Presidential Documents

Proclamation 10615 of August 31, 2023

National Sickle Cell Awareness Month, 2023

By the President of the United States of America

A Proclamation

During National Sickle Cell Awareness Month, we recognize the perseverance and strength of the community of people living with this disease and recommit to developing more effective treatments.

Approximately 100,000 Americans have Sickle Cell Disease (SCD)—a group of inherited red blood cell disorders that can cause acute, chronic pain and serious health complications, including infections, strokes, organ damage, vision problems, and serious fatigue. Living with SCD often means putting the goals and plans of everyday life on hold to accommodate the demands of the disease, enduring frequent unplanned hospital stays and struggling to pay for costly treatments not covered by insurance.

There is no widely available cure for SCD. While bone marrow and stem cell transplants can work for some people with SCD, low donor availability and treatment-related complications put those options out of reach for many living with the disease. Although SCD affects people of all backgrounds, it disproportionately affects Black and Hispanic Americans. Combined with the documented disparities in treatment and care, people living with SCD often lack access to specialized care, treatment, and information about the disease, and they face barriers to receiving pain management and treatment support.

That is why my Administration is working tirelessly to close these health disparities and help deliver the care SCD patients and their families deserve. We are working with State, territorial, and local governments, nonprofits, and private sector partners to make that happen. The Centers for Disease Control and Prevention's Sickle Cell Data Collection program is gathering more comprehensive information on the experiences of SCD patients, which will inform new treatments and health care services. The Centers for Medicare & Medicaid Services is developing a Cell and Gene Therapy Access Model, which would help Medicaid beneficiaries gain access to potentially lifechanging, high-cost specialty drugs for illnesses like sickle cell disease. The Health Resources and Services Administration is assisting with early identification and treatment of SCD and helping community-based organizations and clinics conduct testing, counseling, and education. The Food and Drug Administration has approved new drug therapies that help people with SCD manage their pain, and the National Institutes of Health (NÎH) is funding clinical trials to test new advancements in the alleviation of chronic pain for those living with SCD. NIH is also researching possible personalized treatment approaches for SCD-associated pain. And through its "Cure Sickle Cell Initiative," we are accelerating the development of effective and accessible genetic therapies that will help cure SCD once and for all.

This month, we acknowledge all those living with SCD and the many health and medical professionals working to find new treatments and a cure for this disease. May we honor the progress we have made together and strengthen our resolve in finding a cure for SCD.

NOW, THEREFORE, I, JOSEPH R. BIDEN JR., President of the United States of America, by virtue of the authority vested in me by the Constitution

and the laws of the United States, do hereby proclaim September 2023 as National Sickle Cell Awareness Month. I call upon the people of the United States to learn more about Sickle Cell Disease and the progress we are making to reduce the burden of this disease on our fellow Americans.

IN WITNESS WHEREOF, I have hereunto set my hand this thirty-first day of August, in the year of our Lord two thousand twenty-three, and of the Independence of the United States of America the two hundred and forty-eighth.

R. Beder. fr

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