2026

SICKLE CELL DISEASE POLICY FORUM

MARCH 17 - 18

SICK CELLS

“VOICES TO ACTION”

“Voices to Action” is more than just a theme, it’s a call to action. The SCD Policy Forum brings together warriors, caregivers, clinicians, and advocates to turn lived experience into legislative impact. From powerful stories to purposeful action, we elevate voices, shape policy priorities, and meet directly with lawmakers to drive meaningful change.

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A LETTER FROM OUR CEO

Dear Advocates,

Welcome to the 2026 SCD Policy Forum!

It is an honor to gather for two days rooted in purpose, connection, and action. Your commitment to showing up for this community and for one another is powerful.

This year's theme, "**Voices to Action**," is more than words. It is a movement. The stories, expertise, and lived experiences within the sickle cell community carry weight. When we come together with intention, those voices influence policy, educate lawmakers, and spark real progress.

Over the next two days, you will gain the tools and confidence to engage directly with federal representatives during a Virtual Hill Day and advance priorities that strengthen care, expand access, and improve outcomes for individuals and families living with sickle cell disease.

Momentum builds when we move together. Together, we are shaping a future where sickle cell disease is met with the attention, investment, and urgency it deserves.

Thank you for bringing your voice and your action to this work. **This is how change happens, and it starts with us.**

With appreciation,
Ashley Valentine
Chief Executive Officer & Co-Founder
Sick Cells

WHO WE ARE

Sick Cells is a national sickle cell disease (SCD) advocacy nonprofit founded in 2017. **Sick Cells' mission is to elevate the voices of the SCD community and our stories of resilience.** In amplifying the challenges this community faces, we influence decision-makers and drive positive change.

Sick Cells has successfully organized and executed numerous policy forums and virtual hill days. A leader in advocacy and policy training, **we strive to provide the community with the tools to empower their own advocacy journeys** and enact positive change at both the state and federal levels.

Website: **sickcells.org**

@sickcells

DAY 1: FORUM & TRAINING

MARCH 17

AGENDA

11:00 AM EST	**Welcome**
11:05 AM EST	**Keynote Address: Voices to Action**
11:15 AM EST	**Your Voice is the Work: How Patient Advocacy Drives Congressional Action**
11:25 AM EST	**From Voices to Action: Our Congressional Ask** Ask #1: Participate in Sickle Cell Disease Congressional Education and Engagement
11:45 AM EST	**Supporting the Work: Legislation to Advance** Ask #2: Support and Advance the Sickle Cell Disease Comprehensive Care Act
12:05 PM EST	**Funding the Work: Turning Policy into Care** Ask #3: Continued Funding for Sickle Cell Disease Programs
12:25 PM EST	**Wellness Break**
12:35 PM EST	**Meeting Platform Walkthrough**
2:00 PM EST	**Hill Day Training** Key terms, resources and legislator meeting demo
2:30 PM EST	**Closing Remarks**
2:40 PM EST	**Breakout Room Sessions** Meet with state teams, practice and prepare for Day 2: Hill Day

DAY 2: VIRTUAL HILL DAY

MARCH 18

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.
- At the end, **ask to take a photo!** Always ask first, then take a screenshot to share with Sick Cells.

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.

SPEAKERS

Ashley Valentine, MREs
CEO & Co-Founder
Sick Cells

Maia Laing, MBA
Chief Policy Officer
Sick Cells

Melissa Akinlawon, MA
Senior Director of Community Programs
Sick Cells

Fabienne Antoine-Nasser
Director of Policy and Government Affairs
Sick Cells

Rep. Glenn Ivey (MD)
Congressman
United States House of Representatives

Ryann Hill
Founder & CEO
Indigo Hill Strategies

Jennifer Bernstein
Principal
Monument Advocacy

Hanif Mouehla
SCD Community Member

Ebony Slaughter-Johnson
Vice President
Indigo Hill Strategies

Dr Edward Donnell Ivy
Vice Chief Medical Officer
Sickle Cell Disease Association of America

Stephanie Kaplan
Director, Government Relations & Public Health
American Society of Hematology

Angela Snyder
Director of Health Policy and Financing
Georgia Health Policy Center

Victoria Gemmes
Director
Leavitt Partners

Marilyn Jo Telen
Director
Duke Comprehensive Sickle Cell Center

Fatmata Williams
Deputy Medicaid Director, Connecticut Social Services

Ayoola Olubukola
Healing Through Artistic Mediums

Fiscal Year (FY) 2027 Federal Requests for Sickle Cell disease

Sickle Cell Disease (SCD) is the most common inherited blood disorder in the US and impacts over 100,000 Americans. Individuals living with SCD face severe health complications, including recurring and life-altering pain crises, repeat infection, acute chest syndrome, lung problems, severe and chronic pain, leg ulcers, organ damage, and stroke.

Through advocacy and congessional action, we see life imporving for the SCD community

Here's how you can help make a difference for individuals and families living with SCD:

JOIN AND ACTIVELY PARTICIPATE IN THE CONGRESSIONAL SICKLE CELL DISEASE CAUCUS

The mission of the **Congressional Sickle Cell Disease Caucus is to elevate the needs of constituents living with SCD** and those who provide care, innovation, and coverage for the community. The SCD Caucus serves as a forum to:

- Advance bipartisan policy solutions and policy-relevant research
- Strengthen education and awareness of sickle cell disease
- Build congressional support for legislation and appropriations that improve care

COSPONSOR THE SICKLE CELL DISEASE COMPREHENSIVE CARE ACT (H.R.5178/S.721)

The **Sickle Cell Disease Comprehensive Care Act incentivizes state Medicaid programs to adopt a Health Home model**, improving care coordination for individuals with SCD enrolled in Medicaid.

This model helps patients navigate complex care needs, reduces preventable hospitalizations, and improves health outcomes. The Congressional Budget Office projects that Medicaid Health Homes will also generate cost savings.

CHAMPION ROBUST FUNDING FOR SICKLE CELL DISEASE PROGRAMS IN FISCAL YEAR (FY) 2027

Thank you for appropriating $21 million across federal programs. Funding levels shown reflect FY 2026 appropriations and are cited to support our request for continued funding in FY 2027.

Appropriate $8.2 million to the Sickle Cell Disease Treatment Demonstration Program (SCDTDP)
The SCDTDP is a Health Resources and Services Administration (HRSA) grant program that expands access to high-quality, coordinated SCD care by training clinicians and strengthening care delivery systems. In FY 2026, the program supported services across 51 sites and reached more than 25,000 individuals—particularly during critical transitions from pediatric to adult care.

Appropriate $7 million to the HRSA Sickle Cell Disease Newborn Screening Follow-up Program
This program ensures that infants and families identified through newborn screening are connected to follow-up care, education, and community-based support. In its first two years, the program strengthened the infrastructure of 25 community-based organizations across 19 states and reached more than 13,000 patients, and assessed over 8,000 individuals in need of a medical home or treatment education.

Appropriate $6 million for Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program
The CDC SCDC Program provides essential data to understand where people with SCD live, how they access care, and which interventions improve outcomes. Since its initial appropriations in 2019, the program has expanded from 2 states to 16 states, now covering approximately half of the U.S. SCD population.

CREATED BY

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For more information, visit sickcells.org.

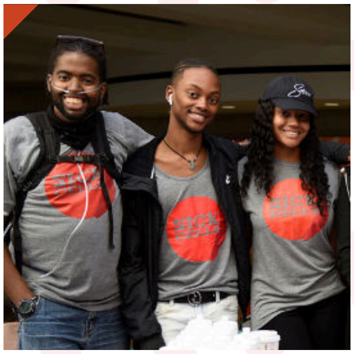
MORE WAYS TO GET INVOLVED

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.



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.

WHAT WE OFFER

Scan to fill out our interest form

Speaking Opportunities

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

FACES OF SCD PROGRAM

Scan to start sharing your story

SPONSORS

SILVER

VERTEX

BRONZE

agios

Pfizer

Fulcrum Therapeutics

SUPPORTER

Beam THERAPEUTICS

Chiesi

Notes

Thank You

CONNECT WITH US

Website
www.sickcells.org

Email
Engage@sickcells.org

SUPPORT SICK CELLS

With your gift, Sick Cells can continue to provide impactful programming and continue elevating the voices of the SCD Community. All funds received directly support our mission and the work needed to advance it.

sickcells.org/donate