

Fiscal Year (FY) 2027 Federal Requests for Sickle Cell disease



Sickle Cell Disease (SCD) is the most common inherited blood disorder in the US and impacts over 100,000 Americans. Individuals living with SCD face severe health complications, including recurring and life-altering pain crises, repeat infection, acute chest syndrome, lung problems, severe and chronic pain, leg ulcers, organ damage, and stroke.

Through advocacy and congressional action, we see life improving for the SCD community

Here's how you can help make a difference for individuals and families living with SCD:

JOIN AND ACTIVELY PARTICIPATE IN THE CONGRESSIONAL SICKLE CELL DISEASE CAUCUS

The mission of the **Congressional Sickle Cell Disease Caucus is to elevate the needs of constituents living with SCD** and those who provide care, innovation, and coverage for the community. The SCD Caucus serves as a forum to:

- Advance bipartisan policy solutions and policy-relevant research
- Strengthen education and awareness of sickle cell disease
- Build congressional support for legislation and appropriations that improve care

COSPONSOR THE SICKLE CELL DISEASE COMPREHENSIVE CARE ACT (H.R.5178/S.721)

The **Sickle Cell Disease Comprehensive Care Act incentivizes state Medicaid programs to adopt a Health Home model**, improving care coordination for individuals with SCD enrolled in Medicaid.

This model helps patients navigate complex care needs, reduces preventable hospitalizations, and improves health outcomes. The Congressional Budget Office projects that Medicaid Health Homes will also generate cost savings.

CHAMPION ROBUST FUNDING FOR SICKLE CELL DISEASE PROGRAMS IN FISCAL YEAR (FY) 2027

Thank you for appropriating \$21 million across federal programs. Funding levels shown reflect FY 2026 appropriations and are cited to support our request for continued funding in FY 2027.

Appropriate \$8.2 million to the Sickle Cell Disease Treatment Demonstration Program (SCDTDP)

The SCDTDP is a Health Resources and Services Administration (HRSA) grant program that expands access to high-quality, coordinated SCD care by training clinicians and strengthening care delivery systems. In FY 2026, the program supported services across 51 sites and reached more than 25,000 individuals—particularly during critical transitions from pediatric to adult care.

Appropriate \$7 million to the HRSA Sickle Cell Disease Newborn Screening Follow-up Program

This program ensures that infants and families identified through newborn screening are connected to follow-up care, education, and community-based support. In its first two years, the program strengthened the infrastructure of 25 community-based organizations across 19 states and reached more than 13,000 patients, and assessed over 8,000 individuals in need of a medical home or treatment education.

Appropriate \$6 million for Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program

The CDC SCDC Program provides essential data to understand where people with SCD live, how they access care, and which interventions improve outcomes. Since its initial appropriations in 2019, the program has expanded from 2 states to 16 states, now covering approximately half of the U.S. SCD population.

CREATED BY



Sick Cells is a national advocacy nonprofit whose mission is to elevate the voices of the sickle cell disease (SCD) community and our stories of resilience. In amplifying the challenges this community faces, we influence decision makers and drive positive change.

For more information, visit sickcells.org.