



MEMO

Date: June 25, 2022
To: External
From: Sick Cells

RE: June 2022 Policy Memo



The end of Q2 brings us to our mid-year point, which is hard to believe. Before we get there, however, we would like to take a moment to remember and honor our Co-Founder, Marqus Valentine. Marqus gained his warrior wings on June 22, 2020. His legacy continues to drive our policy work and direct our advocacy efforts. Thank you, Marqus, for bringing us all into your vision.

- Sick Cells **announced our support for the Sick Cell Care Expansion Act, [HR7177](#)** & its new [Senate counterpart](#).

"Sick Cells is pleased to support the Sick Cell Care Expansion Act of 2022. We hope this will be the first in a series of innovative approaches to improving care and quality of life for individuals living with sickle cell disease across the country."

- Sick Cell continues conversations with co-sponsors in the House and Senate to strengthen the bill and its programs. Our comments include the following:
 - *Remove the phrase "control of sickle cell disease"* to ensure clarity, reduce confusion, and avoid misinterpretation of the bill's purpose
 - *Promote diversity* in scholarship and repayment grantees
 - *Widen scholarship coverage* beyond Doctors of Medicine (MD) and Doctors of Osteopathic Medicine (DO) to include Registered Nurses (RN), Physician Assistants (PA), care coordinators, and nontraditional providers
 - *Ensure public reporting* of results for community feedback
- We encourage the SCD community to read the bill text and provide their input to the sponsoring offices.
 - Martha Sanchez | Legislative Assistant | Senator Van Hollen
Martha_Sanchez@vanhollen.senate.gov
 - David Thompson | Legislative Assistant | Representative Crist
David.Thompson2@mail.house.gov

Sick Cells 501 (C)(3) Nonprofit | www.sickcells.org
Mailing Address | 1042 Maple Ave STE 103 | Lisle, IL. 60532
DC Office | 1012 14th Street STE 500 | Washington D.C. 20005
[Subscribe to our Newsletter](#) | [Donate](#) | [Read Previous Policy Memos](#)
info@sickcells.org



- Sick Cells **joined a meeting with the HHS Office of Intergovernmental & External Affairs (IEA)** to discuss federal opportunities for improvising SCD programing and funding. Our main asks were the following:
 - HHS and the *Biden Administration* should *formally recognize sickle cell disease (SCD)* as a prioritized public health issue.
 - HHS should *convene State Medicaid Directors from across all 50 states and the District of Columbia* to educate them about sickle cell disease (SCD). By equipping the Medicaid Directors with increased knowledge about SCD, we hope to see a reduction in access barriers and improvement of appropriate coverage decisions in their state.
- Sick Cells & SCDA **co-hosted the SCD Legislation: Community Workshop** to share information about current federal legislation on sickle cell disease. Email eandelson@sickcells.org for a copy of the presentation.
- Sick Cells **met with Senator Kyrsten Sinema's office** (D-AZ) to discuss the Personalized Medicine Caucus and how the Caucus can promote causes impacting sickle cell disease.
- **COMING SOON:** This summer, **Sick Cells will launch our State Legislation Repository** as an additional resource of our [Advocacy Map](#). With this information, you will be able to:
 - Filter by state
 - Search all SCD-related legislation from your state
 - Learn more by following links to state legislature websites & other sites
 - Stay tuned!

See you in July!