

118TH CONGRESS
2D SESSION

H. RES. 1495

Expressing support for the designation of September 2024 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.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 24, 2024

Mr. DAVIS of Illinois (for himself, Mr. BURGESS, Ms. LEE of California, Ms. SEWELL, Ms. TLAIB, Ms. KELLY of Illinois, Ms. NORTON, Mr. JOHNSON of Georgia, Ms. BARRAGÁN, Ms. WILLIAMS of Georgia, Mr. CLEAVER, Ms. PLASKETT, Ms. BUSH, Ms. CLARKE of New York, Mr. BISHOP of Georgia, Mr. KENNEDY, Mr. CARSON, Mr. SOTO, Mr. AMO, and Ms. ADAMS) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for the designation of September 2024 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 results from an individual having 2 copies of a sickle cell gene, 1 inherited from each biological parent;

Whereas SCD results in the production of abnormally shaped red blood cells;

Whereas SCD causes episodes of considerable pain in the arms, legs, chest, and abdomen of an individual;

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

Whereas, approximately 2,000 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 a single copy of the sickle cell gene, referred to as sickle cell trait, and 1 in 13 African Americans carries the trait;

Whereas sickle cell trait is found in 100,000,000 people worldwide, and affects people of African, Middle Eastern, South Asian, Hispanic, and southern European Caucasian descent;

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 55 years for a woman and 49 years for a man;

Whereas, according to a 2022 publication, the average lifetime cost for individuals most severely impacted by SCD ranges between \$4,200,000 to \$6,200,000 per patient;

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 approved 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 to help individuals with SCD;

Whereas the Sickle Cell Disease Association of America has been the national voice for SCD, working with more than 50 community-based organizations and affiliates serving over 500,000 children, adults, and caregivers impacted by SCD; and

Whereas September 2024 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) recognizes the important work of the Sickle
3 Cell Disease Association of America in raising
4 awareness of sickle cell disease, supporting patients
5 and families with the disease, and working toward
6 finding a cure for this devastating disease;

7 (2) supports the goals and ideals of “Sickle Cell
8 Disease Awareness Month”;

9 (3) commits to ensuring equitable access among
10 economic, racial, and ethnic groups to new treat-
11 ments in order to improve health outcomes for those
12 with sickle cell disease;

13 (4) calls on the Department of Health and
14 Human Services to create policy solutions aimed at
15 eliminating barriers to equitable access for special-
16 ized treatment and innovative sickle cell disease
17 therapies, including cell, gene, and gene-editing
18 therapies, in the Medicaid and Medicare system for
19 patients who need them most;

20 (5) calls on the National Institutes of Health to
21 increase funding for research on treatments and
22 cures for sickle cell disease;

23 (6) encourages the people of the United States
24 to hold appropriate programs, events, and activities

1 during “Sickle Cell Disease Awareness Month” to
2 raise public awareness of—

3 (A) sickle cell disease trait;

4 (B) preventative care programs, treat-
5 ments, and other patient services for those suf-
6 fering from sickle cell disease;

7 (C) complications from sickle cell disease;

8 and

9 (D) conditions related to sickle cell disease;

10 (7) encourages the President of the United
11 States to form a Sickle Cell Disease Interagency
12 Cabinet, which would be convened by the White
13 House, to begin working toward policies that will
14 support equitable and appropriate access to innova-
15 tive sickle cell disease therapies, by bringing together
16 departments and agencies across the Federal Gov-
17 ernment to address sickle cell disease on multiple
18 fronts, including—

19 (A) the Department of Health and Human
20 Services;

21 (B) the Department of Veterans Affairs;

22 (C) the National Institutes of Health;

23 (D) the Food and Drug Administration;

24 and

1 (E) the Centers for Medicare & Medicaid
2 Services; and

3 (8) urges that the options to be considered by
4 the Sickle Cell Disease Interagency Cabinet not only
5 address access to potential future curative treat-
6 ments, but also address the bias that those with
7 sickle cell disease continue to face within the United
8 States health care system.

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