



## Protect Sickle Cell Disease Data Collection Efforts at CDC

FACT SHEET

**REQUEST: Protect CDC's Sickle Cell Data Collection program & provide at least \$10 million in dedicated funding for the program in FY 2027.**

### 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. 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 Sickle Cell Data Collection (SCDC) program helps to better understand where people with SCD live, transition from pediatric to adult care, and use of healthcare services. States funded by CDC to participate in the SCDC program have achieved significant milestones. Examples include increasing access to specialized health care, informing legislation, and engaging the community. The following examples highlight SCDC data in action:

- ***Expanding Network of Adult SCD Clinics***

The California (CA) program along with other clinical and community partners secured funding to establish a network of 12 adult SCD clinics. This effort, informed by data from CA SCDC, led to reduced emergency department visits and hospitalizations, changing the landscape of SCD care in the state.

- ***Improving Access to SCD Care***

The Georgia (GA) program used SCDC data to strategically offer mobile clinics to reach people with SCD in rural areas. They also provided data that showed where people with SCD live in GA and maps of distance to SCD specialty care, which assisted in identifying underserved areas. This information was used to develop a training program to educate non-specialty providers in SCD care to bridge this gap. Since 2018, 600 non-specialty providers in GA have received a 4-hour training program to better understand how to provide care for individuals with SCD.

- ***Informing State Legislation for Outreach and Support Services for SCD***

The Colorado (CO) program helped inform the passage of a state bill, which sets aside state funds for an outreach program to deliver support services to people with SCD in CO. The new law aims to improve access to critical resources for individuals living with SCD and their families.

**The program is currently funded at \$6 million.**

### Protect and Strengthen CDC's SCD Surveillance and Outreach and Education Programs

ASH is deeply concerned that the CDC's entire Division of Blood Disorders and Public Health Genomics, including staff that implement the data collection program, was placed on administrative leave. Protection and support for this program is essential to help strengthen and expand the program's current efforts, which will help enable individuals living with this disease to receive adequate care and treatment.