

118TH CONGRESS
1ST SESSION

H. RES. 514

Expressing support for the designation of June 19, 2023, as “World Sickle Cell Awareness Day” in order to increase public alertness across the United States and global community about sickle cell disease, the continued need for empirical research, early detection screenings for sickle cell trait carriers, novel effective treatments leading to a cure, and preventative care programs with respect to complications from sickle cell anemia and conditions related to sickle cell disease.

IN THE HOUSE OF REPRESENTATIVES

JUNE 15, 2023

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

RESOLUTION

Expressing support for the designation of June 19, 2023, as “World Sickle Cell Awareness Day” in order to increase public alertness across the United States and global community about sickle cell disease, the continued need for empirical research, early detection screenings for sickle cell trait carriers, novel effective treatments leading to a cure, and preventative care programs with respect to complications from sickle cell anemia and conditions related to sickle cell disease.

Whereas sickle cell disease (referred to in this preamble as “SCD”) is defined as a group of inherited red blood cell

disorders that is a genetic condition present at birth and is a major health problem in the United States and worldwide;

Whereas the 2023 theme of World Sickle Cell Awareness Day, “Shine the Light on Sickle Cell” is an immediate call to action to improve the health and quality of life for individuals living with SCD and their families;

Whereas, in 1972, Dr. Charles Whitten established the Sickle Cell Disease Association of America to improve research, education, and health care for sickle cell patients, which is now headquartered in Hanover, Maryland;

Whereas, in 1972, Congress passed the National Sickle Cell Disease Control Act which, for the first time, provided authority to establish education, information, screening, testing, counseling, research, and treatment programs for sickle cell disease;

Whereas SCD is a gene mutation that causes a single misspelling in the DNA instructions for hemoglobin, a protein that aids in carrying oxygen in the blood, results in chronic complications related to anemia, stroke, infections, organ failure, tissue damage, intense periods of pain referred to as vaso-occlusive crises, and even premature death in persons living with the disease;

Whereas sickle cell trait (SCT) occurs when a person inherits one copy of the sickle cell gene from one of his or her parents, and in the United States an estimated 3,000,000 individuals have SCT with many unaware of their status; if both parents have SCT, there is a 25-percent (or 1 in 4) chance that any child of theirs will have SCD;

Whereas the prevalence of SCD in the United States affects approximately 100,000 individuals, 1 in every 365 African-American births, and 1 in every 16,300 Hispanic-American births, with roughly 1 in 13 African-American babies born with sickle cell trait;

Whereas the global imprint of SCD affects millions of people throughout the world; particularly among those persons whose ancestors came from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy;

Whereas the variance related to disease prevalence of sickle cell trait ranges greatly by region, and there are levels recorded as high as 40 percent in certain areas of sub-Saharan Africa, eastern Saudi Arabia, and central India;

Whereas in countries that are poor in resources, more than 90 percent of children with SCD do not live to see adulthood;

Whereas approximately 1,000 children in Africa are born with SCD daily with more than half who will die before their fifth birthday;

Whereas there is a high prevalence of SCD in India, most notably within the central and western regions that results in nearly 20 percent of babies diagnosed with SCD dying by the age of two;

Whereas, 16 years ago, in 2006, the World Health Assembly passed a resolution recognizing SCD as a public health priority with a call to action that each country implement measures to tackle the disease, and three years later, the United Nations adopted this same resolution in 2009;

Whereas newborn screening for SCD is a crucial first step for families to obtain a timely diagnosis and the establishment of comprehensive care, which in turn helps to decrease mortality and morbidity for higher survival rates in children;

Whereas approved treatments for SCD remain few in number with only four Food and Drug Administration-approved therapies since 2017, and there is a robust SCD pipeline with over 40 therapies in development;

Whereas considering the impact of this molecular disease that results in the suffering of patients as well as their families living with SCD, there is an immediate need for life-saving therapeutics that can improve the duration and quality of patients lives;

Whereas, in 2020, the National Academies of Science, Engineering, and Medicine (NASEM) 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, in 2020, the Department of Health and Human Services, in partnership with the American Society of Hematology and SickleInAfrica, in collaboration with the World Health Organization, hosted a webinar for a joint effort to strengthen SCD efforts during the coronavirus disease (COVID–19) pandemic and beyond;

Whereas American Society of Hematology member and recently deceased Kwaku Ohene-Frempong, M.D., Professor Emeritus of Pediatrics at the Perelman School of Medicine at the University of Pennsylvania, who served on the Global Coalition on SCD, has been a leader in ad-

vancing the body of knowledge in SCD research, public health, and medicine, and is recognized as immeasurably benefitting thousands of children worldwide;

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 crises;

Whereas while hematopoietic stem cell transplantation (commonly known as “HSCT”) is currently the only cure for SCD, and while 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 June 19, 2023, has been designated “World Sickle Cell Awareness Day” to increase public alertness across the United States and global community about sickle cell disease, the continued need for empirical research, early detection screenings for sickle cell disease trait carriers, novel effective treatments leading to a cure, and preventative-care programs with respect to complications from sickle cell anemia and conditions related to sickle cell disease: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports the goals and ideals of World Sick-
3 le Cell Awareness Day;

4 (2) commits to ensuring equitable access by
5 shining the light among economic, racial, and ethnic
6 groups to new treatments in order to improve health
7 outcomes for those living with sickle cell disease;

1 (3) calls on the Department of Health and
2 Human Services to create global policy solutions
3 aimed at providing support for the global community
4 and at-home resources needed to provide access to
5 newborn screening programs, therapeutic interven-
6 tions, and support services in partnership with local
7 governments with the needed infrastructure for re-
8 search and treatment;

9 (4) supports eliminating barriers to equitable
10 access for innovative sickle cell disease therapies, in-
11 cluding cell, gene, and gene-editing therapies in the
12 Medicare and Medicaid systems for patients who
13 need them most;

14 (5) encourages the people of the United States
15 and globally to hold appropriate programs, events,
16 and activities on Sickle Cell Awareness Day to raise
17 public awareness of their sickle cell disease trait,
18 preventative-care programs, treatments, and other
19 patient services for those suffering from sickle cell
20 disease, complications from sickle cell disease, and
21 conditions related to sickle cell disease; and

22 (6) encourages the President of the United
23 States to form a Sickle Cell Disease Interagency
24 Cabinet, which would be convened by the White
25 House, bringing together departments and Federal

1 agencies across Government to address sickle cell
2 disease on multiple fronts, which would include, but
3 are not limited to, the Department of Health and
4 Human Services, Department of Veterans Affairs,
5 National Institutes of Health, Food and Drug Ad-
6 ministration, and Centers for Medicare & Medicaid
7 Services to begin working toward policies that will
8 support equitable and appropriate access to innova-
9 tive SCD therapies, and in this regard, the House
10 of Representatives urges that the options to be con-
11 sidered not only address access to potential future
12 curative treatments, but also address the bias that
13 this population continues to face within both the
14 United States and global health care systems.

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