



# MEMO

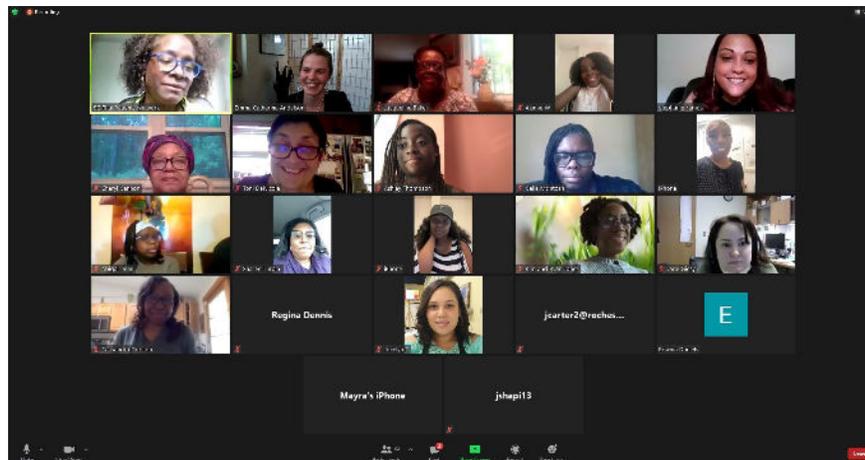
**Date:** June 17, 2021  
**To:** External  
**From:** Sick Cells

RE: May 2021 Policy Update

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It's hard to believe that we're already reflecting on what happened in May. Are we really halfway through June? Sick Cells' policy initiatives remained strong in May, focusing mostly on legislative outreach and working with Ambassadors to hone advocacy skills.

- **Sick Cells connected with 7 more legislator offices in May**, bringing our year-to-date total to over 50 legislator meetings. We continue to prioritize relationships with legislative offices.
  - Sick Cells Ambassador, Stephanie Ramos, led a legislative meeting with Senator Gillibrand's office. We partnered with Sickle Cell Thalassemia Patients Network (SCTPN) to conduct the meeting, which was our most attended meeting yet. Twenty-two (22) advocates from NY joined the call to ask the Senator to support sickle cell disease legislation at the federal level and share their stories.



- **Sick Cells hosted a workshop on data advocacy** as our Ambassador Priority Topic Meeting, following a presentation by CAPT David Wong of the Office of Minority Health at our April Meeting.
  - Helpful SCD data resources discussed:
    - [Medicaid & CHIP SCD Fact Sheet](#)
    - [CTO/OMH Human-Centered Design Report: SCD](#)
    - [2020 NASEM Report on SCD](#)

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- See more [sickle cell resources](#) on our website.
- Join the Ambassador program [here](#)
- **Sick Cells signed on to EveryLife Foundation's letter in support of the Speeding Therapy Access Today Act of 2021 (STAT Act)**, which was delivered to Committee leadership on Tuesday, May 25. Sick Cells joined 108 other organizations to show their support for what EveryLife Foundation calls "targeted, impactful, and attainable policy reforms at the FDA that will accelerate the development of and access to therapies across the spectrum of rare diseases."
  - Find out more about the STAT Act ([H.R. 1730/S. 670](#)) by visiting EveryLife Foundation's website [here](#).

### SPECIAL ANNOUNCEMENT:

## Congressional Hearing Request Letter

- **[June Announcement]** Sick Cells wrote and published a **Congressional Hearing Request Letter**, asking Congress to mandate an annual oversight hearing on the 2020 NASEM report on sickle cell disease.
  - You may remember that this was one of four of our 2021 policy priorities and included in our letter to the [Biden Administration](#). We are happy to announce that we have renewed this initiative with the support of 38 other organizations and have already begun our legislative outreach. You can read the letter [here](#) on our [Policy & Legislation](#) page.

**See you in June!**