



# LEGISLATIVE BRIEFING

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

March 2024

## **NEW!** SICKLE CELL LEGISLATION INTRODUCED IN CONGRESS

On February 23, Representatives Michael Burgess (R-TX-26), Danny Davis (D-IL-7), and Darren Soto (D-FL-9) introduced a new version of the Sickle Cell Disease Comprehensive Care Act ([H.R. 7432](#)). This legislation would allow state Medicaid programs to establish health homes for eligible beneficiaries with SCD. Health homes are currently available to certain eligible Medicaid beneficiaries and offer services such as comprehensive care management, care coordination, and more.

SCDAA supports this legislation and will continue to track its progress as it moves through the legislative process. To learn more, see the American Society of Hematology fact sheet, [here](#).

## **WE'RE ON OUR WAY TO SCDAAs ADVOCACY DAY!**

For those who have registered to participate in SCDAAs Advocacy Day, which will be in person in Washington, DC, May 8-9, 2024, we thank you. We are excited to have you join us as we walk the halls to talk with federal legislators about issues important to the SCD community.

The in-person event will begin at 2 p.m. ET on Wednesday, May 8, with an afternoon program that includes a live briefing and advocacy training sessions. Participants will learn about the importance of telling your story. Legislators need to hear from you on what it means to live with SCD, be a caregiver for someone with SCD, and the role Member Organizations and CBOs play in supporting the SCD community. Sharing these details can educate members of Congress and their staff and make the difference when it comes to supporting legislation. The Wednesday briefing will also review the pieces of legislation we will advocate for on May 9.

On Thursday, May 9, we will board shuttles to the Hill for visits with your members of Congress and their staff to talk about issues impacting the SCD community and request support for specific bills. For those who can return, we'll host a short debrief on the day's activities before we depart for home.

Stay tuned for information about hotel reservations and logistics. See you soon!

## **WHAT'S HAPPENING IN CONGRESS?**

On March 22, after months of delay, Congress finally passed legislation to fully fund federal programs for fiscal year (FY) 2024. There are three major federal SCD programs funded through this bill – the Centers for Disease Control and Prevention (CDC) SCD Data Collection Program, the Health Resources and Services Administration (HRSA) SCD Treatment Demonstration Program and the HRSA SCD

Newborn Screening Follow-up Program. The 2024 funding levels for these programs are the same as 2023:

- \$6 million for the CDC's SCD Data Collection Program
- \$8.205 million for HRSA's SCD Treatment Demonstration Program
- \$7 million for HRSA's SCD Newborn Screening Follow-up Program

President Biden has also released his budget for FY 2025. The President proposed to keep funding levels for these three SCD programs consistent with the 2024 amounts above. The President is required by law to submit a budget annually. It is meant to outline the administration's policy priorities. It is a set of recommendations that Congress may consider but is not required to adopt.



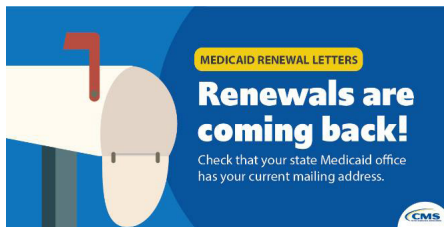
## CMMI ANNOUNCES SICKLE CELL DISEASE AS FIRST FOCUS OF THE CELL AND GENE THERAPY ACCESS MODEL

On January 30, 2024, the Centers for Medicare and Medicaid Services (CMS) and the Center for Medicare and Medicaid Innovation (CMMI) announced that SCD will be the first focus of the new Cell and Gene Therapy (CGT) Access Model. The intent of the model is to help facilitate access to the two recently approved gene therapies for SCD for individuals insured by Medicaid.



CMS will partner with states and the manufacturers of the gene therapies to negotiate an outcomes-based agreement which will tie pricing for SCD treatments to whether the therapy improves health outcomes for people with Medicaid – essentially if the treatment does not work, Medicaid will not have to pay the manufacturer for the product. Details on what else will be provided under the model are still being released, but we do know that manufacturers will have to cover the cost of fertility preservation for individuals living in Model states who choose to undergo gene therapy. The model will begin in January 2025, but states can join anytime between January 2025 and January 2026. Participation by state Medicaid programs will be optional.

Many Member Organizations have reached out with questions about this Model and what it means for the sickle cell community and access to the two new gene therapies. SCDAA has released a summary of the CGT Model as well as some talking points which will help you to better understand SCDAA's position on the Model and can be used to help you talk about the Model.



### REMINDER! MEDICAID UNWINDING

It has been over a year since state Medicaid programs restarted Medicaid redeterminations of eligibility for the first time since the COVID-19 pandemic. This is known as Medicaid Unwinding. Every individual on Medicaid must go through this process by May 31, 2024. Use the resources below to help individuals living with SCD or caring for someone with SCD learn what they can do to prepare or where to look for new coverage.

- Use this flyer to help prepare people to renew their Medicaid and CHIP coverage.
- Use this tip sheet to help people who have lost Medicaid or CHIP find other health coverage.
- There is a Special Enrollment Period for individuals who lose Medicaid or CHIP coverage as a result of the Medicaid Unwinding. This will allow individuals and families in Marketplaces served by HealthCare.gov to enroll in Marketplace health insurance coverage outside of the annual open enrollment period. This will extend through November 30, 2024.

For questions, contact Regina Hartfield, President and CEO, Sickle Cell Disease Association of America, Inc. at [rhartfield@sicklecelldisease.org](mailto:rhartfield@sicklecelldisease.org).

The Sickle Cell Disease Association of America 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 more than 50 member organizations support sickle cell research, public and professional health education and patient and community services. [www.sicklecelldisease.org](http://www.sicklecelldisease.org)

