



Expand Sickle Cell Disease Data Collection Efforts at CDC

FACT SHEET

REQUEST: Provide at least \$10 million in dedicated funding for the Sickle Cell Data Collection program at the CDC in FY 2025.

Sickle Cell Disease (SCD)

Affecting nearly 100,000 Americans, sickle cell disease (SCD) is an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle-shaped causing them to block blood and oxygen flow to the body. Though new approaches to managing SCD have led to improvements in diagnosis and supportive care, and the development of potentially curative therapies, many people living with the disease are still unable to access quality care. Our ability to treat patients with SCD is hampered by the lack of data about this patient population.

CDC Current Activities and Funding History

The Centers for Disease Control and Prevention (CDC) has established a program to collect and analyze longitudinal data about people living in the U.S. with SCD. A provision in the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (P.L. 115—327), which was signed into law in December 2018, authorizes CDC to award SCD data collection grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience.

Currently, 16 states participate in the data collection program, with data being collected from multiple sources (e.g., newborn screening programs and Medicaid) in order to create individual healthcare utilizations profiles. Funding through the CDC Foundation has allowed Georgia and California to collect data since 2015; additional CDC Foundation funding, along with discretionary funding from CDC and the Department of Health and Human Services (HHS), and funding provided by Congress, has allowed 14 additional states (Alabama, Arizona, Colorado, Florida, Indiana, Michigan, Minnesota, Missouri, New Jersey, North Carolina, Rhode Island, Tennessee, Texas, and Wisconsin) to begin their data collection programs. These 16 states are estimated to include roughly 50 percent of the U.S. SCD population.

The program is currently funded at \$6 million.

Expanding CDC's SCD Surveillance and Outreach and Education Programs

Strengthening and expanding current efforts will help enable individuals living with this disease to receive adequate care and treatment.

Additional federal funding for CDC's SCD Data Collection Program is necessary to allow the program to be expanded to include additional states with the goal of covering the majority of the U.S. SCD population over the next five years.

The American Society of Hematology (ASH) represents more than 18,000 physicians, researchers, and medical trainees committed to the study and treatment of blood and blood-related diseases. ASH members include clinicians who specialize in treating children and adults with SCD and researchers who investigate the causes and potential treatments of SCD manifestations. In 2015, ASH has launched a transformative, multi-faceted, patient-centric initiative to improve outcomes for individuals with SCD, both in the United States and globally, by bringing together stakeholders in the public and private sectors committed to significantly improving the state of SCD worldwide. Visit www.hematology.org/scd to learn more about ASH's efforts to make significant a difference in SCD access to care, research, and ultimately, cure.