

MEMO

Date: September 2, 2021

To: External **From:** Sick Cells

RE: August 2021 Policy Update

For Sick Cells, August was a time to begin wrapping up some early-year projects and launch our Q3 planning for our FY22 policy initiatives. Below you'll find what kept our staff occupied throughout the month.

- 1. **Sick Cells continued strategizing** on our <u>Congressional Hearing Request</u> after 10+ meetings with legislative offices. Stay tuned for our September update, which will announce next steps.
- NORD announced that <u>CA Senate Bill 247</u> passed through the Assembly Committee on Appropriations at the end of August & passed the California Assembly in the first couple days of September. We continue to support NORD's work on this project and sign on as supporters for each new RDAC bill.
 - a. This bill would establish a Rare Disease Advisory Council in California. These councils are a great way for the SCD community to get involved in state-level policy.
 - b. To learn more about this initiative, visit NORD's Project RDAC page.
- 3. Sick Cells began planning for upcoming state Medicaid meetings. Check back in September for updates on that month's meetings & notices on later meetings, as details often change. Email info@sickcells.org to get involved with our DURB/P&T Committee outreach.
 - a. September
 - i. Minnesota
 - ii. Pennsylvania
 - b. November
 - i. <u>Nebraska</u>
 - ii. Wisconsin
 - iii. Maryland
- 4. Suggested Reading: After doing our own deep dive into the 2020 NASEM report on SCD, Sick Cells is following along with Nancy Rene's blog series on the NASEM report as part on oneSCDvoice. This is a great way for those in the SCD community to learn more about this important resource.

See you in September!