



LEGISLATIVE BRIEFING

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

June 2024

NEW!

SCDAA URGES CONGRESS TO ADVANCE THE SICKLE CELL DISEASE COMPREHENSIVE CARE ACT

SCDAA joined the American Society of Hematology (ASH) and dozens of other organizations in a [letter](#) to the leadership of the U.S. House of Representatives Energy and Commerce Committee requesting that the committee mark up the Sickle Cell Disease Comprehensive Care Act of 2024 (H.R. 7432) as soon as possible.

The Sickle Cell Disease Comprehensive Care Act would allow states to establish health homes for Medicaid beneficiaries with sickle cell disease. SCDAA supports this legislation and included it during our May Advocacy Days. A “mark up” is an important part of moving a bill through the legislative process. It provides members of Congress an opportunity to make changes to the bill prior to voting on it.

The Energy and Commerce Committee is the committee in the House with jurisdiction over this bill. SCDAA will continue to monitor the bill’s progress and will provide any relevant updates to the member organizations.

RECAP OF SCDAA’S ADVOCACY DAYS!

SCDAA’s in-person Advocacy Days were a huge success! On May 8 and 9, representatives from 13 SCDAA member organizations across 11 different states traveled to Washington, D.C., to meet with members of Congress and their staff to talk about issues impacting the SCD community. Attendees, including sickle cell warriors, met with 23 offices and talked about the importance of SCD community-based organizations (CBOs), the services they provide and why they are a trusted source of information and a lifeline to the SCD community. Attendees also had the opportunity to provide staff with firsthand information on what it is like to live with SCD, the intensity of pain crises and the challenges faced in accessing care from providers who often don’t understand SCD. We asked for support on three pieces of legislation:



- The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act (H.R. 3884/S.1852), which would reauthorize HRSA’s Sickle Cell Disease Treatment Demonstration Program from 2024 through 2028.
- The Sickle Cell Care Expansion Act (H.R. 3100/S.1423), which would authorize loan repayment and scholarships under the National Health Service Corps to physicians that care for patients and participate in SCD research.
- The Sickle Cell Disease Comprehensive Care Act (H.R. 7432), which would allow states to establish health homes for Medicaid beneficiaries with sickle cell disease.

As a result of SCDAA’s advocacy, Representative Jonathan Jackson, a Democrat from Illinois’ first district, cosponsored H.R. 3100. We thank all of those who attended for helping to make these events a success. We are already looking forward to 2025!



KNOW YOUR RIGHTS IN THE EMERGENCY DEPARTMENT – BIDEN ADMINISTRATION RELEASES NEW GUIDANCE

The Centers for Medicare & Medicaid Services (CMS) is promoting new resources to remind individuals about their rights in the emergency room. Under the Emergency Medical Treatment and Labor Act, better known as EMTALA, all hospitals that participate in the Medicare program are required to provide medical screening exams for individuals arriving at hospital emergency departments to determine if the person has an emergency medical condition. If an emergency medical condition is confirmed, hospitals must provide stabilizing medical treatment (or, if unable to stabilize the person within its capability), to appropriately transfer the patient.

SCDAA has heard countless stories of SCD warriors receiving inadequate care or even no care at all in emergency departments across the country. Under EMTALA, hospital emergency departments are required to:

1. Give you an appropriate medical screening.
2. Treat you until your condition is stable if you are found to have an emergency medical condition.
3. Transfer you if necessary.

Learn more [here](#).

If you believe your EMTALA rights have been violated, CMS now allows you to file a complaint online. You can file anonymously or provide contact information. The federal government and the states will determine if an investigation is needed. If so, the federal government will review the case and determine if a hospital violated EMTALA – the process can take weeks or months depending on the complaint. Filing an EMTALA complaint is not a legal action. You are helping to make sure hospitals stabilize emergency medical conditions and follow the law.

If a hospital or a physician is found to have violated EMTALA, the federal government can impose a civil monetary penalty and/or may exclude physicians from participating in the Medicare and Medicaid programs.

SCDAA ENGAGES WITH THE SOCIAL SECURITY ADMINISTRATION TO IMPROVE ACCESS TO DISABILITY FOR SCD WARRIORS

Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI) provide financial assistance and access to Medicaid and Medicare for individuals who meet certain criteria. The purpose of the programs, run by the Social Security Administration (SSA), is to aid individuals living with a disability or a disease that may impair their ability to work, attend school and/or complete daily tasks. Receiving SSI and SSDI is an alternative pathway to eligibility for Medicaid and Medicare, respectively.

In December, a national CBS [news report](#) highlighted the challenges SCD warriors face when trying to access these disability payments. In fact, they are often denied as a result of the overly restrictive criteria. Dr. Lewis Hsu, SCDAA chief medical officer, is quoted as saying that the current Social Security disability standards for kids with sickle cell disease are “out of date” and “probably 15 to 20 years behind the medical standard.”

SCDAA has been engaging on this issue with the SSA for several months and sent a letter to the SSA earlier this year asking them to review and update the eligibility criteria for SCD. SCDAA was pleased to receive [this response](#) and views it as an indication that the SSA is willing to work with the community to improve and update the criteria.

Since then, the National Academies of Sciences, Engineering, and Medicine (NASEM), an independent organization that is often called upon by the government for policy analysis, held a meeting to discuss the disability criteria for SCD and how they compare to current SCD treatments, measures and standards of care. SCDAA has also participated in a listening session hosted by the SSA where SCDAA representatives were able to share evidence as to why the current criteria are outdated and provide recommendations for updated criteria. Sick Cells and the Sickle Cell Consortium also participated in the listening session. SCDAA thanks Drs. Monica Hulbert, Lewis Hsu and Donnell Ivy for their presentations at these meetings.

The process of updating the disability criteria for SCD may take several years, but we are pleased that the SSA continues to reach out to our community for more information. SCDAA will provide updates on this effort as it continues to move forward. If you have any resources or toolkits that you use to help warriors access disability payments, we would love to see them. Please email them to Kristen Cox at kcox@sicklecelldisease.org.

For questions, contact Regina Hartfield, President and CEO, Sickle Cell Disease Association of America, Inc. at hartfield@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

