



MEMO

Date: November 28, 2022

To: External

From: Sick Cells

RE: November 2022 Policy Memo

November is always a tricky month in policy; it's when some folks try hard to push their last policy goals through before the end of year, while others prefer to not embark on anything new. This year was even more special with the midterm elections. This month's highlights include conversations with staffers, a Wisconsin Medicaid meeting, and an HHS roundtable.

1. Sick Cells **met with staffers** in Senator Van Hollen and Senator Tim Scott's office to track progress on current SCD legislation.
 - a. Senator Van Hollen's office hopes to garner more Republican support on the bills the Senator is leading.
 - b. Senator Tim Scott's office plans to continue supporting the Sickle Cell Disease Treatment Centers Act as an original sponsor in the next Congressional session
2. We **submitted written comments and trained one advocate to speak** at a Wisconsin Prior Authorization Advisory Committee [meeting](#).
 - a. Currently, hydroxyurea, siklos, droxia, and Endari are listed as "preferred" on the pharmacy benefit formulary; Oxbryta is listed as "not preferred," and Adakveo is unlisted.
 - b. The committee did not recommend any changes to the formulary.
3. We **co-hosted a Community Legislation Workshop** with the SCDA on November 9, 2022.
 - a. Content was focused on the upcoming ICER for SCD gene therapies & the current status of three federal bills for SCD and how to advocate for them.
4. Emma Andelson, Sick Cells Program Manager, **presented on "Advocacy and Legislation"** at a SiNERGe meeting.
 - a. She focused on the three current SCD bills, special tools to help with state advocacy, and how to best organize advocacy efforts across states.
5. Sick Cells **participated in a roundtable** 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.

6. We **signed one sign-on letter** this month, circulated by ASH.
 - a. The letter was sent to majority and minority leaders in the House and Senate and expressed support for the [SCD Comprehensive Care Act](#).
 - b. The letter requested that the leaders help move the legislation forward.

7. November's [Ambassador](#) Priority Topic Meeting focused on "Fundraising & Social Media"
 - a. We also produced new toolkits in November to support advocacy efforts:
 - i. ["The Power of the Pen"](#) – Letter writing for policy change & advocacy
 - ii. ["State Legislation"](#) – Navigating policy at the state level
 - iii. ["How to Build a CHW Program"](#) – Bolstering the power of community health workers in the SCD community

REMINDER: Sick Cells will host the Ambassador Policy Forum & Hill Day on March 21-22, 2023.

- The first day of this event features information on the year's federal priorities, training on how to share your story with legislators, important updates from federal partners, and mock legislator meetings. The second day is a virtual fly-in with over 70 Hill meetings.
- The Policy Forum is open to individuals enrolled in the [Sick Cells Ambassador Program](#)
- To learn how to attend or sponsor the event, visit our [Policy Forum Home Page](#)

See you in December!