LEGISLATIVE BRIEFING

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

October 2024

NEW! SSA RELEASES NEW PUBLICATION TO ASSIST WARRIORS WITH SSA DISABILITY EVALUATION PROCESS

The Social Security Administration (SSA) released a new publication to help individuals living with sickle cell disease understand and navigate the disability evaluation process. This is the first time SSA has done this. In a few weeks, SSA will be releasing a similar publication specific to children living with sickle cell disease.

CONGRESS AND LEGISLATION IMPACTING SICKLE CELL DISEASE

Congress Recognizes September as Sickle Cell Disease Awareness Month

The Senate and the House of Representatives recently introduced resolutions expressing support for the designation of September 2024 as Sickle Cell Disease Awareness Month. In the Senate, the resolution was led by Senators Tim Scott (R-SC) and Cory Booker (D-NJ) along with 10 bipartisan Senators. In the House, it was led by Representatives Danny Davis (D-IL-7) and Michael Burgess (R-TX-26). The House resolution has an additional 18 cosponsors. The resolutions highlight issues related to equitable access to care, the need for continued research and a focus on awareness and education. The House resolution also recognizes the important work done by SCDAA, specifically our commitment to raising awareness, supporting patients and families and working toward finding a universal cure. SCDAA is grateful for the continued leadership of Sen. Scott, Sen. Booker, Rep. Davis and Rep. Burgess in advancing policies aimed at improving the lives of SCD warriors.

Senator Van Hollen Reintroduces the Sickle Cell Disease Treatment Centers Act

Senator Van Hollen (D-MD), along with Senator Booker (D-NJ), reintroduced the Sickle Cell Disease Treatment Centers Act. Identical legislation was introduced in the House by Representatives Lee (D-CA-12), Adams (D-NC-12) and Davis (D-IL-07). The bill would create a hub-and-spoke model of care for individuals living with sickle cell disease and specifically recognizes the work done by SCD community-based organizations. This is the second time this bill has been introduced. SCDAA appreciated the opportunity to work with Senator Van Hollen's office and provide feedback on the legislative text. Read more in Sen. Van Hollen's press release on the introduction.

Sickle Cell Disease Legislation Passes House!

On September 23, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act (H.R. 3884) passed the U.S. House of Representatives. SCDAA supports this legislation and is pleased to see this important step toward this bill becoming law. The same version of the bill still needs to pass the Senate and be signed into law by the President. The legislation reauthorizes the Health Resources and Services Administration's (HRSA) Sickle Cell Disease Treatment Demonstration Program from 2024 through 2028. Reps. Danny Davis (D-IL-7), Michael Burgess (R-TX-26) and Buddy Carter (R-GA-1) are the lead sponsors on this legislation.

SCDAA Supports Legislation to Help Kids on Medicaid Access Care Out-of-State

SCDAA sent a letter to Representatives Trahan (D-MA-3) and Miller-Meeks (R-IA-1) and Senators Grassley (R-IA) and Bennet (D-CO), the sponsors of the Accelerating Kids' Access to Care Act (H.R. 4758/S. 2372), to announce SCDAA's support of this legislation. The bill would help children living with medically complex conditions like sickle cell disease who are insured by Medicaid or the Children's Health Insurance Program (CHIP) access care out-of-state faster by alleviating administrative burdens and streamlining the enrollment process for providers. Individuals with SCD deserve to be treated by a provider with expertise in SCD, but due to a lack of specialists, appropriate care may not be available in-state. Allowing children with SCD to more easily access out-of-state providers will lead to better clinical outcomes and quality of life. The legislation passed the House of Representatives on September 17. The bill will still need to be voted on by the Senate and signed into law by the President.

Congress Passes Short-Term Funding Bill

On September 25, Congress passed a short-term funding bill (also known as a continuing resolution or CR) just before the September 30 deadline. The bill enables the government to function at current funding levels with a few exceptions through December 20. Congress will need to act again by the December 20 deadline to avert a government shutdown.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES SICKLE CELL DISEASE ACTIVITIES

Dr. Edward Donnell Ivy giving the opening keynote. Photo courtesy of the U.S. Department of Health and Human Services.

HHS Inaugural Sickle Cell Disease Summit

On September 24, the Department of Health and Human Services (HHS) hosted its first Sickle Cell Disease Summit as part of the department's commemoration of Sickle Cell Disease Awareness Month. The theme of the summit was Empowered and Thriving SCD Warriors and Communities. Dr. Edward Donnell Ivy, SCDAA's vice chief medical officer, provided the keynote address. Staff from SCDAA member organizations also participated in panels, including Annie Ross-Womack from the Ohio Sickle Cell and Health Association and Ashley Valentine from Sick Cells.

New Sickle Cell Disease Webinar Series

The Department of Health and Human Services (HHS) Office of the Assistant Secretary for Health (OASH) announced a new virtual series called Sickle Cell Disease Services, Opportunities, Activities, Resource (SCD S.O.A.R.). The goal of SCD S.O.A.R. is to connect the SCD community with federal agencies to learn about the resources that can help address many of the different social issues and needs of warriors and their families (e.g., mental health, transportation, housing, civil rights and more). The first webinar, which focused on mental health and featured speakers from the Substance Abuse and Mental Health Services Administration (SAMHSA), was on August 19 and is available to watch here.

The next webinar will be in October and will focus on housing. It will include speakers from the Department of Housing and Urban Development (HUD). SCDAA will send an announcement with the date, time and registration details when they are available.

Medicaid Unwinding Update

The Centers for Medicare and Medicaid Services (CMS) created a temporary special enrollment period (SEP) to help people who are no longer eligible for Medicaid or CHIP transition to marketplace coverage in states using HealthCare.gov. The SEP will run through November 30, 2024, which will overlap with the November 1 start of marketplace open enrollment.

As part of the COVID-19 public health emergency, state Medicaid programs were not allowed to conduct the typical annual re-determination process for beneficiaries. Stated simply, state Medicaid programs could not remove anyone from their rolls. This policy ended, however, and between February 1, 2023, and May 31, 2024, every person enrolled in Medicaid – approximately 90 million people – had to have their eligibility redetermined (this is known as the Medicaid Unwinding). As of late summer 2024, all but five states have completed their initial redeterminations. Coverage losses have been large; according to KFF, almost 25 million Americans were disenrolled nationally, with wide variations in disenrollment rates across the states.

SOCIAL SECURITY ADMINISTRATION DISABILITY PROGRAMS

SSA Announces new SCD Project with NASEM

The Social Security Administration (SSA) recently announced a new sickle cell disease (SCD) project with the National Academies of Sciences, Engineering, and Medicine (NASEM). SSA has asked NASEM to form a committee of experts to explore a number of topics related to SCD, including the prevalence and effectiveness of hospitalizations and parenteral narcotic pain medications in the management of SCD pain crises. SCDAA and our Medical and Research Advisory Committee both nominated five individuals to sit on the committee.

SCDAA has been actively engaged with SSA for several months trying to get the agency to update the eligibility criteria used to assess individuals living with SCD in order to provide access to SSA disability programs (SSDI/SSI) and Medicaid and Medicare. This announcement is a step in the right direction.

For questions, contact Regina Hartfield, president and CEO, Sickle Cell Disease Association of America, Inc., at rhartfield@sicklecelldisease.org.