SCD Policy Forum Recap | March 17-18, 2026

Sick Cells hosted its annual SCD Policy Forum on **March 17-18, 2026.** This two-day virtual convening brought together advocates, caregivers, healthcare professionals, and community members from across the country to engage in federal advocacy for the sickle cell community.

This year's theme, "Voices to Action," highlighted the power of lived experience in shaping and advancing legislative change.

Forum Recap | March 17, 2026

The 2026 SCD Policy Forum launched with **215 participants** joining interactive sessions designed to educate, connect, and prepare advocates for Hill meetings.

During opening remarks, Sick Cells announced the **relaunch of the Congressional Sickle Cell Disease Caucus**, led with bipartisan support by Rep. Glenn Ivey (D-MD) and Rep. Rich McCormick (R-GA). The caucus will focus on:

- Strengthening SCD education and awareness
- Advancing federal legislation and appropriations
- Driving continued research and innovation

This milestone reflects the direct impact of community advocacy, and Sick Cells looks forward to supporting the caucus in advancing meaningful federal action.

The **keynote address,** delivered by **Maia Laing**, Chief of Policy at Sick Cells, emphasized the urgency of elevating SCD on the national policy agenda. Her remarks reinforced the need for sustained investment in care and encouraged advocates to use their voices to drive change, because "policy is about people."

The forum also featured recorded remarks from **Rep. Glenn Ivey**, who spoke about the importance of advancing medical research and strengthening federal support for the SCD community.

Policy Priorities

Participants were equipped with the knowledge and tools to advance Sick Cells' 2026 federal priorities:

1. Join and actively participate in the Congressional Sickle Cell Disease Caucus
2. Cosponsor the Sickle Cell Disease Comprehensive Care Act (H.R. 5178/ S.721)
3. Champion robust FY2027 funding for sickle cell disease programs
    - $8.2M – Sickle Cell Disease Treatment Demonstration Program (HRSA)
    - $7M – Sickle Cell Disease Newborn Screening Follow-Up Program (HRSA)
    - $6M – Sickle Cell Data Collection Program (CDC)

Educational Sessions

Three expert-led panels deepened participants' understanding of federal policy and advocacy strategy:

- Congressional Action & Advocacy: The role of Congress and the importance of constituent engagement
- Comprehensive Care Act Overview: Key provisions and impact of the legislation
- Federal Funding Landscape: The importance of sustained investment in programs supporting care, screening, and data collection

Speakers included community leaders, individuals living with SCD, providers, and national partners who translated complex policy into actionable advocacy strategies.

Community & Preparation

The Forum also prioritized connection and readiness:

- **Wellness Break:** Led by **Ayoola Olubukola**,reminding participants that advocacy includes self care
- **Tech Walkthrough:** Ensured participants were fully prepared for their virtual meetings
- **State-Based Breakout Sessions:** Allowed advocates to align on roles, messaging, and meeting flow

These sessions helped build confidence and cohesion ahead of Hill Day.

Virtual Hill Day Recap | March 18, 2026

Advocates put their preparation into action during Virtual Hill Day, engaging directly with lawmakers and staff to elevate the needs of the SCD community.

- **172 advocates**
- **132 meetings** conducted across **26 states**

Meeting Breakdown:

- 45 Senate offices
- 87 House offices
- 90 meetings with Democratic offices
- 42 meetings with Republican offices

Throughout the day, advocates shared personal stories, highlighted systemic challenges, and called for meaningful policy change. Many meetings resulted in follow-up requests, demonstrating strong momentum and engagement.

Real-Time Support

Sick Cells provided real-time support to ensure a seamless experience, including:

- Schedule coordination and updates
- Technical troubleshooting
- Policy and messaging support
- Ongoing check-ins and encouragement

This high-touch approach enabled advocates to fully participate and maximize their impact.

Additional Highlights

Advocate Leadership: 41 trained volunteers served as State Team Leads, guiding discussions, supporting participants, and helping ensure a seamless participant experience across both days of the Forum.

Advocate Storytelling & Engagement: Kwaku Aurelien, a SCD Warrior and Sick Cells Ambassador from Connecticut, participated as a State Team Lead and shared his experience in a post-event blog, highlighting the impact of advocacy and the importance of community voice.

Events & Pre-Forum Outreach: In the lead-up to the Forum, Sick Cells implemented a comprehensive outreach and engagement strategy to recruit and prepare advocates, particularly first-time participants.

Key efforts included:

- A partner webinar focused on the current policy landscape
- Engagement during the 2026 Rare Disease Week in Washington D.C.
- Activation of past participants, community-based organization (CBO) partners, and social media audiences

To further drive participation, Sick Cells conducted targeted direct outreach, including:

- 200+ phone calls
- 270+ text messages
- 1,700+ emails
- 12+ hours of phone banking

These combined efforts contributed to strong national participation and an expanded pipeline of informed and engaged advocates.

Advocate Storytelling & Engagement: Kwaku Aurelien, a SCD Warrior and Sick Cells Ambassador from Connecticut, participated as a State Team Lead and shared his experience in a post-event blog, highlighting the impact of advocacy and the importance of community voice.

Participant Experience & Support: Participants consistently reported a highly supported and accessible experience throughout Virtual Hill Day. Real-time assistance with logistics, technology, and coordination enabled advocates to stay focused on engagement, contributing to strong participation and meaningful interactions with congressional offices.

Thank You to Our Sponsors:

This work would not be possible without the generous support of our sponsors. Your partnership helps amplify community voices, strengthen advocacy efforts, and advance equitable policy change for individuals and families affected by sickle cell disease. Thank you to Vertex Pharmaceuticals, Agios, Fulcrum Therapeutics, Pfizer, Beam Therapeutics, and Chiesi for sponsoring the 2026 SCD Policy Forum.