

## **MEMO**

Date: September 30, 2022

**To:** External **From:** Sick Cells

RE: September 2022 Policy Memo

September brought us back to the full swing of things! From working on exciting new legislation for sickle cell disease to a whirlwind of Sickle Cell Awareness Month presentations, the Sick Cells team has been hard at work. Here are our September highlights:

- 1. Sick Cells President, Ashley Valentine, **attended a Senate event** to officially mark the introduction of the <u>Sickle Cell Disease Treatment Centers Act</u>.
  - a. Ashley shares, "The Sickle Cell Disease Treatment Centers Act of 2022 offers a bold, new, system-wide approach to structuring comprehensive care for Sickle Cell Disease. For a community that has lacked full medical and social support, relevant data, and needed auxiliary services for so long, this legislation illustrates what stakeholders might achieve through a collaborative approach with dedicated funding."
  - b. Read the full press release <u>here</u>.
- 2. Sick Cells participated in a meeting with key staff at the Centers for Medicare & Medicaid Services (CMS) as part of the Sickle Cell Disease Partnership
  - a. The group introduced the partnership and our policy priorities and spoke about CMS programs that support sickle cell disease and how programs could be expanded and refined.
- 3. Sick Cells met with key staff at the Centers for Disease Control & Prevention (CDC).
  - a. The meeting focused on current CDC programs for sickle cell and opportunities for future collaboration.
  - b. CDC released the most recent issue of <u>Vital Signs</u>, focusing on sickle cell disease for the first time.
- 4. Sick Cells staff presented at Cayenne Wellness Center's 14th Annual Sickle Cell Disease Seminar on legislative updates.
  - a. The presentation was in collaboration with SCDAA and focused on current legislation and how to get involved.

See you in October!