

## The Sickle Cell Disease Treatment Centers Act

Approximately 100,000 Americans in the United States are currently living with sickle cell disease (SCD), an inherited blood disorder that causes chronic pain, infections, stroke, and kidney, liver, and heart disease. The disease disproportionately affects Black Americans and Hispanic Americans, occurring in approximately one in every 365 Black or African-American births and one out of every 16,300 Hispanic-American births. While the estimated life expectancy of patients with SCD has increased with improved screenings and treatment, too many Americans lack access to specialized care and providers with an understanding of SCD, chronic care management, and multidisciplinary care teams.

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 care.

The Sickle Cell Disease Treatment Centers Act of 2024, introduced by **Senator Chris Van Hollen (D-Md.), Senator Cory Booker (D-N.J.), and Representatives Barbara Lee (D-Calif.), Danny Davis (D-Ill.), and Alma Adams (D-N.C.)** would address the unmet needs of patients with SCD, sickle cell trait, and other inherited blood disorders through the establishment of and funding for a nationwide system of treatment centers, as well as much-needed education, outreach, and social services for patients.

The Sickle Cell Disease Treatment Centers Act of 2024 would:

- Establish a National Sickle Cell Disease Treatment Centers Grant Program. The program would include a nationwide hub-and-spoke framework to treat patients with SCD or other blood disorders, enabling hospitals that offer specialized SCD care to partner with smaller providers and community-based organizations to provide comprehensive care, including:
  - Integrated care management, including primary care, specialty care, and mental health services;
  - Sickle cell trait testing and genetic counseling services; and
  - Social services, including supporting patients navigating health insurance coverage and transportation, as well as educating patients, providers, and caregivers on disease management.
- Establish a National SCD Coordinating Center to work in collaboration with the CDC SCD Data Collection Program. The Center would coordinate the National Sickle Cell Disease Treatment Centers Program and collaborate with the CDC to collect and maintain up-to-date data on SCD and disseminate best practices, public awareness campaigns, and educational materials.
- Authorize appropriations as may be necessary for fiscal year 2025 and each fiscal year thereafter, allocated as follows:
  - 70% to support the activities of the hub-and-spoke networks;
  - 20% to support the activities of the community-based organizations;
  - 5% to establish and maintain the National Coordinating Center; and
  - 5% to support the activities of the CDC Sickle Cell Data Collection Program.

**Endorsing Organizations:** Sickle Cell Disease Association of America, American Society of Hematology, Maryland Sickle Cell Disease Association, Sickle Cell Coalition of Maryland, Children's National Hospital, Linda Loma University Children's Hospital