

MEMO

Date: March 31, 2023
To: External
From: Sick Cells

RE: March 2023 Policy Memo

March was a busy month for Sick Cells, leading up to the National SCD Policy Forum. We were working hard to ensure that as many advocates as possible could participate in this year's expanded event. This month's highlights include a recap of Rare Disease Week, the final report from the National SCD Policy Forum, and conversations with HHS and the CDC about the importance of data.

1. Almost the entire Sick Cells team made it to **Rare Disease Week** in Washington, D.C. this year.
 - a. Our staff coordinated with rare disease advocates from across the country to shine a light on sickle cell during this nationwide advocacy event.
 - b. This year's event ran from February 28 - March 2, 2023.
2. Sick Cells participated in the second of three roundtables hosted by the U.S. Department of **Health & Human Services (HHS)** and the **American Society of Hematology (ASH)**
 - a. The roundtable convened data experts and leaders to discuss the current and future landscape of SCD data collection.
3. Sick Cells attended the **Centers for Disease Control & Prevention (CDC) site visit** to their Wisconsin site.
 - a. Staff learned about data collection methods for SCD in Wisconsin and helped brainstorm ways to strengthen the program even more.
4. Sick Cells co-hosted the **tri-collaborative National SCD Policy Forum** with the Sickle Cell Disease Association of America, Inc., and the Sickle Cell Community Consortium on March 21-22
 - a. This year's Virtual Hill Day resulted in:
 - i. 100+ advocates engaged in educating legislators
 - ii. 148 Hill meetings with the House and Senate
 - iii. 29 states represented





5. Sickle Cell Disease Comprehensive Care Act
 - a. On March 21st, 2023, the **Sickle Cell Disease Comprehensive Care Act** was reintroduced into legislation. The bill had previously died in the 117th congress.
 - b. This **bipartisan bill** was reintroduced by U.S. Senators Cory Booker (D-N.J.) and Tim Scott (R-S.C.), along with U.S. Representatives Danny Davis (D-IL) and Michael Burgess (R-TX).
 - c. Directs the Centers for Medicare and Medicaid Services (CMS) to create a demonstration to improve access to quality care for SCD Warriors enrolled in Medicaid
 - d. Sick Cells endorses this legislation. Read Sick Cells' President Ashley Valentine's statement in the press release ([Here!](#))

State Highlights

You can expect to see 2-3 noteworthy state-level SCD bills every month with a brief summary and the most recent action, along with a link to the state's website.

1. Michigan | [HB4308](#) | "Michigan Vehicle Code"
 - a. Establishes a SCD-specific fundraising license plate
 - b. The License plate is designed in conjunction with the SCDA, Michigan Chapter
 - c. Funds are dispersed to the SCDA, Michigan Chapter
2. Florida | [HB1481](#) | "Sickle Cell Disease Medications, Treatment, and Screening"
 - a. Requires notification of newborn screening status for SCD to PCPs and the Department of Health (DoH)
 - b. Requires notification of newborn screening status for SCD to parents and guardians
 - c. Requires the DoH to establish a SCD registry in the state
 - d. Provides authorization for parents and guardians to remove minors from the registry
 - e. Stipulates \$250,000 in appropriations