

MEMO

Date:February 28, 2023To:ExternalFrom:Sick Cells

RE: February 2023 Policy Memo

With new legislators getting settled on the Hill, February brought a flurry of activity and opportunity. The Sick Cells team kept busy preparing for the National SCD Policy Forum (March 2023) and connecting with federal agencies and Hill offices to learn about their 2023 plans. This month's highlights include the launch of event registration, two meetings with CMMI, an HHS event, and a few meetings on the Hill.

- The <u>National SCD Policy Forum</u> brings together sickle cell advocates from across the country for a two-day federal advocacy event. This tri-collaborative event is hosted by Sick Cells, the <u>Sickle</u> <u>Cell Disease Association of America, Inc.</u> (SCDAA) and the <u>Sickle Cell Community Consortium</u> (SCCC).
 - Day One features educational sessions on federal advocacy trends and provides an opportunity to discuss concrete solutions to existing gaps in sickle cell disease (SCD) policy.
 - b. **Day Two** features the Virtual Hill Day. Advocates will have the opportunity to meet with their legislators and educate them about sickle cell disease issues and policy recommendations.
 - c. <u>REGISTER HERE!</u>
 - d. Note: While the event is public and open, it is intended for members of the sickle cell disease community. For more information on becoming a sponsor, sponsor benefits, and allocated sponsor tickets, please contact info@sickcells.org.
- 2. Sick Cells participated in **two meetings with the CMS Innovation Center** (CMMI) to discuss the importance of models for sickle cell disease and provide feedback on their programs. Sick Cells main points included:
 - a. Utilization management techniques, such as step therapy and prior authorization, can have detrimental impacts on those with SCD.
 - b. Collaboration with CBOs and inclusion of patient-important outcomes in model design will strengthen models and their success.
- 3. Sick Cells attended the <u>HHS Black Health Summit</u> on Wednesday, February 22.
 - a. The event focused on the agency's upcoming initiatives to address gaps in care and new programs supporting health equity initiatives.
 - b. For a short recap of the event, please see the American Hospital Association.



- 4. Sick Cells **met with Hill offices** to discuss legislation, SCD payment models, and emerging therapies. Offices contacted included:
 - a. Senator Chris Van Hollen (D MD)
 - b. <u>Representative Barbara Lee</u> (D-CA-12)
 - c. <u>Representative Matt Guthrie</u> (R-KY -2)
 - d. The House Energy & Commerce Committee