

FY24 SCDA A LEGISLATIVE PRIORITIES

118TH CONGRESS



Legislation

The Sickle Cell Disease Comprehensive Care Act (S.904/HR.1672)

- The Sickle Cell Disease Comprehensive Care Act directs CMS to create a demonstration program in up to 10 states to improve access to comprehensive, high-quality, outpatient care for SCD Warriors enrolled in Medicaid.
- Sponsors: Representatives Danny Davis (D-IL) and Michael Burgess (R-TX) and Senators Cory Booker (D-NJ) and Tim Scott (R-SC).
- Improve patient access to clinical, mental health, and ancillary and support services.
- Promote coordination through multidisciplinary teams.
- Provide support to community-based organizations, community health centers, hospitals, and academic health centers.
- Develop infrastructure to recruit providers and provide specialized training.
- **Appropriations: \$25M (planning grants) & \$50M (CMS).**

Appropriations Requests

Asking for increased funding for existing federal programs

SCD Treatment Demonstration Program

- **The Request: \$15 million** in funding for the Sickle Cell Disease Treatment Demonstration Program (SCDTDP), which is overseen by the Health Services and Resources Administration, be included in the fiscal year (FY) 2024 appropriations bill.
- The 2018 SCD law reauthorized the Sickle Cell Disease Treatment Demonstration Program (SCDTDP) to help coordinate service delivery for individuals with SCD, train health professionals, and provide access to genetic counseling and testing.
- The reauthorization also calls for SCDTDP to develop best practices for the coordination of services for adolescents transitioning from pediatric to adult healthcare. Due to the lack of adequate protocols and care coordination, people with SCD struggle with the transition to adulthood.
- Impact: Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care.

CDC Sickle Cell Data Collection Program

- **The Request: \$25 million** in dedicated funding for the Centers for Disease Control and Prevention's (CDC) Sickle Cell Data Collection program be included in the fiscal year (FY) 2024 appropriations bill.
- Key findings and recommendations from the NASEM report on SCD highlight the critical need to establish a national system for SCD data collection.
- Dedicated appropriations for SCD will allow the CDC to continue and expand state public health surveillance and support a national longitudinal registry of all persons with sickle cell disease.
- 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.

PAST FEDERAL SUPPORT FOR SCD



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

Expected to be reintroduced in 118th 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).
- Aims 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.