

SCD Advocacy

Update

Q2 2026



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



SCDAA HOSTS ANOTHER SUCCESSFUL ADVOCACY DAYS

From May 6-7, 24 representatives from 13 SCDAA members organizations across 11 states traveled to Washington, D.C., for SCDAA's Advocacy Days. Attendees participated in a briefing on May 6, which included information about how to have a successful Congressional meeting, an overview of the issues and asks and a visit from Representative Glenn Ivey (D-MD-04), one of the new co-chairs of the recently relaunched Congressional Sickle Cell Disease Caucus. On May 7, advocates took to Capitol Hill and met with 34 offices to ask Members of Congress to support the sickle cell disease community. This year, attendees requested that Members of Congress:

- **Help protect the federal Sickle Cell Disease Newborn Screening Follow-Up Program by signing a Congressional letter to Secretary Kennedy and HRSA Administrator Engels** asking that the grants for the program be extended and that the notice of funding be released quickly to allow grantees to apply for funds for FY 2027. (*Read more about the letter below.*)
- **Show support and interest in furthering issues of importance to the SCD community by joining the bipartisan Sickle Cell Disease Caucus.** The Caucus was recently relaunched by Reps. Rich McCormick (R-GA) and Glenn Ivey (D-MD) and will work to advance policies and programs that improve the lives of individuals and families affected by sickle cell disease (SCD).
- **Cosponsor the Sickle Cell Disease Comprehensive Care Act (H.R.5178 or S.721) to help improve clinical and cost-effective care for Medicaid beneficiaries with SCD.** The bill would allow states to create a Medicaid Health Home to improve access to comprehensive, high-quality, outpatient care for Medicaid beneficiaries with a single qualifying diagnosis of SCD.

SCDAA would like to extend a big thank you to all who took the time to come to Washington, D.C., to advocate on behalf of the sickle cell disease community. **Your advocacy made a difference** — the [sign-on letter](#) closed with 27 total signers — a huge showing of support from members of Congress on this important issue. There are also two new members of the Congressional Sickle Cell Disease Caucus as a result of SCDAA's Hill Days, Reps. Mfume (D-MD) and Doggett (D-TX).



HRSA's Sickle Cell Disease Newborn Screening Follow-Up Program provides grant funding to 25 SCD community benefit organizations (CBOs) across the country. The funding is used to support different programs and services offered by CBOs, including training community health workers. The program has been funded by Congress every year since 2002. The current five-year grant cycle ends August 2026 and yet, the Department of Health and Human Services (HHS)/HRSA has yet to issue a new notice of funding opportunity for 2027 and beyond. This is why SCDAAs worked with Representatives Troy Carter (D-LA) and Alma Adams (D-NC) to draft a letter to Secretary Kennedy and HRSA Administrator Thomas Engels, asking that they work quickly to issue the new funding notice to ensure there is no gap in funding to SCD CBOs. SCDAAs were thrilled to see 27 members of Congress join the letter.

SCDAAs will continue to provide updates to members on the status of the HRSA Sickle Cell Disease Newborn Screening Follow-Up Program and the Congressional Sickle Cell Disease Caucus.

HHS OFFICE OF MINORITY HEALTH SICKLE CELL DISEASE WEBINARS

On May 14, the Department of Health and Human Services Office of Minority Health held the first of two webinars focused on advancing comprehensive systems of care for sickle cell disease. Dr. Edward Donnell Ivy, SCDAAs' chief medical officer, presented on the webinar. The second webinar is scheduled for Thursday, June 18 from 2:00 to 3:30 p.m. ET. The objective of this webinar is to provide information about available resources and specific efforts across HHS and address challenges in achieving sickle cell disease comprehensive systems of care. [Registration](#) is now open.

CMS ISSUES GUIDANCE ON MEDICAID WORK REPORTING REQUIREMENTS

On June 1, the Centers for Medicare and Medicaid Services (CMS) released long-awaited [guidance](#) directing states on how to implement the H.R. 1 Medicaid work reporting requirements (also known as community engagement requirements). It is important to note that we will not fully know how these requirements will be implemented until each state issues its own guidance.

Beginning January 1, 2027, states must require applicable individuals (adults between 19-64 who are not pregnant, entitled to or enrolled in Medicare and are not disabled or receiving SSI) to demonstrate work reporting requirements as a condition of eligibility for Medicaid at application and renewal. To meet these requirements, individuals must complete at least 80 hours of work, community service or participation in a work program each month, be enrolled in an educational program at least half-time or have a monthly income of at least \$580 (or any combination of these things).

There are exclusions to the work requirements for individuals who meet certain criteria. Based on this guidance, having sickle cell disease will not automatically exclude someone from the work requirements. Exclusions will be based on the severity of the sickle cell disease and the impact the disease has on one's ability to work. We anticipate further guidance from states to better understand how this will work.

A full summary of the guidance and an FAQ will be provided soon. Please refer to SCDAAs' [Preparing for Medicaid Changes](#) document for what SCD warriors can do now to help protect Medicaid coverage.

SCDAA AWARDS GIVEN TO SENATORS BOOKER (D-NJ) AND SCOTT (R-SC)



As part of SCDAA's 2025 Annual National Convention, Senators Cory Booker (D-NJ) and Tim Scott (S-SC) were awarded the SCDAA Champion's Award. This honor is awarded to those who help to advance the understanding, education and awareness of sickle cell disease through meaningful and important legislation. Senators Booker and Scott have joined together in a bipartisan fashion to lead on a number of different policy initiatives important to the sickle cell disease community, including supporting funding for the federal sickle cell disease programs every year as part of the Congressional appropriations process. Although the Senators were unable to make it in person to the Convention to receive their awards, Regina Hartfield, SCDAA president and CEO, had the opportunity to present the awards in person on Capitol Hill.

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 50 member organizations support sickle cell research, public and professional health education and patient and community services. sicklecelldisease.org

