



MEMO

Date: March 31, 2021

To: External

From: Sick Cells

RE: January-March 2021 Policy Update

Q1 was a busy time for Sick Cells. We worked hard to establish our policy priorities at the beginning of the year and met with multiple legislators and other nonprofits to solidify our vision for the future of sickle cell disease funding, research, and treatment. Below are the updates for our Q1 policy initiatives.

- 1. We published our [Letter to the Biden Administration, FY22 appropriations request, and Congressional Hearing Request Letter](#)**
 - a. The Biden letter represented the community's unified requests for 2021 and 2022
 - b. There were 47 sign-ons from other CBOs and SCD nonprofits
 - c. This year's appropriations request is \$25M for the CDC [SCD Data Collection Program](#) and \$15M for the [HRSA SCD Treatment Demonstration Program](#)
 - d. The Congressional Hearing Request letter outlines Sick Cells' request to Congress for annual hearings on the 2020 NASEM report, including its hosting committee and assigned witnesses
- 2. We signed on to three RDAC request letters**
 - a. We joined other national orgs to support NORD's [Project RDAC](#)
 - b. This program is led by NORD and works to establish Rare Disease Advisory Councils (RDACs) in every state
 - c. We co-signed letters to the California, Texas, and Arkansas state Senate & House
- 3. We coordinated and submitted three letters to the [March 4th D.C. P&T meeting](#)**
 - a. These letters represented the caregiver perspective, medical providers, and our own perspective as a national advocacy organization
 - b. We highlighted the issues with step therapy and "fail first" treatments, and the requirement of prior authorization for many SCD therapies on the D.C. formulary.
 - c. In March, we also worked with SCDAI to coordinate submissions for an upcoming Illinois DURB meeting on 4/15.
 - d. We are in the process of preparing for upcoming Texas and Missouri DURB/P&T meetings. Check the calendar at the bottom of our [Access & Coverage](#) page to keep track of DURB meetings.
- 4. We hosted our annual [Ambassador Policy Forum \(3/23\)](#) & [Virtual Hill Day \(3/24\)](#)**
 - a. Guest speakers at this year's Forum included **Yvonne Carroll**, Director of Patient Services in Hematology at St. Jude Children's Research Hospital; **Dr. Mary Hulihan**, Researcher and Health Scientist at the CDC; and **Kimberly Miller-Tolbert** and **Gloria Nuñez**, the



Health Policy Advisor (Kimberly) and Legislative Correspondent (Gloria) for Senator Cory Booker (D-NJ). The Forum also featured an Ambassador Panel with **Elodie Ontala** and **Regina Dorsey. Dr. Marjorie Dejoie-Brewer** provided Warrior Yoga Breaks throughout the full session.

- b. We worked with Advocacy Associates to schedule **49 meetings with legislators**, both in the Senate and the House. We met with Democratic and Republican offices to bring our appropriations request, Congressional hearing request, and Letter to the Biden Administration to their attention and request much-needed change for the SCD community.
- c. **To get involved with the Ambassador Program, please visit our [website to learn more](#).**

Q1 is a busy time of the year for Sick Cells' annual policy and legislation work, but we continue to meet with legislative offices, industry and nonprofit partners, and coalition leaders throughout the year to implement policy initiatives at all levels. **Check back next month for our next update!**

Please contact info@sickcells.org with questions.