

MEMO

Date:August 31, 2023To:ExternalFrom:Sick Cells

RE: August 2023 Policy Memo

This month's highlights include a presentation for HRSA and a meeting with CMMI.

- 1. Sick Cells Co-Founder & President, Ashley Valentine, **presented on community collaborations to the Health Resources and Services Administration** (HRSA). Presentation highlights included:
 - a. Sick Cells' policy and government affairs work
 - b. Collaborative efforts across the SCD community
 - c. Cross-industry partnerships centered on improving the lives of those living with SCD
- 2. Sick Cells **met with staff from the Center for Medicare and Medicaid Innovation** (CMMI) to provide feedback on the <u>Cell & Gene Therapy (CGT) Access Model</u>. Comments centered around:
 - a. Capturing patient-reported outcomes
 - b. Beneficiary engagement in model design & evaluation
 - c. Roles of CBOs in patient education and access to care
- 3. Sick Cells says goodbye to Emma Andelson, our Senior Program Manager (Government Affairs & External Relations). For future correspondence on policy or government affairs topics, please contact Mariah Scott (Research Coordinator) at mscott@sickcells.org

State Highlights

- 1. New York | <u>A 2609</u> | State advising on sickle cell disease
 - a. Directs the minority health council to advise the Commissioner of Health regarding sickle cell disease
 - b. Encourages the increased information and communication about sickle cell disease screening and detection
 - c. Passed the Senate

See you in September!

Sick Cells 501 (C)(3) Nonprofit | <u>www.sickcells.org</u> Mailing Address | 1042 Maple Ave STE 103 | Lisle, IL. 60532 DC Office | 1012 14th Street STE 500 | Washington D.C. 20005 <u>Subscribe to our Newsletter | Donate | Read Previous Policy Memos</u> info@sickcells.org