



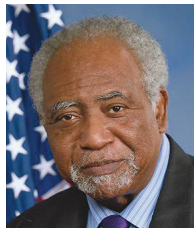
LEGISLATIVE BRIEFING

AN UPDATE FROM SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC.

September 2025



Rep. Neal Dunn



Rep. Danny Davis

REPS. DUNN AND DAVIS INTRODUCE SICKLE CELL DISEASE COMPREHENSIVE CARE ACT

On September 8, Representatives Neal Dunn (R-FL-02) and Danny Davis (D-IL-07) and 19 original co-sponsors [introduced](#) the Sickle Cell Disease Comprehensive Care Act (H.R. 5178), legislation which will allow states to submit a State Plan Amendment to establish Health Homes for individuals with sickle cell disease as the only qualifying condition. Health Homes are an existing Medicaid program aimed at improving access to care for individuals living with chronic diseases. Health Homes help to integrate and coordinate care, working to ensure that SCD warriors have access to coordinated clinical, mental health and ancillary services to address physical, mental and social needs. Senators Cory Booker (D-NJ) and Tim Scott (R-SC) introduced the Senate version (S. 721) of this bill in February. SCDAAs supports this legislation and looks forward to working to advance it through the legislative process.



Sen. Cory Booker



Sen. Tim Scott

FEDERAL FUNDING UPDATE

Congress is racing against the clock as federal funding for fiscal year (FY) 2025 is set to expire September 30. It is looking likely that they will pass a short-term funding bill (also known as a continuing resolution or CR) to provide federal funding through mid-November. A CR continues to fund the government at current levels – meaning all the federal sickle cell disease programs will continue to be funded.



A CR through mid-November, however, will not give Congress much time to move the 12 appropriations bills needed to fully fund federal programs. The House and the Senate have already advanced some bills, including the appropriations bill for the federal health programs. Both chambers maintained support and level funding for the three federal sickle cell disease programs. In a year of uncertainty, this was very promising. SCDAAs will continue to support these programs as the appropriations process continues.

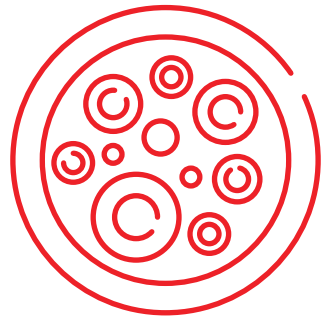
CONGRESS PASSES H.R. 1 TO MAKE SWEEPING CHANGES TO MEDICAID



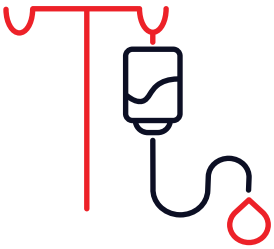
On July 4, President Trump signed into law H.R. 1, also known as the One Big Beautiful Bill Act. This law makes significant changes to the Medicaid program over the next few years. SCDAAs spent much of the spring and early summer advocating against these changes and fighting to protect access to Medicaid. Now that the bill has become law, SCDAAs has shifted its focus to educating member organizations about what is coming and how they can help sickle cell warriors be prepared. This includes launching a new “Keep Your Medicaid” campaign which will provide tips on what sickle cell warriors can do now to protect their Medicaid coverage. SCDAAs will continue to provide guidance to members as more information on the Medicaid changes is released.

CELL & GENE THERAPY ACCESS MODEL UPDATE

In July, the Centers for Medicare and Medicaid Services (CMS) announced that 33 states plus the District of Columbia and Puerto Rico will be participating in the Cell and Gene Therapy Access Model, which aims to improve access to sickle cell disease gene therapies for individuals insured by Medicaid. CMS has now also made [available](#) the information on which states have applied for and been awarded the additional grant funding, which can be used to support the implementation of the model, including through contracts with SCD CBOs. This additional funding will go to Connecticut, District of Columbia, Illinois, Mississippi, North Carolina, Pennsylvania, Rhode Island and Vermont.



SOCIAL SECURITY ADMINISTRATION ADDS STEM CELL TRANSPLANTATION TO COMPASSIONATE ALLOWANCES LIST



In August, the Social Security Administration (SSA) [added](#) 13 conditions, including stem cell transplantation, to the compassionate allowances list (CAL). The CAL program accelerates the SSA disability application process for individuals with diseases or conditions on the list, meaning a sickle cell warrior who is undergoing stem cell transplantation would have access to a quicker application process when applying for social security disability. Individuals still must wait five months once approved for access to the benefits.

HHS EXPANDS ACCESS TO CATASTROPHIC HEALTH COVERAGE

On September 4, the U.S. Department of Health and Human Services (HHS) announced that it was implementing new policies to expand access to catastrophic health coverage on the federal exchange for the 2026 plan year. This guidance streamlines access to catastrophic coverage for consumers who are ineligible for Marketplace tax credits or cost-sharing reductions (CSRs).

Consumers under the age of 30 have been eligible for catastrophic plans through HealthCare.gov and this change would make it easier for people of any age to purchase them. While catastrophic plans cover the essential health benefit (EHB) categories that other private plans have to cover, they trade lower premiums for extremely high out-of-pocket costs. Under this coverage, the plans cover less, leaving the patient to pick up more of the cost. The out-of-pocket maximum and deductible are set as high as allowed and the only services covered pre-deductible are three primary care visits and preventive services.

Due to the expected increase in premiums for next year, these plans may be attractive for people, but they would likely not be sufficient for sickle cell warriors.



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

