



FEDERAL REQUESTS FOR SICKLE CELL DISEASE IN 2025

Continued federal program efforts for Sickle Cell Disease (SCD) are critical to ensuring individuals with SCD have access to appropriate care and treatment, ultimately making the provision of care more efficient and effective, lowering health care utilization, and producing financial savings.

The following requests align with these goals:

SPONSOR AND PASS SCD LEGISLATION

S.735/H.R.1796. Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023: Reauthorizes the SCD Demonstration Program at \$8.205 million for each of the fiscal years 2024 through 2028 at the Health Resources and Services Administration (HRSA). The program supports initiatives to improve SCD treatment and to better prevent and treat SCD complications.

Senate Sponsors: Sens. Tim Scott (R-SC) and Cory Booker (D-NJ). House Sponsors: Reps. John James (R-MI), Marc A. Veasey (D-TX), Troy Carter (D-LA), Danny Davis (D-IL), and Jennifer A. Kiggans (R-VA)

S.721. Sickle Cell Disease Comprehensive Care Act: Incentivizes state Medicaid programs to adopt a Health Home model, which improves the coordination of care for individuals with SCD enrolled in Medicaid. Medicaid Health Homes are a proven and effective tool to improve health outcomes, enhance quality, and reduce unnecessary expenditures in Medicaid. State Medicaid directors have supported this model, and more than 90 organizations are supporting this legislation.

Sponsors: Sens. Cory Booker (D-NJ) and Tim Scott (R-SC)

APPROPRIATE \$10 MILLION FOR CDC SCD DATA COLLECTION - FY 2026

Appropriate \$10 million for the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program. The SCDC program gathers health information from multiple sources to determine how many people live with SCD in a particular state, their insurance information, and how and where individuals receive health care services.

- Covers **16 states**, which are home to approximately **50% of the SCD Population** in the USA, with plans to expand.
- Goals include **learning where people with SCD live** and **gathering information on the transition from pediatric care to adult care**.
- Data collection is necessary to **efficiently allocate federal resources** by allowing policymakers to understand national incidence and prevalence data, and to **evaluate effective strategies to improve quality of life and lower costs** associated with treating SCD.

APPROPRIATE \$15 MILLION FOR PROGRAMS UNDER THE HRSA SICKLE CELL DISEASE TREATMENT ACT - FY 2026

Appropriate \$8.205 million to the Sickle Cell Disease Treatment Demonstration Program (SCDTDP). SCDTDP is a HRSA grant program that:

- Increases the number of clinicians or health professionals knowledgeable about SCD care and treatment.
- Improves the quality of care provided to individuals with SCD, including care coordination with other providers.
- Develops best practices for coordination of services during the transition from pediatric to adult care, which is a critical time period for individuals with SCD in ensuring the continuity of comprehensive care, thereby minimizing an increase in health care costs resulting from inadequate disease management into adulthood.

Appropriate \$7 Million to the Sickle Cell Disease Newborn Screening Follow-up Program through the Special Projects of Regional and National Significance. The program is critical to ensuring that all individuals with SCD are connected to follow-up care, support services, and care coordination. This program supports community-based organizations and the support services that they provide to individuals with SCD.