



# MEMO

**Date:** May 17, 2021

**To:** External

**From:** Sick Cells

RE: April 2021 Policy Update

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Spring is here! In addition to tulips, April also brought new opportunities and advances in the realm of policy and legislation. We are still waiting for the President's official budget for FY22 but we are seeing new state-level bills being introduced and we are continuing to meet with legislators to let them know how they can create a better future for the sickle cell community. We hope you enjoy reading about our April policy activities!

- **We contributed resources to the SCDA's Advocacy Days. Our resources cited in their training included:**
  - [FY2022 Federal Appropriations Request One-Pager](#)
  - [Sickle Cell Disease Fact Sheet](#)
  - [2021 Letter to the Biden Administration](#)
  - [2021 Letter to Congress - NASEM Report Hearings](#)
- **We continued to schedule meetings with federal staffers.**
  - We conducted three meetings in April with roughly 15 more coming in May. (Our Virtual Hill Day was March 24th, on which we scheduled meetings for Ambassadors with 49 offices.)
- **We participated in two Medicaid meetings.**
  - Illinois: [P&T Meeting, April 15](#)
    - Sick Cells worked with the Sickle Cell Disease Association of Illinois (SCDAI) to prepare **6 advocates** to provide public comment at the meeting.
    - Discussion: Placement of Oxbryta on the formula (currently "nonpreferred")
    - Decision: No change to formulary
  - Texas: [DURB Meeting, April 23](#)
    - Sick Cells submitted written comments and worked with the Sickle Cell Association of Texas - Marc Thomas Foundation to prepare **4 advocates** (including 2 Sick Cells Ambassadors) to provide public comments.
    - Discussion: Placement of all SCD treatments on the formulary. (Hydroxyurea currently listed as "preferred," Endari & Oxbryta: currently listed as "nonpreferred with prior authorization required", Adakveo - currently unlisted).
    - Decision: The board recommended Endari, Oxbryta, and Siklos (Hydroxyurea) be added to the preferred drug list. Final decision to come in July.



- **We signed three important letters circulated by other organizations.**
  - National Organization for Rare Diseases (NORD) - Project RDAC
    - We joined other national orgs to support NORD's [Project RDAC](#)
    - This program is led by NORD and works to establish Rare Disease Advisory Councils (RDACs) in every state
    - This month, we signed two letters in support of establishing RDACs: California [SB 247](#) and Louisiana [HB 460](#).
  - Sickle Cell Thalassemia Patients Network (SCTPN) - Support for SCD in NY state
    - According to SCTPN, "Three important New York State sickle cell bills sponsored by Assemblywoman Hyndman and Senator Sanders. These bills, if enacted, would increase education of high-risk sickle cell New Yorkers, create a sickle cell disease advisory council, and would designate sickle cell centers for excellence and outpatient treatment centers in New York State."
    - The three bills included in the letter were [A.6429-A/S.5606-A](#), [A.6430/S.5605](#), [A.6431/S.5604](#)
- **We discussed how to be a "data advocate" at our April Ambassador Priority Topic Meeting (PTM).**
  - Captain David Wong, MD of the Office of Minority Health guest presented.
  - Helpful SCD data resources discussed:
    - [Medicaid & CHIP SCD Fact Sheet](#)
    - [CTO/OMH Human-Centered Design Report: SCD](#)
    - [2020 NASEM Report on SCD](#)
  - See more [sickle cell resources](#) on our website.
  - Join the Ambassador program [here](#)

Please contact [info@sickcells.org](mailto:info@sickcells.org) with questions.