



Sickle Cell Disease Treatment Centers Act

Approximately 100,000 Americans are currently living with sickle cell disease (SCD), an inherited blood disorder that causes pain, infection, and stroke. The disease disproportionately affects Black Americans but is found among people from different racial and ethnic backgrounds, occurring in approximately one in every 365 Black or African-American births and one out of every 16,300 Hispanic-American births. While the life expectancy of patients with SCD has increased with improved childhood treatment, too many Americans lack access to specialized providers with an understanding of chronic care management and a comprehensive care team including primary care and mental health services.

Comprehensive Care Centers exist across the country, but if a patient does not live nearby, they can face hours of travel and even overnight stays. A patient who needs regular treatment or transfusions may need to take days off to access care. Someone who experiences an acute pain episode may have no choice but to go to a local emergency room that is ill-equipped to provide effective treatment.

The **Sickle Cell Disease Treatment Centers Act of 2022**, introduced by **Senator Chris Van Hollen (D-Md.)**, **Senator Cory Booker (D-N.J.)**, **Representative Barbara Lee (D-Calif.)**, and **Representative Danny Davis (D-Ill.)**, would address the unmet needs of patients with SCD, sickle cell trait, and other heritable hemoglobinopathies through the establishment of and funding for a nationwide system of treatment centers as well as much-needed provider and patient training and education resources.

The **Sickle Cell Disease Treatment Centers Act of 2022** would:

- **Establish a National Sickle Cell Disease Treatment Center Grant Program.** The program would include a nationwide hub-and-spoke network to treat patients with SCD or other hemoglobinopathies, teaming major care centers with smaller providers and community-based organizations to provide comprehensive care, including:
 - Integrated care management, including primary care, specialized care, and mental health services
 - Sickle Cell trait testing and genetic counseling
 - Social work services and education on disease management
- **Establish a National Coordinating Center to work in collaboration with the CDC.** The Center would coordinate the National Sickle Cell Disease Treatment Center Program at the Health Resources and Services Administration (HRSA) and collaborate with the Centers for Disease Control to monitor data and disseminate best practices and educational materials.
- **Authorize appropriations of \$535,000,000 for fiscal year 2023 and each fiscal year thereafter.**
 - 70% of the funding will be allocated to support the hub-and-spoke network
 - 20% of funding will go to community-based Sickle Cell Disease organizations and nonprofits
 - 10% of funding would go towards the National Coordinating Center and funding the data collection and outreach campaign by the CDC

Endorsed By: *Sickle Cell Disease Association of America, American Society of Hematology, Sick Cells, Maryland Sickle Cell Disease Association, Sickle Cell Coalition of Maryland, Johns Hopkins Medicine, Children's National Hospital, Linda Loma University Children's Hospital*