



MEMO

Date: March 28, 2022
To: External
From: Sick Cells

RE: March 2022 Policy Memo

March is always a busy month for the Sick Cells team since it is host to our Annual Policy Forum and Hill Day. We spent the month finalizing our federal priorities for the year and preparing advocates to meet with their legislators, but that's not all! Read on to hear what we focused on in March.

- Sick Cells **hosted our annual Policy Forum & Hill Day** on March 22nd and 23rd
 - 54 Ambassadors in 20 states met with 72 offices
 - The keynote address was given by Adam Taliaferro from Bristol Myers Squibb
 - Other speakers included: Dr. Titilope Fasipe (Co-Director, Texas Children's Sickle Cell & Thalassemia Program); Levell Strong (Campaign Director, People's Action); and John Otsuki (Government Relations Manager, SCDA)
 - Access the full event brochure [here](#)

- Sick Cells **posted the read-out** from a February meeting with CMS Administrator Chiquita Brooks-LaSure. Read it [here](#).

- Sick Cells **published a White Paper**, "[Advancing Stakeholder Engagement with Medicaid: Centering the Patient Voice in Coverage Decisions](#)"
 - This paper outlines the process Sick Cells follows to ensure the patient voice is reflected and prioritized in Medicaid coverage decisions across the country, and reviews current barriers and potential solutions to improve stakeholder engagement at these committee meetings.

- Sick Cells **prepared advocates for a [Florida P&T Meeting](#)** on March 25th
 - Mass class review of all SCD treatments
 - Current formulary placement:
 - Unrestricted: Droxia
 - Prior Authorization Required: Oxbryta
 - Prior Authorization & Step Therapy Required: Endari, Siklos
 - Mixed Access/Unlisted: Adakveo
 - The Committee recommended moving Endari from non-preferred to preferred with automatic prior authorization, and changing Siklos from requiring a clinical prior authorization to an automatic prior authorization. Final decisions TBD.



- **Sick Cells wrote a letter of support** for Minnesota [HF3786/SF3566](#)
 - The [Sickle Cell Foundation of Minnesota](#) testified the week of March 21st in support of this bill, “...an act relating to health care; modifying the definition of intractable pain; modifying the criteria for prescribing controlled substance for the treatment of intractable pain; amending Minnesota Statutes 2020, section 152.125.”
 - Sick Cells provided two letters of support in support of their efforts in Minnesota
- Sick Cells continued **support for the National Organization of Rare Disease’s [Project RDAC](#)**. In March we signed one letter to support the establishment of an RDAC in:
 - Maine - Urging lawmakers to “include [LD 972](#) in the supplemental budget...” to establish a Rare Disease Advisory Council in the state

See you in April!