



MEMO

Date: April 28, 2023
To: External
From: Sick Cells

RE: April 2023 Policy Memo

Launching Q2 means we've made our way through Appropriations season and wrapped up outreach related to the National SCD Policy Forum. This month's highlights include prepping advocates for a few Medicaid coverage decision meetings and signing on to a couple of group letters.

1. Sick Cells staff attended the [Missouri Rare Disease Advisory Council](#) meeting on April 12th.
 - a. RDACs are a body of experts in rare diseases and can provide clinical recommendations to Medicaid coverage decision bodies in their state.
 - b. The committee discussed potential recommendations for clinical criteria for Hemgenix® (gene therapy; hemophilia B) and Tzielid™ (monoclonal antibody; type 1 diabetes).
 - c. Tracking current discussions of gene therapies in other disease states may provide insight into future discussions on SCD gene therapies.

2. Sick Cells prepared **two advocates** to provide public comments at Medicaid coverage decision committee meetings.
 - a. Missouri | April 18 | Prior Authorization Committee | [Agenda](#)
 - i. One advocate associated with the [Sickle Cell Disease Foundation of the Midwest](#) spoke about her personal experience gaining access to SCD treatments under Medicaid and the issues she has encountered. She highlighted the individuality of the disease and recommended that the committee remove barriers like prior authorization and step therapy from all SCD treatments.
 - b. Washington | April 19 | Pharmacy & Therapeutics Committee | [Agenda](#)
 - i. One advocate associated with the [Metropolitan Seattle Sickle Cell Task Force](#) spoke from the perspective of a caregiver to two SCD warriors and asked the committee to consider how utilization controls like prior authorization and step therapy impact access at the individual level.
 - ii. Sick Cells submitted written comments.
 - c. Read more about Sick Cells' continued engagement with state Medicaid committees [here](#).



3. Sick Cells **signed two group letters**

- a. Council for Affordable Healthcare (CAHC) | Letter in support of the bipartisan MVP Act
 - i. Sent to Majority Leader Schumer, Minority Leader McConnell, Speaker McCarthy, and Minority Leader Jeffries
 - ii. Shares support for the Medicaid VBPs for Patients Act ([HR 2666](#): MVP Act)
 - iii. The bill codifies value-based purchasing arrangements under Medicaid
- b. National Organization for Rare Disorders (NORD) | Letter in support of a Texas RDAC
 - i. Sent to Chair Kolkhorst and Members of the State Senate Health and Human Services Committee
 - ii. Shares support for [SB 1408](#), which would establish a rare disease advisory council (RDAC) in the state

See you in May!