MEMO

Date: June 30, 2023
To: External
From: Sick Cells

RE: June 2023 Policy Memo

This month's highlights include an HHS and ASH data roundtable, new legislation for SCD, the submission of witness statements to a Congressional hearing, and more.

From the reintroduction of the landmark 2018 sickle cell bill, to cross-stakeholder conversations about data collection, June was a busy month for policy at Sick Cells. We are wrapping up the second quarter of the year, meaning we take stock of policy initiatives that can be closed out and others that can be reinvigorated.

1. Programs authorized by Public Law 115-327, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention and Treatment Act of 2018 were reintroducted in June legislation through S.1852 and H.R.3884 by Reps. Michael Burgess (R-TX), Danny Davis (D-IL) and Buddy Carter (R-GA) in the House and Sens. Tim Scott (R-SC) and Cory Booker (D-NJ) in the Senate. Authorization for treatment and surveillance programs outlined in the original bill ends in calendar year 2023.
    a. The Senate version of the bill is called the "Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023." The House version is not formally named.
    b. The new legislation was reviewed during a June 14 E&C Committee Hearing and a June 15 HELP Committee Markup.
    c. Sick Cells **submitted witness statements for the record** to the House Energy and Commerce Committee (E&C) and the Senate Committee on Health, Education, Labor and Pensions (HELP). View them on our website here. *The same statement (with edits to the recipient) was sent to leadership of both committees.*

2. Sick Cells' Director of Advocacy (Maggie Jalowsky) and Senior Program Manager, Government Affairs & External Relations (Emma Andelson) **attended the Sickle Cell Disease Registry Leaders' Data Roundtable**, hosted by the U.S. Department of Health and Human Services (HHS) and the American Society of Hematology (ASH).
    a. Opening remarks were given by Xavier Becerra Secretary of Health and Admiral Rachel L. Levine, MD, Assistant Secretary for Health (ASH).
    b. Comments from Sick Cells were centered around the need for data collection to accurately reflect the experience of individuals living with SCD through the incorporation

of patient-reported outcomes, and underscored that data collection efforts should actively engage with community organizations.

3. Last month's policy memo highlighted that Sick Cells participated in a Patient Listening Session (PLS) with the U.S. Food and Drug Administration (FDA) alongside the Sickle Cell Disease Foundation, the SCDAA, SC RED, and 6 Warrior/caregiver representatives. **Read the newly-released summary here.**

State Highlights

1. Florida | CS/CS/SB 1352 | "Sickle Cell Disease Medications, Treatment, and Screening"
    a. Full details on this bill can be found in the March Policy Memo
    b. Establishes a program to conduct a "biennial review of Medicaid enrollees with sickle cell disease"
    c. View the House and Senate versions
    d. **Signed into law** on June 18, 2023 after a similar bill died in the 2022 Regular Session

2. Texas | HB 181 | "Relating to the establishment of a sickle cell disease registry"
    a. Filed in 2022 but introduced in February 2023
    b. Requires Texas to create and maintain a registry for sickle cell disease
    c. **Vetoed by the governor** on June 17, 2023 after unanimous "Ayes" in the State House and Senate

See you in June!