

SCD Advocacy

Update

March 2026

An update from Sickle Cell Disease Association of America, Inc.



Congress Passes Fiscal Year 2026 Funding Package with Big Wins for the Sickle Cell Disease Community



In early February, Congress finally advanced, and the President signed into law, a funding package for federal programs for fiscal year (FY) 2026, which runs through September 30, 2026. All three federal sickle cell disease programs — Health Resources and Services Administration’s (HRSA’s) Sickle Cell Disease Treatment Demonstration Program, HRSA’s Sickle Cell Disease Newborn Screening Follow Up Program and the Centers for Disease Control and Prevention’s (CDC) Sickle Cell Data Collection Program — were maintained with the same funding levels as FY25.

The funding package also included the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act (H.R. 1796/S. 735) which reauthorizes HRSA’s SCD Treatment Demonstration Program for another five years. SCDA has been working to advance this legislation since it was introduced in the 118th Congress. Thank you to all who have advocated for this legislation and a special thanks to our Congressional champions Senators Tim Scott (R-SC) and Cory Booker (D-NJ); and Representatives John James (R-MI-10), Danny Davis (D-IL-07), Jen Kiggans (R-VA-2), Troy Carter (D-LA-2) and Marc Veasy (D-TX-33) for helping to get this bill across the finish line.

SCDAA Turns Focus to Funding for FY27

2027

Now that funding for FY26 is wrapped up, SCDA has begun advocating to secure funding for sickle cell disease federal programs for FY27. SCDA has secured a bipartisan effort in the House of Representatives — Reps. Danny Davis (D-IL) and Jen Kiggans (R-VA) are leading a letter in support of FY27 funding for the federal sickle cell programs. We are also working with staff for Sens. Booker (D-NJ) and Scott (R-SC) and are hopeful that they will send a letter to the Senate Appropriations Committee as they have done in the past. Several Members of Congress have asked SCDA to complete their Appropriation’s request forms, which shows broader support for the federal SCD programs. These requests and letters of support from Members of Congress to the relevant Appropriations Committees are an important step in securing funding for federal programs.

SCDAA Engages with Federal and State Medicaid Programs on Work Reporting Requirements



SCDA is closely tracking the coming changes to the Medicaid program. In December, SCDA met with staff at the Centers for Medicare and Medicaid Services (CMS) to talk about the coming work-reporting requirements and to request that individuals living with sickle cell disease are exempt from these requirements. Since then, SCDA has sent a follow-up letter to CMS as well as to all state Medicaid directors providing information about sickle cell disease and again, requesting that individuals with sickle cell disease are exempt from these requirements.

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SCDAA Engages with Federal and State Medicaid Programs on Work Reporting Requirements *cont.*

States are required to implement work-reporting requirements as a basis of Medicaid eligibility for certain beneficiaries by January 1, 2027, although some states have indicated that they will get started sooner (Nebraska is set to implement as soon as May 1, 2026). Federal guidance is anticipated in June, although implementation details will likely be left up to the states. SCDAA will continue to provide information to members as it becomes available.

SCDAA continues to encourage members to engage with their state Medicaid programs. SCDAA will be sharing information soon about state Medicaid Advisory Committees and Beneficiary Advisory Councils, which are now mandatory in each state, and provide an opportunity for the public to weigh in on Medicaid policy.

Outreach to Social Security Administration on Disability Evaluations

In early February, SCDAA joined other sickle cell disease advocacy organizations, including Sick Cells and the American Society of Hematology, in a letter to the Social Security Administration (SSA) requesting again that the agency update the existing criteria used to evaluate sickle cell warriors to determine eligibility for disability benefits. The letter specifically requested that the agency review the report issued by the National Academies in December 2025, which includes strong support for revising the current criteria used by SSA. The agency responded that they are actively reviewing the report. SCDAA will continue to push for these criteria to be updated to better reflect current treatment practices and the reality of living with sickle cell disease.



For questions, contact Regina Hartfield, president and CEO, Sickle Cell Disease Association of America, Inc., at rhartfield@sicklecelldisease.org.

The Sickle Cell Disease Association of America Inc. advocates for people affected by sickle cell conditions and empowers community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. The association and its more than 55 member organizations support sickle cell research, public and professional health education and patient and community services. sicklecelldisease.org

