



MEMO

Date: January 31, 2022

To: External

From: Sick Cells

RE: January 2023 Policy Memo

Though it's the first month of the new year, January is by no means a slow month. While we waited to see where activity on the Hill brought us, Sick Cells was busy planning activities for the year and organizing our federal priorities. This month's highlights include an event announcement, meetings with CMMI and the E&C Committee, and more.

1. **SAVE THE DATE! Sick Cells is proud to present the first-ever National SCD Policy Forum on March 21 & 22, 2023.** This tri-collaborative event is hosted by Sick Cells, the Sickle Cell Disease Association of America, Inc. and the Sickle Cell Community Consortium.

Our three organizations are working hard to host a comprehensive advocacy event for the sickle cell disease (SCD) community to date. The goal of this event is to bring together SCD advocates from across the country and:

- Build awareness of federal opportunities for SCD
- Educate legislators on funding and policy interventions that support the needs of the SCD community as a whole

Day 1 will be full of trainings on the 2023 federal priorities for SCD. Day 2 is our virtual Hill Day, a time for advocates to connect directly with their federal legislators. Stay tuned for details!

2. Sick Cells participated in a **meeting with the CMS Innovation Center**. Our talking points included comments about:
 - a. The importance of patient centricity in the design of care models
 - b. Barriers to existing SCD treatments through utilization management controls like step therapy and prior authorization
 - c. Sick Cells' [2022 Medicaid Access & Landscape Review](#)
3. Sick Cells **presented at BIO's Patient Advocacy Coffee Chat**
 - a. Emma Andelson, *Senior Program Manager*, presented at BIO's monthly patient advocacy event on 2023 strategies for Congressional outreach and how to approach policy when working with a growing team.



4. Sick Cells **met with staff from the Energy & Commerce Committee** to discuss gene therapies for SCD and opportunities for community input.
5. Sick Cells staff **attended Leavitt Partner's Policy Forum**
 - a. This event focused on health policy and provided insights into what we can expect from the House and Senate in the coming months. The event also captured what government agencies like CMS and HHS have planned for the year.

NEW SEGMENT: State Highlights

Starting this month, we'll highlight key state legislation that is SCD-specific. You can expect to see 2-4 bills every month with a brief summary and the most recent action, along with a link to the state's website.

1. New York | [A2661](#) | "Establishes the Sickle Cell Treatment Act"
 - a. Sponsor: Assemblymember Alicia Hyndman (D-NY-29)
 - b. Summary: This bill identifies centers for excellence and outpatient care in the state.
 - c. Latest Action: Referred to Assembly Health Committee
2. Oregon | [HB2927](#) | "Relating to Sickle Cell Disease"
 - a. Sponsor: Rep. Travis Nelson (D-OR-44)
 - b. Summary: Establishes Statewide Steering Committee on Sickle Cell Disease. The committee will have various responsibilities related to support and improve SCD care in the state.
 - c. Latest Action: Referred to Behavioral Health and Health Care Committee
3. Florida | [HB247](#) | "Sickle Cell Program"
 - a. Sponsor: Rep. Daryl Campbell (D-FL-99)
 - b. Summary: Requires the Florida Department of Public Health to create an all-encompassing program to support & improve SCD care in the state.
 - c. Latest Action: Referred to Healthcare Regulation Subcommittee