareness Month;

4               (2) commits to ensuring equitable access among  
5       economic, racial, and ethnic groups to new treat-  
6       ments in order to improve health outcomes for those  
7       with sickle cell disease;

8               (3) calls on the Department of Health and  
9       Human Services to create policy solutions aimed at  
10      eliminating barriers to equitable access for innova-

1       tive sickle cell disease therapies, including cell, gene,  
2       and gene-editing therapies, in the Medicaid and  
3       Medicare system for patients who need them most;  
4       and

5               (4) encourages the people of the United States  
6       to hold appropriate programs, events, and activities  
7       during Sickle Cell Disease Awareness Month to raise  
8       public awareness of—

9                       (A) sickle cell disease trait;

10                      (B) preventative care programs, treat-  
11       ments, and other patient services for those suf-  
12       fering from sickle cell disease;

13                      (C) complications from sickle cell disease;

14       and

15                      (D) conditions related to sickle cell disease.

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