

FISCAL YEAR (FY) 2026 FEDERAL REQUESTS FOR SICKLE CELL DISEASE

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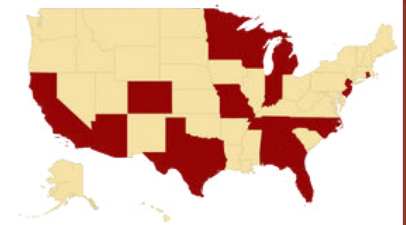
SUPPORT AND PASS SICKLE CELL DISEASE (SCD) LEGISLATION

- **Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2025 (119th Congress, S.735):** Reauthorize 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 the treatment of SCD and to better prevent and treat complications of SCD, focused on populations with a high proportion of individuals with SCD.
- **Sickle Cell Disease Comprehensive Care Act (119th Congress, S.721):** This legislation 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.**

PROVIDE FUNDING FOR KEY SCD PROGRAMS

Appropriate \$25 million for 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 the disease in a particular state.

- The SCDC covers 16 states which are home to approximately 50% of the SCD Population in the USA with plans to expand.
- The goals of the SCDC 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

- **Appropriate \$8.205 million to the Sickle Cell Disease Treatment Demonstration Program (SCDTDP).** SCDTDP is a HRSA grant program with the following goals:
 - Increase the number of clinicians or health professionals knowledgeable about the care of SCD.
 - Improve the quality of care provided to individuals with SCD, including care coordination with other providers.
 - Develop 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 diagnosed with SCD are connected to appropriate follow-up care, support services, and care coordination.
- **In its first two years, the program:**
 - Expanded the infrastructure of 25 community-based organizations in 19 states.
 - Launched the National SCD Community Health Workers Training Program – and trained 85 community health workers who reached more than 13,000 patients.
 - Assessed over 8,000 individuals in need of a medical home or education on SCD medication.
 - Launched a Shared Management System, which allows HRSA to analyze patient outcomes.

Continued program efforts will accelerate the identification of individuals requiring follow-up care for SCD, expand care coordination, increase medical home participation, improve the number of community health workers trained in SCD, and implement best practices and procedures for SCD care.