

MEMO

Date: July 6, 2021

To: External

From: Sick Cells

RE: June 2021 Policy Update

In June, Sick Cells focused on remembering Marqus Valentine, Co-Founder of Sick Cells and winged warrior. Marqus loved people. He was drawn to helping them, even if he had never met them. His favorite part about working with SCD warriors and advocates in the community was their ability to gather together and make change, whether this was through telling stories, talking to legislators, or advocating for better access and coverage in health care. A year after he gained his warrior wings, we continue to honor his vision for Sick Cells, and the community as a whole, through our policy work and outreach. Please enjoy the June 2021 policy updates and help us by remembering our Co-Founder.



- **Sick Cells is excited to announce the release of the [Congressional Hearing Request Letter](#)** from the sickle cell disease community.
 - We wrote and fielded a request letter to key legislators regarding a community request for an annual hearing on the [2020 NASEM report](#) on sickle cell disease - *This is an updated version of our original letter, released in February.*
 - Hard copies of the letter were sent to leaders in the Senate, House, and relevant committees.
 - We have continued building relationships with legislative offices through new meetings to discuss this request.
- **Sick Cells prepared three advocates in Washington state** to provide public comments at a [DURB Meeting](#) on June 16, in addition to submitting our own written comments. The Board discussed the placement of SCD treatments on the Washington Preferred Drug List (PDL). Further updates to come in July.



- **Sick Cells continues to support NORD's [Project RDAC](#).** In the month of June:
 - The New Jersey letter of support was finalized with Sick Cells as a co-signer.
 - Support for [Assembly Bill 4016/SB 2682](#)
 - The establishment of the Louisiana RDAC was confirmed ([HB 460](#)).
 - This is the 18th RDAC in the United States.
 - To see a full list of RDACs click [here](#).
 - California [SB247](#) was heard in the Assembly Committee on July 6th at 1:30pm PT. Further updates to come in July.

Please contact info@sickcells.org with questions.

See you in July!