



MEMO

Date: September 30, 2023

To: External

From: Sick Cells

RE: September 2023 Policy Memo

This month's highlights include National Sickle Cell Awareness Month and updates on federal priorities.

1. President Joseph R. Biden, Jr. proclaimed September 2023 National Sickle Cell Awareness Month. The Biden Administration is closely improving the state of healthcare for people living with Sickle Cell Disease by improving these programs:
 - a. The CDC's Sickle Cell Data Collection program is gathering more comprehensive information on the experiences of patients living with SCD.
 - b. Centers for Medicare & Medicaid Services (CMS) is developing a Cell and Gene Therapy (CGT) Access Model to help Medicaid beneficiaries gain access to potentially life-changing, high-cost specialty drugs like SCD.
 - c. The Health Resources and Services Administration (HRSA) is assisting with helping community-based organizations and clinics conduct testing, counseling, and education.
 - d. The National Institutes of Health (NIH) is funding clinical trials to test new advancements in alleviating chronic pain for SCD patients.

2. Sick Cells, American Society of Hematology, Sickle Cell Disease Association of America, and the Sickle Cell Community Consortium Co-Sponsored a congressional briefing: Comprehensive Sickle Cell Disease Care in a Time of Innovation. Presentations from this briefing included:
 - a. An overview of the current state of health care for individuals with SCD.
 - b. An SCD warrior's efforts to find comprehensive care.
 - c. A presentation of proposed policy strategies to improve the health outcomes of individuals with SCD.

3. The [Food and Drug Administration \(FDA\)](#) announced the Cellular, Tissue, and Gene Therapy Advisory Committee on **October 31, 2023**. The advisory committee will give expert advice and recommendations for gene therapy for SCD, Exa-cel by Vertex Pharmaceuticals, Inc.
 - a. Oral presenters are encouraged to register by October 16, 2023, to make formal oral comments on October 31, 2023.
 - b. Participants who want to submit written comments to present data, information, or views are encouraged to submit by October 24, 2023.
 - c. Sick Cells will hold its October Priority Topic Meeting (PTM) on October 19, 2023, to present more information on the importance of this committee and how to be involved.



4. Sick Cells hosted their September Priority Topic Meeting (PTM) on “Engaging with Medicaid” with our Ambassadors. Our guest speaker, Joshua Moore, PharmD, presented as a representative from Missouri Medicaid to gain a better understanding of cost-sharing.

5. The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023 ([H.R. 3884](#), [S. 1852](#)) aims to reauthorize the Health Resources and Services Administration (HRSA) SCD Treatment Demonstration Program for the 2023 fiscal year. This bill should be ready for a vote later this year.

See you in October!