MEMO

To: External
From: Sick Cells
RE: October 2026 Sick Cells Policy Update

Welcome to the latest Sick Cells Policy Update. This memo provides updates on federal and state policy developments affecting the sickle cell disease (SCD) community, along with advocacy opportunities and recent organizational activities.

Sick Cells Policy Programming

Medicaid Work Requirements
The Centers for Medicare & Medicaid Services (CMS) announced a new Medicaid work requirements rule on June 1, 2026. This rule requires that Medicaid enrollees complete at least 80 hours per month of work, which could include a combination of employment, volunteering, education, or other qualifying activities.

With this new requirement, there is an open definition of 'medical frailty' which would exempt a person from the work requirements. Sick Cells highlighted to CMS potential implications for people living with SCD and asked for the agency to consider SCD when determining exemption status and defining what it means to be medically frail.

The states will implement the rule on or before January 1, 2027. CMS guidance on the rule has recently been released. Sick Cells has begun to use this information to create state-specific resources for both the state Medicaid offices and the SCD community. These resources will also be included in the State Advocacy Map. For additional information, the following resources are available:

- **Medicaid Work Requirements Rule**
- **Webinar Part 1 Recording**
- **Webinar Part 2 Recording**
- **Frequently Asked Questions (FAQ)**
- **Sick Cells Comment Letter**
- **CBO Sign-On Letter**
- **Public Comment Toolkit**
- **CMS Guidance on Implementing Medical Frailty Slidedeck**

Federal Policy Updates

FY 2027 Appropriations: Where Things Stand

Congress passed a continuing resolution (CR) in early September to fund the federal government through December 11, ahead of the start of the 2027 Fiscal Year (FY) on October 1. Members of Congress will spend the next few weeks making the closing case for their reelection bids. Their return to Capitol Hill in early November will leave them with a limited number of legislative days in which to finalize the FY 2027 cycle, increasing the likelihood of another CR.

The results of the midterm elections may complicate matters, as well. A good night for congressional Democrats may prompt them to delay the completion of the FY 2027 cycle to allow more time to write appropriations bills that are more favorable to Democratic policy priorities. Congressional Republicans, meanwhile, will be incentivized to finalize the FY 2027 cycle before the start of the new Congress to cement their policy priorities into law. We will have a better sense of the appropriations landscape in November.

Sickle Cell Disease Related Bills

A group of House and Senate Democrats led the reintroduction of the two SCD bills.

- **Sickle Cell Care Expansion Act (S. 5489)**
- **Sickle Cell Disease Treatment Centers Act (S. 5488)**.

The former would finance educational supports to incentivize medical professionals to specialize in SCD care, while the latter would invest in a National Sickle Cell Disease Treatment Center Grant Program to connect warriors with a diverse array of care, including specialized SCD treatment and social services.

With only a handful of legislative days remaining in the 119th session of Congress, these bills are not expected to make meaningful progress in either chamber. We expect them to be reintroduced during the early days of the 120th session of Congress.

Congressional Sickle Cell Disease Caucus

Caucus Briefing

The Congressional Sickle Cell Disease Caucus held its inaugural briefing on September 23. The briefing convened the caucus Co-Chairs, Rep. Glenn Ivey (D-MD) and Rep. Rich McCormick (R-GA), alongside practitioners and advocates to discuss **“Reimagining Emergency Care for Sickle Cell Disease.”**

Sick Cells was thrilled to be joined by the National Alliance for Sickle Cell Centers (NASCC), the Sickle Cell Reproductive Education Directive (SC Red), the Sickle Cell Community Consortium (SC3), the American Society of Hematology (ASH), and the Sickle Cell Disease Association of America (SCDAA) as community sponsors for the briefing. The briefing elicited an enthusiastic response from the audience.

If you would like to learn more about the caucus please visit the website at https://sickcells.org/sickle-cell-disease-caucus/. If you would like to recruit a congressional member to join the caucus please send an email to SCDcaucus@sickcells.org.

Food and Drug Administration's (FDA) Patient Focused Drug Development (PFDD) Meetings

FDA PFDD: Nonhealing Chronic Wounds

On August 25, 2026 the FDA hosted a hybrid Patient-Focused Drug Development (PFDD) meeting on Nonhealing Chronic Wounds. The sickle cell community was represented in each session, highlighting the impact of leg ulcers. There is still time to make your voice heard. Individuals are encouraged to submit written comments to the FDA by **October 26, 2026**. The FDA will publish a *Voice of the Patient* report based on the feedback. If you need assistance submitting a public comment, Sick Cells created a toolkit for submitting comments.

FDA PFDD: Patient Voice in Rare Disease Medical Product Development

On October 16, the FDA's PFDD meeting, "Patient Voice in Rare Disease Medical Product Development," will bring together experts, advocates, and the patient community to highlight the importance of involving the patient perspective in medical product development. Sick Cells CEO and Co-Founder Ashley Valentine has been invited to participate as an expert panelist, representing the patient voice and the lived experiences of those in the SCD community. The hybrid meeting will take place from 1–5 p.m. ET at White Oak Campus (10903 New Hampshire Ave, Silver Spring, MD 20993). Register here**.**

FDA EL-PFDD: Sickle Cell Disease

On January 27, 2027, The Sickle Cell Voices Alliance will host an externally led Patient-Focused Drug Development (EL-PFDD) meeting to bring together the SCD community across the U.S. and around the world. The virtual meeting will provide opportunities for the community to participate in live testimony, panel discussions, audience polling, and written comments on their lived experiences. Input gathered during the forum will inform a *Voice of the Patient Report* for submission to the FDA and other regulatory agencies.

State Policy Spotlight

Drug Utilization Review Board (DURB) Updates

Several states recently held Drug Utilization Review Board (DURB) meetings to evaluate Medicaid coverage policies related to SCD treatments, including emerging gene therapies.

Updates provided below:

September 22, 2026 - New Hampshire DUR Meeting *Casgevy®*

- Click here for the meeting agenda.
- This meeting reviewed Casgevy® (exagamglogene autotemcel) for SCD, and was hybrid.

September 24, 2026 - Pennsylvania P&T Meeting *Sickle Cell Disease*

- Click here for the meeting agenda.
- This meeting reviewed policies related to SCD, and was virtual.
- **Meeting outcome:** Siklos tablets were recommended to be added to the Preferred Drug List (PDL). This guideline change was presented and approved by the committee.

September 30, 2026 - Louisiana DUR Meeting *Casgevy®*

- Click here for the meeting agenda.
- This meeting reviewed Casgevy® (exagamglogene autotemcel) for SCD and was in-person only.
- The DURB has not yet released any outcomes or recommendations.

Upcoming Meetings:

The following meetings have been announced. If you have any questions, comments, or are interested in participating in your state's DURB, email Alyssa Davenport at adavenport@sickcells.org

October 7, 2026 - Ohio Unified Preferred Drug List (UPDL) Annual Review

October 7, 2026 - Arizona Sickle Cell Anemia

October 15, 2026 - Virginia Blood Modifiers - Sickle Cell (Closed Class)

October 20, 2026 - Missouri Sickle Cell Disease (Agenda TBA)

October 21, 2026 - Minnesota Specialty Drugs for Continued PA

October 22, 2026 - Delaware Hematological Agents

October 27, 2026 - Mississippi Sickle Cell Disease (Agenda TBA)

October 28, 2026 - Nebraska Sickle Cell Disease (Agenda TBA)

November 4, 2026 - West Virginia Sickle Cell Disease (Agenda TBA)

November 4, 2026 - Wisconsin Sickle Cell Disease (Agenda TBA)

November 5, 2026 - Maryland Sickle Cell Disease (Agenda TBA)

November 19, 2026 - Iowa Sickle Cell Disease (Agenda TBA)

November 19, 2026 - Connecticut Sickle Cell Disease (Agenda TBA)

Stay Connected

Advocacy is strongest when our community stays engaged and sticks together. Be sure to:

- Check out our calendar for upcoming Sick Cells policy events
- Share our recent newsletters with your networks
- Encourage your legislators to join the SCD Congressional Caucus
- Join our Ambassador Program to collaborate with other advocates
- Follow Sick Cells on Facebook, Instagram, LinkedIn, and Threads for the latest policy updates