LEGISLATIVE BRIEFING

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

March 2025

WHAT'S HAPPENING IN WASHINGTON?

It has been a chaotic couple of months in Washington. The 119th Congress kicked off in early January, and President Trump was sworn into office later that month. Since taking office, President Trump has issued more than 80 executive orders (EOs) and rescinded 78 of President Biden's EOs. SCDAA continues to track these EOs and any potential impact on the SCD community.

The Senate has been focused on confirming President Trump's nominees for federal agencies. Most notably for the health care community, Robert F. Kennedy Jr. has been confirmed to lead the Department of Health and Human Services (HHS). Congress is also working out how to fund the federal government ahead of the March 14 funding deadline.

Congress is also looking to move a large legislative package which could include significant cuts to Medicaid, which insures approximately half of the individuals in the U.S. living with SCD. On the last Leadership Academy call, SCDAA member organizations were encouraged to email their representative/senators about the importance of Medicaid for the SCD community.

SICKLE CELL DISEASE LEGISLATION REINTRODUCED IN CONGRESS

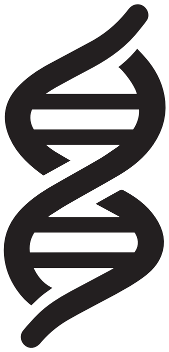
In February, Congress reintroduced the [Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act]() (S. 735/H.R. 1796), which would reauthorize the Health Resources and Services Administration's (HRSA) Sickle Cell Disease Treatment Demonstration Program for another five years. In the Senate, the bill was introduced by long-time SCD champions Senators Cory Booker (D-NJ) and Tim Scott (R-SC). Thanks to the advocacy of Dr. Wanda Whitten-Shurney (SCDAA-MI) and Dr. Sarah Reeves (Michigan Sickle Cell Data Collection Program), SCDAA was able to secure a new Republican lead in the House of Representatives — Representative John James (R-MI-10). He was joined by long-time SCD Champion Danny Davis (D-IL-07) and Representatives Jen Kiggans (R-VA-2), Troy Carter (D-LA-2) and Marc Veasy (D-TX-33).

Senators Booker and Scott also reintroduced the [Sickle Cell Disease Comprehensive Care Act]() (S. 721), which would allow state Medicaid programs to provide comprehensive and coordinated care to sickle cell warriors through a health home model. SCDAA supports both pieces of legislation and will track them as they move through the legislative process.

REGISTRATION IS OPEN FOR SCDAA'S IN-PERSON 2025 ADVOCACY DAYS — MAY 7-8

Registration is now live for SCDAA's in-person Advocacy Days, which will take place in Washington, D.C., on May 7-8. Similar to last year, there will be a training session during the afternoon of May 7, and on May 8, we will head to Capitol Hill to talk with legislators and their staff about issues important to the SCD community. SCDAA member organizations received an email on February 24 with more information and a link to register. We encourage each SCDAA member organization to send a representative. Additionally, a room block is reserved at the Kellogg Conference Hotel at Gallaudet University. Hotel reservation information and a link will follow in a separate email. SCDAA will cover accommodation on the night of May 7 for a maximum of two attendees per member organization. Any additional rooms or accommodation required will be the individual's responsibility. Each attendee is responsible for the cost of their own transportation. Please reach out to Regina Hartfield at [rhartfield@sicklecelldisease.org]() for more information and/or [click here to register]().

CELL AND GENE THERAPY ACCESS MODEL



The Centers for Medicare and Medicaid Services' (CMS) Cell and Gene Therapy (CGT) Access Model extended the deadline by which states must apply to March 14, 2025. As a reminder, the CGT access model provides state Medicaid programs with access to a federally negotiated price for SCD gene therapies. In addition, states can apply for additional funds outlined in the Notice of Funding Opportunity (NOFO) – the deadline to apply for these funds has also been extended to March 14. A summary of the NOFO is available here. These funds will be awarded on July 1, 2025, and can be used by states to fund required and optional services outlined in the model program, including contracting with CBOs to provide education, screening, care coordination and peer support services as well as childcare services.

In mid-February, SCDAA encouraged member organizations to reach out to their state Medicaid programs to urge them to apply for participation in the model as well as for the extra funding.

NEW! SCDAA JOINS THE PARTNERSHIP TO PROTECT CARE

SCDAA is now a member of the Partnership to Protect Coverage (PPC), a coalition of patient and consumer advocacy organizations including groups like the American Heart Association and American Lung Association that work together to advance the shared goal of ensuring that health care coverage is affordable, accessible and adequate. PPC works at both the federal and state level. Right now, the coalition is focused on protecting access to Medicaid. SCDAA recently joined this statement in opposition to proposed cuts to Medicaid.

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. www.sicklecelldisease.org.*