

FY24

FEDERAL REQUESTS FOR SICKLE CELL

As you consider programmatic appropriations for Fiscal Year (FY) 2024, we respectfully request that you include robust funding to support and expand critical initiatives for research, surveillance, and treatment of sickle cell disease (SCD).

HRSA 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
- Improve care coordination with other providers
- Develop best practices for coordination of services during pediatric to adult transition.

Impact: Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care.

FY24 REQUEST:

\$15
MILLION

CDC SICKLE CELL DATA COLLECTION (SCDC) PROGRAM

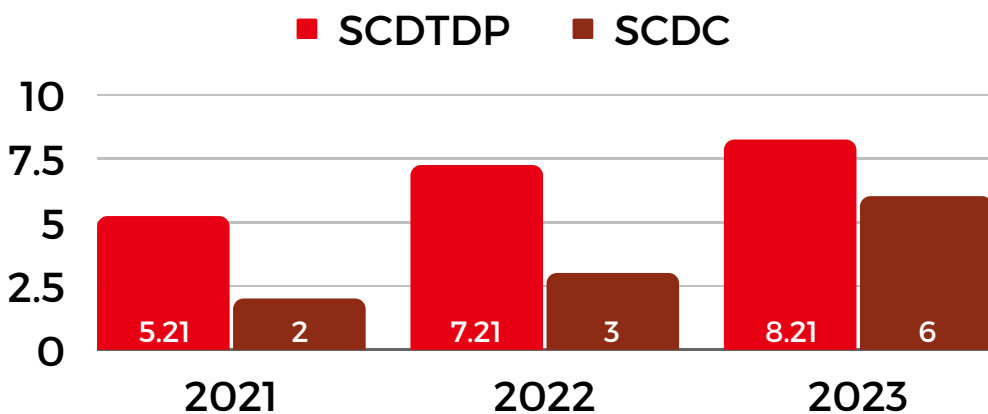
The Sickle Cell Data Collection (SCDC) program gathers health information from multiple sources to determine how many people live with the disease in a particular state.

- The SCDC currently covers 11 states with plans to expand.
- The goals of the SCDC include learning where people with SCD live, gathering information on the transition from pediatric care to adult care, gathering demographic information, and much more.

Impact: Data collection is necessary to improve national incidence and prevalence data; better identify health disparities; and evaluate strategies to improve quality of life and lower costs associated with treating the population.

FY24 REQUEST:

\$25
MILLION



RECENT APPROPRIATIONS FOR FEDERAL SCD PROGRAMS
(in millions of US Dollars)



The purpose of this guide is provide information on past support for sickle cell disease at the federal level.

PAST SUCCESSES

National Sickle Cell Anemia Control Act of 1972 (PL 92-294)

- Signed into law 5/16/1972 by President Richard Nixon
- First major legislation for SCD
- Established guidance for SCD education, screening, testing, counseling, and research
- Created the first federal programs for SCD
- **Passed & Funded**

The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (PL 115-327)

- Signed into law 12/18/2018 by President Donald Trump
- Sponsors: Senator Tim Scott (R-SC) and Senator Cory Booker (D-NJ), Congressman Danny Davis (D-IL), Congressman Michael Burgess (R-TX)
- Reauthorizes SCD prevention and treatment grants awarded by the Health Resources and Service Administration (HRSA)
- Authorizes the Centers for Disease Control and Prevention to award SCD surveillance grants to states, academic institutions and non-profit organizations
- **Passed & Funded**

PAST ATTEMPTS: DEAD BILLS

The Sickle Cell Comprehensive Care Act (H.R. 6216/S. 3389)

- Introduced in December 2021 by Representatives Davis (D-IL-7) and Burgess (R-TX-26) in the House and Senators Booker (D-NJ) and Scott (R-SC) in the Senate
- Directs the Centers for Medicare and Medicaid Services (CMS) to create a demonstration to improve access to quality care for SCD Warriors enrolled in Medicaid
- **Died in 117th Congress**

The Sickle Cell Care Expansion Act (H.R. 7177/S. 4425)

- Introduced in March 2022 by Representatives Crist (D-FL-13) and Lee (D-CA-13) in the House, and Senators Van Hollen (D-MD) and Booker (D-NJ) in the Senate (June 2022)
- Hopes to increase the number of physicians treating SCD through a loan forgiveness and scholarship program
- **Died in 117th Congress**

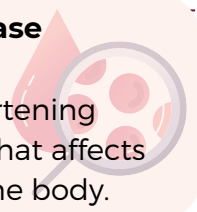
The Sickle Cell Disease Treatment Centers Act (H.R. 8855/S. 4866)

- Introduced in September 2022, by Senators Van Hollen (D-MD) and Booker (D-NJ) in the Senate, and Representative Lee (D-CA-13), Davis (D-IL-7) and Adams (D-NC-12) in the House.
- Establishes a hub-and-spoke model for caring for SCD Warriors and requires collaboration with SCD CBOs and nonprofits
- **Died in 117th Congress**

SICKLE CELL DISEASE FACT SHEET

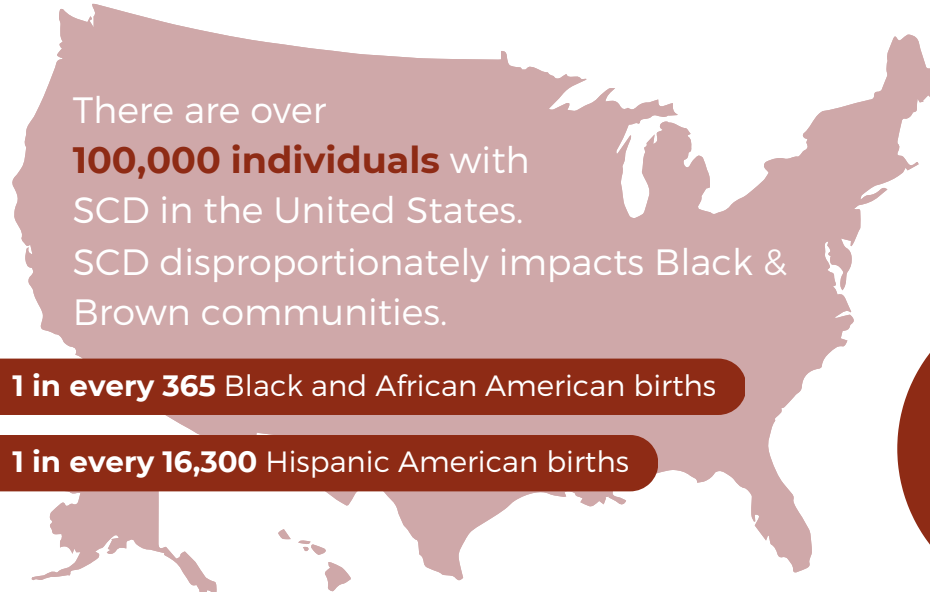
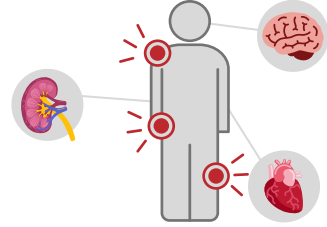
Sickle cell disease

(SCD) is a rare, genetic, life-shortening blood disorder that affects every organ in the body.



SCD is the most common inherited blood disorder in the U.S. It is caused by abnormal red blood cells. Instead of being soft and round, these red blood cells are **hard and sticky**, and shaped like a "sickle." This can **block blood flow** and oxygen from reaching all parts of the body.

The most common symptoms of SCD are recurring **pain crises**. The disease can also cause chronic complications such as organ damage, death of bone tissue, skin ulcers, stroke, blindness, neurocognitive impairment, pulmonary hypertension, heart and kidney failure, and early mortality.



1 in every 365 Black and African American births

1 in every 16,300 Hispanic American births

4
FDA-approved drugs since 1998

Limited treatments:

- Bone marrow/stem cell transplant
- Chronic transfusions

- People with SCD have **less access** to comprehensive team care than people with genetic disorders such as hemophilia and cystic fibrosis.
- Current **standard of care for SCD treatments** is not appropriate for all individuals living with SCD.
- **Gene therapy is on the horizon** for SCD. This development creates opportunities for legislative action to improve access to care and address issues with outdated healthcare payment models.

WHAT DOES IT COST?

\$2.98B
Annual direct cost of SCD to the U.S. federal government

Source: Huo et al., (2018) "[The Economic Burden of SCD...](#)"

\$10,000
Annual individual cost of caring for an insured child with SCD

Source: Kauf et al., (2009) "[The Cost of Healthcare...](#)"

\$30,000
Annual cost to an insured adult with SCD

Source: Kauf et al., (2009) "[The Cost of Healthcare...](#)"

Expenditures for patients with SCD are **6 times higher** than non-SCD patients on Medicaid and **11 times higher** than non-SCD patients with private insurance.

Source: HHS, "[Sickle Cell Disease](#)"