

2024 SICKLE CELL DISEASE POLICY FORUM

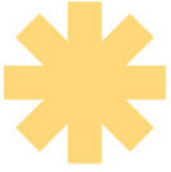


MARCH 19 - 20

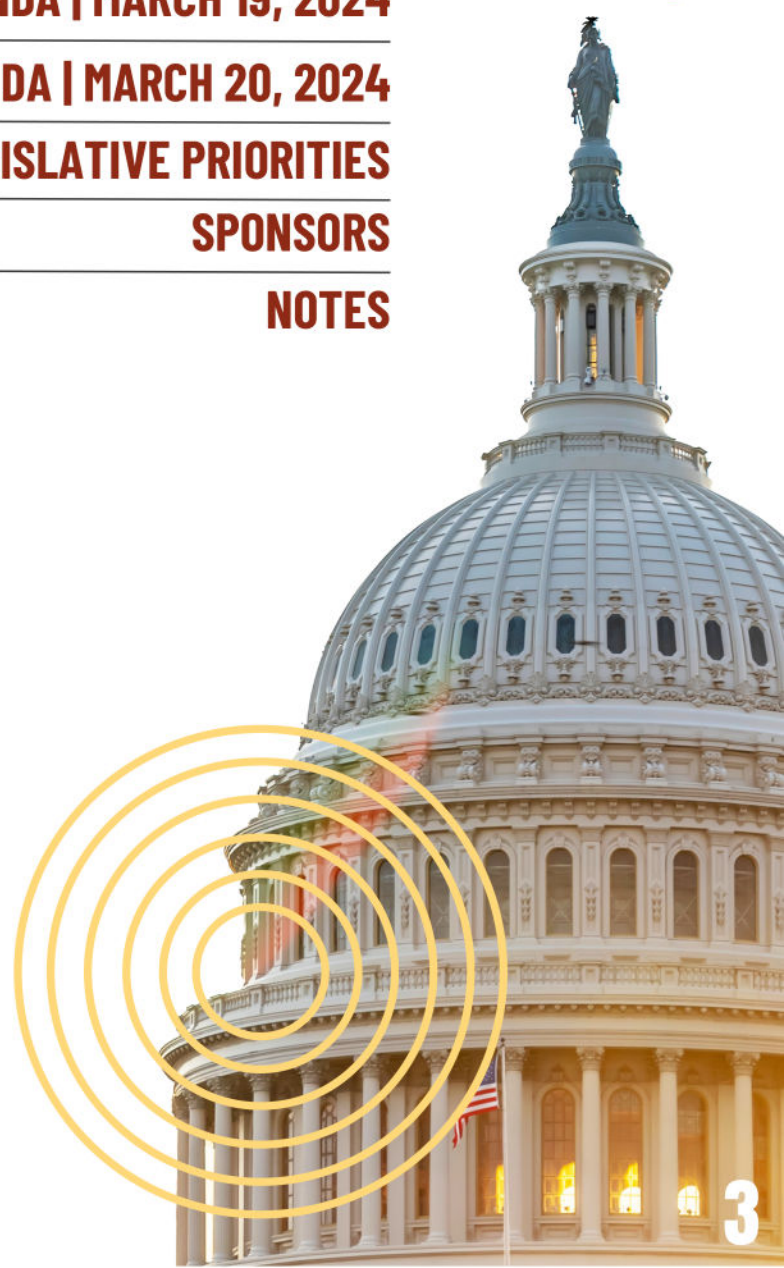




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A LETTER FROM OUR LEADERS



Dear Advocates,

On behalf of Sick Cells and the Sickle Cell Community Consortium, we are thrilled to welcome you to the 2024 SCD Policy Forum on March 19 and 20, 2024. **We believe that when our community is united and focused, we can achieve real change.**

It is essential for our community to be informed and equipped with the necessary tools to translate the daily experiences of sickle cell disease (SCD) Warriors and their loved ones into meaningful policy advancements. At the 2024 SCD Policy Forum, you will have the opportunity to learn about and discuss the current and future landscape of federal programs and policies for SCD. We will provide training through interactive workshops to help you feel more comfortable and prepared for the Virtual Hill Day. After a day of education and preparation, you will have the opportunity to directly engage with Members of Congress and their staff. Your presence and participation will make a difference in our efforts to bring attention to SCD on Capitol Hill and to improve the lives of those affected by sickle cell.

We are honored to have you join us for this virtual event. Thank you for your support, and we look forward to a successful event.

Sincerely,



Dr. Lakiea Bailey
Executive Director
Sickle Cell Community Consortium



Ashley Valentine, MRes
Co-Founder & President
Sick Cells





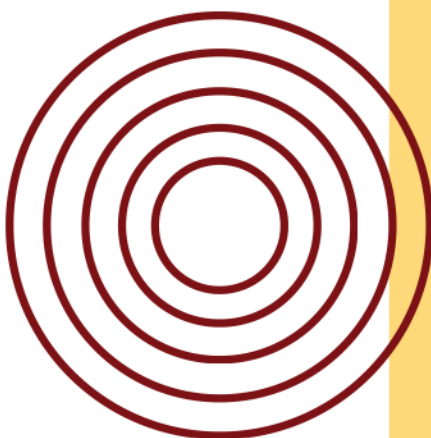
Sick Cells is a national sickle cell disease (SCD) advocacy nonprofit founded February 28, 2017. Sick Cells' mission is to elevate the voices of the SCD community and their stories of resilience. In highlighting the grave disparities this community faces, we hope to influence decision-makers and propel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

sickcells.org
 instagram.com/sickcells
 twitter.com/SickCells
 facebook.com/sickcells
 linkedin.com/company/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.

sicklecellconsortium.org
 instagram.com/sccconsortium
 facebook.com/SCCConsortium
 twitter.com/SCCConsortium



WE ARE WHO WE ARE



HERE'S

HOW *

TO

*** GET**

INVOLVED

PROGRAMS
AND EVENTS



Sickle Cell Consortium UPCOMING

EVENTS

**Check Out Our
Upcoming Events**

All dates are attentive

2024

**Apr
10-14**

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 information

**July
17-21**

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
14-17**

Caregiver Summit

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

*For more information:
www.sicklecellevents.org*



JOIN *Sick Cells'*

AMBASSADOR PROGRAM

Activate. Advocate. Educate.

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: www.sickcells.org

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.

**Learn
more &
Join Today!**



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.

Contact us at info@sickcells.org

DC Office 1012 14th St Suite 500 | Washington, DC 20005

IL Mailing 1042 Maple Ave Suite 103 | Lisle, IL 60532

DAY 1

11: 00 AM EST

KICK-OFF + WELCOME

11: 05 AM EST

KEY NOTE ADDRESS

11: 15 AM EST

FEDERAL ASK #1

Co-Sponsor Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023

11: 30 AM EST

FEDERAL ASK #2

Appropriate \$25 Million for the CDC Sickle Disease Data Collection Program

11: 45 AM EST

FEDERAL ASK #3

Appropriate \$15 Million for Programs under the HRSA Sickle Cell Disease Treatment Act

12:30 PM EST

FEDERAL ASK #4

Encourage state Medicaid Director to Participate in the Cell and Gene Therapy Access Model

12:45 PM EST

WELLNESS BREAK

1:00 PM EST

HILL DAY TRAINING

1:45 PM EST

MOCK LEGISLATOR MEETINGS

2:35 PM EST

PLATFORM DEMONSTRATION

For Hill Day

2:55 PM EST

CLOSING REMARKS

AGENDA



MARCH 19


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 FY25 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.
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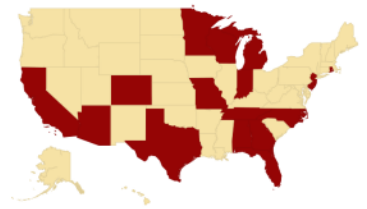
FISCAL YEAR (FY) 2025 FEDERAL REQUESTS FOR SICKLE CELL

Co-Sponsor Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023 (H.R.3884 / S.1852)

- **Authorize the appropriations of \$8.205 million** each year from 2024 through 2028 for the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) to conduct research, surveillance, prevention, and treatment of sickle cell disease and related blood disorders.
- **Reauthorize** the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (PL 115-327).
- **Continue funding** for the HRSA Demonstration Programs.

Appropriate \$25 Million for the CDC Sickle Disease Data Collection Program

- **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 currently 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, gathering information on the transition from pediatric care to adult care, gathering demographic information, and much more.
- Data collection is necessary to improve national incidence and prevalence data; better identify health disparities; and evaluate strategies to improve quality of life and lower costs associated with treating the population.



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, care coordination with other providers.
 - Develop best practices for coordination of services during pediatric to adult transition.
- **Appropriate \$7 Million to The Sickle Cell Disease Newborn Screening Follow-up Program (FP) through the Special Project of Regional And National Districts.**
 - Fund sickle cell disease activities performed by community-based organizations.
 - Provide education for people living with SCD, families, and clinicians.
 - Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care.

Encourage your state Medicaid Director to participate in the Cell and Gene Therapy (CGT) Access Model.

- The CGT Access Model will focus on treatments for people living with sickle cell disease (SCD). **Letters of Intent (LOIs) for states are due April 1, 2024.**
- The CGT Access Model aims to improve the lives of people with Medicaid by increasing access to potentially transformative treatments.
- Cell and gene therapies have high upfront costs but have the potential to reduce health care spending over time by addressing the underlying causes of disease, reducing the severity of illness, and reducing health care utilization.
- The CGT Access Model is a strategy to increase equitable solutions for individuals with SCD and their families and reduce health disparities.

SPONSORS

GOLD LEVEL



BRONZE LEVEL



SUPPORTER LEVEL

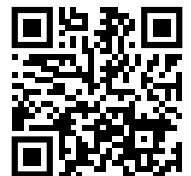


Driving the community's
mission forward.

The sickle cell community has always shown up.
We're proud to partner with inspiring people
as we work together to help improve the lives
of those impacted by sickle cell.

 **Pfizer** Breakthroughs that change patients' lives

To learn more, visit
[TogetherForRare.com](https://www.togetherforrare.com)



PP-LTV-USA-2693



I am working everyday to make sure that **I speak up about sickle cell disease as much as possible** to help people understand it.

Kevin Wake

Living with sickle cell disease



Vertex is committed to people living with sickle cell disease, and we are driven to make a difference. We know that committing to you, the sickle cell community, goes beyond our science. It's about showing up and partnering with the community to work together toward meaningful change.

Visit vrtx.com to learn more and follow us on social media.



Virtual **SICKLE**
CELL DISEASE
POLICY FORUM

