2025 SICKLE CELL DISEASE POLICY FORUM

MARCH 11 - 12

SICK CELLS

sickle cell community consortium

CONTENTS

A LETTER FROM OUR LEADERS

Dear Advocates,

Sick Cells and the Sickle Cell Community Consortium are excited to welcome you to the 2025 SCD Policy Forum! Your voice belongs in policy discussions, and together, we have the power to create meaningful change.

With every new administration comes an **opportunity to educate, engage, and create new champions for SCD.** This is a crucial moment to strengthen advocacy efforts and build relationships with legislative representatives. This year's SCD Policy Forum will provide key insights into federal programs and policies and offer interactive workshops to prepare you for Virtual Hill Day, where you'll meet directly with Members of Congress and their staff to advance policy priorities for the SCD community.

Advocacy is powerful when individuals come together with a shared purpose. United, we can ensure that SCD remains a national priority and push for policies that improve the lives of those affected. We are honored to have you join us for this virtual event, and we appreciate your commitment to elevating the voices of the SCD community.

We look forward to an engaging and impactful forum!

Sincerely,

Dr. Lakiea Bailey
Executive Director
Sickle Cell Community Consortium

Ashley Valentine, MRes
Co-Founder & President
Sick Cells

WHO WE ARE

Sick Cells is a national sickle cell disease (SCD) advocacy nonprofit founded February 28, 2017. Sick Cells' mission is to elevate the voices of the SCD community and their stories of resilience. In highlighting the grave disparities this community faces, we hope to influence decision-makers and propel change.

Website: **sickcells.org**

@sickcells

The Sickle Cell Community Consortium is a US-based non-profit formed in 2014 to "harness and amplify the power of the patient voice." The Consortium is comprised of sickle cell community-based organizations (CBOs), patient and caregiver advocates, community partners and medical and research advisers.

Website:
sicklecellconsortium.org

@sccconsortium

HERE'S HOW TO GET INVOLVED

PROGRAMS AND EVENTS

Sickle Cell Consortium

UPCOMING

EVENTS

Check Out Our Upcoming Events

All dates are attentive

Apr 23-27

Leadership Summit

The Summit is the primary meeting of the Sickle Cell Community Consortium. Normally, every March all Consortium partners travel to Atlanta Georgia to participate in the Leadership Summit and to convene the annual General Assembly of Patients, Caregivers and CBOs.

Jun 19

World Sickle Cell Day

June 19th, we will celebrate World Sickle Cell Day with other sickle cell communities from all over the world. Visit www.sicklecellday.org for more inforamtion

July 23-27

Warriors Convention

Each year, the Annual Warriors Convention is organized by the Sickle Cell Consortium and is hosted by a partnership of sickle cell community-based organizations, patients, and advisors. Go to www.sicklecellconvention.org

Nov 13-16

Caregiver Summit

Are you a #Caregiver for a loved one with #SickleCell? We have designed a summit designed JUST for you! Visit www.scdcaregivers.org to learn more.

sickle cell
communityconsortium

For more information:

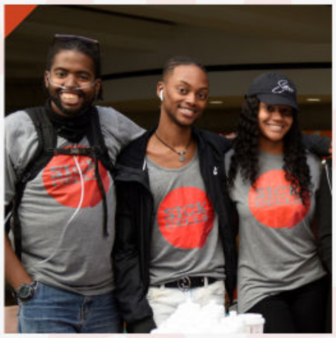
www.sicklecellevents.org

ABOUT *the* AMBASSADOR PROGRAM

The Sick Cells Ambassadors Program is a volunteer network of individuals dedicated to changing the landscape of sickle cell disease and empowered to spread awareness through policy change.

Sick Cells is shifting the social conversation around sickle cell disease and activating sickle cell advocates to engage in priorities for sickle cell disease. Our Ambassadors advocate for programs and policies that help advance research and drug development, improve access to care, and raise awareness about sickle cell disease (SCD). Read more on our website.

Activate. Advocate. Educate.



WHAT WE OFFER

Tea Chats

30-minute monthly meetings to discuss upcoming events

Priority Topic Meetings

1-hour monthly skill-building advocacy workshops. Each month has a different theme, from wellness to federal legislation.

Toolkits

Helpful guides for all types of advocacy. Find them here.

Medicaid Advocacy

Ambassadors learn about important opportunities to advocate for access & coverage of SCD treatments. Ambassadors will be able to share their stories with Medicaid committees across the country to influence their decisions.

Online Community

Sick Cells has a Facebook group for Ambassadors. You can also follow us on Instagram, Facebook, and Twitter at @sickcells

Speaking Opportunities

Ambassadors have the chance to speak at outside opportunities through other organizations, sponsors & partners.

Meet Your Staff Liaisons

Kelly Hawthorne
Director of Community Programs
khawthorne@sickcells.org

Arielle Krahenbuhl
Community Programs Coordinator
akrahenbuhl@sickcells.org

AGENDA

DAY 1

MARCH 11

11:00 AM EST	**WELCOME + KICK OFF**
11:05 AM EST	**KEYNOTE ADDRESS**
11:15 AM EST	**FEDERAL REQUESTS OVERVIEW** Legislative asks run-through & opportunities for new champions
11:25 AM EST	**LEGISLATION TO SUPPORT & PASS (PANEL)** Ask #1: Reauthorize Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023 Ask #2: Support the Sickle Cell Disease Comprehensive Care Act
11:55 PM EST	**FY26 APPROPRIATIONS: FUNDING FOR VITAL PROGRAMS (PANEL)** Ask #3: Appropriate $25 Million for the CDC Sickle Disease Data Collection Program Ask #4: Appropriate $15 Million for Programs under the HRSA Sickle Cell Disease Treatment Act
12:30 PM EST	**WELLNESS BREAK**
12:40 PM EST	**MEETING PLATFORM WALKTHROUGH**
1:00 PM EST	**HILL DAY TRAINING** Key terms, resources and legislator meeting demo
1:30 PM EST	**BREAKOUT ROOM SESSIONS** Meet with state teams, practice and prepare for Day 2
2:25 PM EST	**CLOSING REMARKS**

ACCESS YOUR VIRTUAL HILL DAY SCHEDULE

- **If you registered** to participate in the Virtual Hill Day, you will receive an automated email from Advocacy Associates. *Please make sure this email is not in your Spam/Junk folder.*
- **If you did not register** for the Virtual Hill Day, you will not receive a schedule.
- Click on the link in the email to access the event platform and your personal meeting schedule. You will need to use the login information from the email.
- Once logged in, you will see a home dashboard with your confirmed meetings and times. **All times will be displayed in your local time zone.**

JOIN A MEETING WITH YOUR LEGISLATOR

- On the Home page, click on a legislator to pull up your meeting specifics, including the name of the staff member you will meet with and any other attendees who will be attending the meeting with you.
- To access the virtual meeting, **click on the green button that says "Connect to the Meeting."** This will connect you directly with the meeting link. *Most of your meetings will be hosted on Zoom.*
- You will also have the option to **dial-in using a phone,** if you must connect this way. We do encourage all attendees to join with video on Zoom if possible. You should join all meetings 5 minutes prior to the start time.

USING THE EVENT PLATFORM

- On the event platform, you can view the **event toolkits and the FY26 Requests one-pager.**
- You can read **Talking Points** that we recommend using during your pitch to the legislator.
- During the meeting, you can use the **"Take Notes"** option as a blank notepad. These notes will not be shared.
- After the meeting, each Team Lead will hit **"Send Thank You"** to send a pre-written script for your legislator. *The system will automatically pull the contact information for the staff person that you met with.*
- Each Team Lead will fill out the **"Meeting Report Form"** which will send feedback to event hosts about your meeting.

FISCAL YEAR (FY) 2026 FEDERAL REQUESTS FOR SICKLE CELL DISEASE

LAST UPDATED: MARCH 5, 2025

SUPPORT AND PASS SICKLE CELL DISEASE (SCD) LEGISLATION

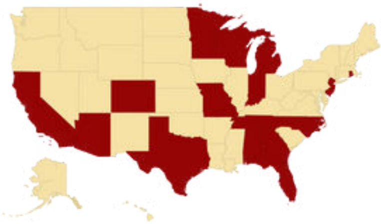
- **Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2025 (119th Congress, S.735):** Reauthorize the SCD Demonstration Program at $8.205 million for each of the fiscal years 2024 through 2028 at the Health Resources and Services Administration (HRSA). The program supports initiatives to improve the treatment of SCD and to better prevent and treat complications of SCD, focused on populations with a high proportion of individuals with SCD.

- **Sickle Cell Disease Comprehensive Care Act (119th Congress, S.721):** This legislation incentivizes state Medicaid programs to adopt a Health Home model, which improves the coordination of care for individuals with SCD enrolled in Medicaid. Medicaid Health Homes are a proven and effective tool to improve health outcomes, enhance quality, and reduce unnecessary expenditures in Medicaid**. State Medicaid directors have supported this model and more than 90 organizations are supporting this legislation.**

PROVIDE FUNDING FOR KEY SCD PROGRAMS

Appropriate $25 million for Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program. The SCDC program gathers health information from multiple sources to determine how many people live with the disease in a particular state.

- The SCDC covers 16 states which are home to approximately 50% of the SCD Population in the USA with plans to expand.
- The goals of the SCDC include learning where people with SCD live and gathering information on the transition from pediatric care to adult care.



- Data collection is necessary to efficiently allocate federal resources by allowing policymakers to understand national incidence and prevalence data; and to evaluate effective strategies to improve quality of life and lower costs associated with treating SCD.

APPROPRIATE $15 MILLION FOR PROGRAMS UNDER THE HRSA SICKLE CELL DISEASE TREATMENT ACT

- **Appropriate $8.205 million to the Sickle Cell Disease Treatment Demonstration Program (SCDTDP).** SCDTDP is a HRSA grant program with the following goals:
  - Increase the number of clinicians or health professionals knowledgeable about the care of SCD.
  - Improve the quality of care provided to individuals with SCD, including care coordination with other providers.
  - Develop best practices for coordination of services during the transition from pediatric to adult care, which is a critical time period for individuals with SCD in ensuring the continuity of comprehensive care, thereby minimizing an increase in health care costs resulting from inadequate disease management into adulthood.

- **Appropriate $7 Million to The Sickle Cell Disease Newborn Screening Follow-up Program through the Special Projects of Regional and National Significance.** The program is critical to ensuring that all individuals diagnosed with SCD are connected to appropriate follow-up care, support services, and care coordination.

- **In its first two years, the program:**
  - Expanded the infrastructure of 25 community-based organizations in 19 states.
  - Launched the National SCD Community Health Workers Training Program – and trained 85 community health workers who reached more than 13,000 patients.
  - Assessed over 8,000 individuals in need of a medical home or education on SCD medication.
  - Launched a Shared Management System, which allows HRSA to analyze patient outcomes.

Continued program efforts will accelerate the identification of individuals requiring follow-up care for SCD, expand care coordination, increase medical home participation, improve the number of community health workers trained in SCD, and implement best practices and procedures for SCD care.

SPONSORS

GOLD	Pfizer	VERTEX
SILVER	agios	
BRONZE	Beam THERAPEUTICS	
SUPPORTER	Chiesi	Fulcrum Therapeutics

SUPPORT SICK CELLS

With your gift, Sick Cells will be able to continue have impactful programming like the 2025 SCD Policy Forum, and advance our community's advocacy priorities.

DONATE

VERTEX

> *“In recognizing the many experiences within the sickle cell community, we know that our work is just beginning. We are committed to continuing research in the hopes of reaching as many patients as possible.”*

Amit Sachdev,
Chief Patient and
External Affairs Officer

Hear more from Amit
on our commitments
to the community:

Virtual

Sickle Cell Disease Policy Forum

SICK CELLS

sickle cell
communityconsortium