



MEMO

Date: July 31, 2023

To: External

From: Sick Cells

RE: July 2023 Policy Memo

This month's highlights include submitting comments for a House committee markup, preparing advocates for an Illinois Medicaid meeting, and more.

1. Sick Cells **submitted a statement for the record** for the July 19, 2023 Energy & Commerce Committee health bill markup.
 - a. See a similar letter we submitted earlier in the process on our website [here](#).
 - b. We supported 5 CBOs in drafting their own statements to include in the package of letters Sick Cells submitted.

2. Sick Cells **prepared 6 advocates** for an Illinois Drug & Therapeutics Advisory Board Meeting On July 13, 2023.
 - a. Sick Cells submitted written comments for the Board to review.
 - b. Warrior, Caregiver, and Provider advocates shared testimony about:
 - i. Personal experiences navigating Medicaid in Illinois as a beneficiary;
 - ii. On-the-ground prescribing issues: provider burden, delays in treatment due to paperwork, inconsistencies and administrative issues within Medicaid;
 - iii. Delays & denials leading to extended pain and the delay of needed treatments;
 - iv. Racism and stigma in the healthcare system that continue to negatively impact care and treatment; and more.
 - c. Current formulary placements:
 - i. Hydroxyurea & Droxia®: preferred, no prior authorization
 - ii. Adakveo®, Oxbryta®, Endari™, Siklos®: non-preferred, prior authorization required
 - d. Board recommendations:
 - i. Move Endari™ from **non-preferred to preferred with prior authorization**
 - e. Read more about the Illinois D&T Advisory Committee [here](#).

3. July's [Ambassador Priority Topic Meeting](#) was about "Understanding Medical Benefits."
 - a. The guest speaker was La'Shardae Scott, a Sick Cells Ambassador, PhD Candidate in Social Work, and overall health equity leader in the SCD community.



- b. Topics like these help prepare Ambassadors for future advocacy opportunities within the healthcare system, such as providing public comments to a Medicaid coverage decision committee.

State Highlights

1. Michigan | [HB4437](#) | Appropriations Omnibus
 - a. Allocates \$2.5M in funding to the Sickle Cell Disease Association of America, Sickle Cell Center of Excellence in Michigan.
 - b. Includes a provision for the Michigan Department of Health to include “special formulas” for adults with SCD over the age of 26. This would help increase access to SCD treatments in the state.
 - c. **Conference report accepted, reported to the Governor**
2. Massachusetts | [SB 678](#) & [HB 1161](#) | “An Act to improve sickle cell care”
 - a. Introduced on 2/15/2023 in both the House and the Senate
 - b. Establishes statewide steering committee for SCD to improve patient education and care in the state
 - c. Services mentioned include: care coordination, genetic testing, fertility preservation, the discussion of establishing a SCD registry in the state, and more.

See you in August!