



MEMO

Date: February 24, 2022
To: External
From: Sick Cells

RE: February 2022 Policy Memo

Q1 is always an exciting time for Sick Cells. This is the part of the year where we get to wrap up old projects, launch new ones, and start setting the scene for our annual Policy Forum. While we're only two months into the new year, we have been as busy as ever.

1. Sick Cells participated in a **historic listening session** at the Centers for Medicare & Medicaid Services (CMS) on February 17, 2022
 - a. We joined 5 other organizations to speak with CMS Administrator Chiquita Brooks-LaSure and other CMS staff about the challenges the SCD community faces and discuss potential solutions
 - b. Other participating organizations included:
 - i. American Medical Association
 - ii. American Society for Hematology
 - iii. MTS Sickle Cell Foundation
 - iv. Sickle Cell Disease Association of America (SCDAA)
 - v. Sickle Cell Reproductive Health Education Directive (SC RED)
 - c. Sick Cells will release a meeting read-out in March 2022
 - d. Special thank you to our friends at the Sickle Cell Reproductive Health Education Directive for requesting this important meeting

2. Sick Cells worked with SCDAA to **establish federal priorities**. This year, our two organizations will be advocating for:
 - a. Appropriations of \$25M for the [CDC SCD Data Collection Program](#) in FY23
 - b. Appropriations of \$15M for the [HRSA SCD Treatment Demonstration Program](#) in FY23
 - c. Co-sponsorship of [HR6216/S3389](#), the Sickle Cell Disease Comprehensive Care Act

Sick Cells looks forward to continuing to work with SCDAA on aligning our guiding federal priorities and working together to create a better future for individuals living with SCD. Sick Cells & SCDAA will publish any changes or additions to our federal priorities throughout the year.



3. Sick Cells continued support for the National Organization of Rare Disease's [Project RDAC](#). In February we signed three letters to support the establishment of RDACs in:
 - a. California - Submission of a budget proposal after [SB-247](#) was vetoed in 2021
 - b. Colorado - Requesting approval of draft language to establish an RDAC
 - c. Georgia - [HB918](#): Establishes an RDAC

4. **Sick Cells will host our annual Policy Forum** on March 22nd & 23rd
 - a. The Policy Forum is open to individuals enrolled in the [Sick Cells Ambassador Program](#)
 - b. To learn how to attend or sponsor the event, visit our [Policy Forum Home Page](#)

See You in March!