2025 SCD Policy Forum Event Recap

Sick Cells and the Sickle Cell Community Consortium hosted the annual [SCD Policy Forum]() on **March 11th – 12, 2025.** This two-day virtual event brought together advocates, caregivers, healthcare professionals, and community members from across the country to engage in federal-level advocacy for the sickle cell community. This year's theme, "Your Voice Belongs", emphasized inclusion, representation, and collective action.

Recap of Advocacy Training Day (March 11, 2025)

The 2025 SCD Policy Forum opened with a full day of virtual advocacy training, welcoming **253 participants** on Zoom for interactive sessions designed to educate, connect, and prepare advocates for their upcoming Hill meetings.

The **Keynote Address** was delivered by **James Griffin**, a sickle cell disease advocate, author, motivational speaker, and Sick Cells Ambassador. James shared powerful reflections on the importance of self-advocacy, community leadership, and storytelling as tools for change. His message set the tone for a day centered on empowerment and collective action.

The day also featured remarks from **Representative John James**, who spoke about the critical role of bipartisan support in driving sickle cell policy forward and encouraged advocates to keep sharing their stories with lawmakers.

To deepen participants' understanding of our legislative priorities, the agenda included two robust federal policy panels. These sessions walked advocates through the four key asks for 2025—covering surveillance, funding, reauthorization, and comprehensive care. Presenters included CBO leaders, providers, and partners who broke down the issues, explained relevant legislation, and shared messaging strategies tailored for Hill meetings.

Midway through the day, attendees were invited to pause and recharge during a **Wellness Break** led by **Ayoola Olubukola**, a sickle cell advocate and wellness practitioner. This moment encouraged participants to reset, breathe, and reflect—emphasizing that advocacy also includes caring for ourselves.

A **Tech Walkthrough & Support Session** followed to ensure participants had access to the scheduling platform, knew how to navigate their virtual meetings, and felt supported throughout the experience.

Participants then ended the day with **Breakout Sessions** facilitated by Sick Cells staff to meet their state-based teams. These sessions gave advocates the opportunity to:

- Review their assigned Hill Day schedules
- Coordinate roles and share personal introductions
- Clarify talking points and meeting flow
- Build rapport and confidence ahead of Day 2

View the full agenda in the program book [here]().

Recap of Virtual Hill Day (March 12, 2025)

Following a successful training day, advocates reconvened for Virtual Hill Day, where they put their preparation into action by meeting with federal lawmakers and staff. This day of direct advocacy

reflected the power of lived experience in policy change and demonstrated the strength of the national sickle cell community.

A total of **222 trained constituents** participated in meetings with **Congressional offices across 29 states**, resulting in **160 total meetings**—including three with members of Congress.

Breakdown of Hill Meetings:

- **46** Senate offices
- **114** House offices
- **3** member-level meetings with Reps. Cleo Fields, Rashida Tlaib, and Brian Mast
- **106** meetings with Democratic offices
- **54** meetings with Republican offices

2025 Federal Legislative Asks

1. Appropriate $25 million for the CDC's Sickle Cell Data Collection (SCDC) Program
2. Appropriate $15 million for programs under the HRSA Sickle Cell Disease Treatment Act
3. Reauthorize the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2025
4. Support and pass the Sickle Cell Disease Comprehensive Care Act

View the **Sickle Cell Legislative One-Pager: FY 2026** here.

Throughout the day, Sick Cells' support team remained online to provide:

- Real-time schedule adjustments and meeting updates
- Login support and tech troubleshooting
- Last-minute talking point refreshers and member bios
- Encouragement and check-ins between meetings

Thanks to strong preparation and coordination, canceled meetings were reduced by **91%** compared to 2024—dropping from 35 to just 3 in 2025. This milestone speaks to the quality of training, the dedication of team leads, and the growing professionalism of the national advocacy movement.

Advocates shared stories, offered insight into real-world challenges, and called on legislators to prioritize policy change that addresses the unique needs faced by the SCD community. Many meetings ended with follow-up requests showing clear momentum from the collective effort.

Notable Moments & Storytelling Highlights

First-Time Advocate Feature: Olivia Sessi, a mother and entrepreneur from Utah, joined Hill Day for the first time and shared her experience in a post-event blog. Read her story.

Roadshow Events & Pre-Forum Outreach: In the lead-up to the Forum, Sick Cells hosted four community events, including support groups and webinars. Over 140 calls, 200 text messages, and 10 hours of phone banking helped drive turnout.

Advocate Leadership: 25 trained volunteers served as team and breakout room leads, guiding discussions and ensuring a seamless participant experience on Day One and Two.

Thank You to Our Sponsors:

This year’s SCD Policy Forum was supported by Vertex Pharmaceuticals, Pfizer, Beam Therapeutics, Agios, Chiesi and Fulcrum Therapeutics.