



MEMO

Date: May 26, 2022

To: External

From: Sick Cells

RE: May 2022 Policy Memo

With the Policy Forum and Hill Day behind us, we spent May continuing to work on policy initiatives started in Q1 and began planning for the second half of the year. Read ahead to learn what we were up to in May.

1. **Sick Cells met with the co-chairs of the Personalized Medicine Caucus**
 - a. Offices: Representative Swalwell (D-CA), Senator Tim Scott (R-SC), and Representative Emmer (R-MN). We will meet with the office of Senator Sinema (D-AZ) in June.
2. **We signed a letter of support** circulated by the American Society of Hematology for the Sickle Cell Disease Comprehensive Care Act
 - a. 60+ organizations signed
 - b. Sent to the Senate Finance Committee and House Energy & Commerce Committee
 - c. Purpose: Request to advance the bill and pass the program into legislation
3. **Our Ambassadors learned about Advocacy Strategies in the ER** during the May Priority Topic Meeting
 - a. Guest Speakers:
 - i. Dana Star Kiwacz, Founder of Inspired Life Design Studio, Sick Cells Ambassador
 - ii. Dr. Jeffrey Glassberg, Associate Prof of Emergency Medicine, Hematology & Oncology, Mount Sinai
 - b. Relevant Materials shared:
 - i. Video: "[Understanding Sickle Cell Patients' Pain in the ER](#)"
 - ii. Video: "[CRISIS: Experiences of People with Sickle Cell Disease Seeking Health Care for Pain](#)"
 - c. Our Ambassadors discussed ways ERs can better provide care and what SCD Warriors and their families can do to advocate for themselves in the clinical setting.

See you in June!