

MEMO

Date: October 31, 2023

To: External **From:** Sick Cells

RE: October 2023 Policy Memo

This month's highlights include the Food and Drug Administration Advisory Committee and updates on federal priorities.

- The Center of Medicare & Medicaid Services (CMS) released the CMS <u>Sickle Cell Disease Action</u>
 <u>Plan</u> to address the challenges specific to CMS programs and is designed to improve health
 outcomes and reduce health disparities for individuals with SCD.
- 2. The <u>Food and Drug Administration (FDA)</u> 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. Members of the community and community-based organizations have been selected to present oral comments and submit written comments.
- 3. Sick Cells hosted their October Priority Topic Meeting (PTM) on "FDA Advisory Committee: Submit Public Comments" with our Ambassadors. Our guest speaker, Mariah J. Scott, MS, MPH from Sick Cells and Links2Equity presented the background and history of FDA advisory committees for Sickle Cell Disease and how to compose oral and written comments.
- 4. The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023 (<u>H.R. 3884</u>, <u>S. 1852</u>) 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.

State Highlights

- 1. North Carolina | H 259 | 2023 Appropriations Act
 - a. Make base budget appropriations for current operations of state services.
 - b. Appropriate \$100,000 for sickle cell centers under Women and Children Health Services.
 - c. Signed into Law



- 2. Michigan Department of Health and Human Services (MDHHS)
 - a. MDHHS has been awarded two grants for sickle cell clinic expansion and enhancement.
 - b. \$100,000 was awarded to the Children's Hospital of Michigan to improve access to preventive screening for pediatric strokes.
 - c. \$100,000 was awarded to the Bronson Health Foundation to improve access to care and implement a sickle cell-specific data collection module.

See you in November!