

A TRI-COLLABORATIVE EVENT



NATIONAL
SCD POLICY
FORUM
MARCH 21-22, 2023

20
23 VIRTUAL

LETTER FROM OUR LEADERS

Dear Advocates,

On behalf of the Sickle Cell Disease Association of America, Inc. (SCDAA), Sick Cells, and the Sickle Cell Community Consortium, we are thrilled to welcome you to the first-ever National SCD Policy Forum on March 21 and 22, 2023. We believe that when our community is united and focused, we can achieve real change. This year, our three organizations are combining our efforts to amplify our collective voice as we speak to our elected officials in Congress.

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 National 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 also 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; thank you for your support, and we look forward to a successful event.

Sincerely,



Dr. Lakiea Bailey
Executive Director
SC3



Regina Hartfield
CEO & President
SCDAA



Ashley Valentine
Co-Founder & President
Sick Cells

WHO WE ARE

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 through policy at all levels.



www.sickcells.org



Sickle Cell Disease Association of America, Inc.

Sickle Cell Disease Association of America, Inc. advocates for people affected by sickle cell conditions and empowers community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. The association and more than 50 member organizations support sickle cell research, public and professional health education and patient and community services.



www.sicklecelldisease.org



Sickle Cell Community Consortium

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.



www.sicklecellconsortium.org



GET INVOLVED

Sick Cells Ambassador Program

The Sick Cells Ambassadors Program is a volunteer network of individuals dedicated to changing the landscape of sickle cell disease and spreading 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).

Sick Cells Ambassadors are notified of research & speaking opportunities and important advocacy events. They also get access to monthly training webinars to help strengthen their ability to educate on and advocate for SCD. To learn more, email Program Manager Elodie Ontala at eontala@sickcells.org.

Sickle Cell Disease Association of America, Inc. Membership

Sickle Cell Disease Association of America, Inc. (SCDAA) offers membership to community-based organizations (CBOs) to join us in our efforts to provide education, increase awareness, support individuals living with sickle cell disease and sickle trait and their families, and find a universal cure for this life-threatening disease.

SCDAA has categorized our CBOs into three categories based on the services provided:

- **Direct Service Agency** – These include but are not limited to: Case management, testing and screening, counseling, and/or medical home assistance.
- **Support Service Agency** – These include but are not limited to: Medical bill assistance, transportation, career counseling/planning, medical co-pay, funeral/burial assistance, housing, clothing, food, SSI/Disability, and insurance application assistance.
- **Advocacy Service Agency** – These services include but are not limited to: Disseminating SCD/SCT information, attending health fairs, and participating in and/or host local advocacy events.

If your organization is interested in becoming an SCDAA CBO member, please email Kristen Cox, SCDAA's Member Engagement Coordinator at kc Cox@sicklecelldisease.org. To be eligible, your organization is required to be a 501(c)(3) nonprofit organization with a 990 form.

Sickle Cell Community Consortium Partners

The Sickle Cell Consortium is comprised of sickle cell community-based organizations, patient and caregiver advocates, community partners, as well as medical research advisers. Together, they collectively identify the problems, needs, and gaps in the sickle cell community while developing creative, collaborative solutions to these problems.

Partners of the Consortium receive benefits such as training for capacity building and professional development, resources such as microgrants, emergency services, and much more. There are various partner types, ranging from interested individuals to registered nonprofits and for-profit organizations.

For more information on partnering with the Consortium and all the benefits, please contact Dominique Goodson at dgoodson@sicklecellconsortium.org.

DAY 1

AGENDA | MARCH 21, 2023

11:00-11:10am ET

Kick-Off & Welcome

11:10-11:20am ET

Keynote Address

Andy Lord, Sick Cell Foundation of Georgia

11:20-12:20pm ET

Panel: "Policy Efforts to Promote Comprehensive Care for SCD"

Dr. Andrew Campbell, Children's National

Dr. Titilope Fasipe, Texas Children's

Gina Glass, Dreamsickle Kids Foundation

Stephanie Kaplan, American Society of Hematology

This panel discussion will define a comprehensive care model for sickle cell disease (SCD) and explore the plan of action to develop SCD care centers and networks.

12:20-12:40pm ET

Guided Break

Dr. Marjorie Dejoie-Brewer, Vertex

10-minute guided meditation + 10-minute free break

12:40-2:40pm ET

Hill Day Training

Event Hosts

This session will highlight this year's federal priorities and allow attendees to practice their pitch through mock legislator meetings and regional breakout rooms in preparation for Day 2.

2:40-2:45pm ET

The Next Generation

Hear from the youngest SCD advocates on what inspires them.

2:45-3:00pm ET

Closing Remarks



ACCESS YOUR VIRTUAL HILL DAY SCHEDULE

1. 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.*
2. If you did not register for the Virtual Hill Day, you will not receive a schedule.
3. 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.
4. Once logged in, you will see a home dashboard with your confirmed meetings and times. **All times will be displayed in your local timezone.**

JOIN A MEETING WITH YOUR LEGISLATOR

1. 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 Ambassadors who will be attending the meeting with you.
2. To access the virtual meeting, **click on the green button that says "Connect to the Meeting."** This will connect you directly with the Zoom meeting link. *Most of your meetings will be hosted on Zoom.*
3. You will also have the option to **dial-in using a phone**, if you must connect this way, but we encourage all attendees to join with video on Zoom.
4. You should join all meetings **5 minutes prior to the start time.**

USING THE EVENT PLATFORM

1. On the event platform, you can review the event **toolkits and the FY24 Requests one-pager.**
2. You can read **Talking Points** that we recommend using during your pitch to the legislator.
3. During the meeting, you can use the **"Take Notes"** option as a blank notepad. These notes will not be shared.
4. 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.*
5. Each Team Lead will fill out the **"Meeting Report Form"** which will send feedback to event hosts about your meeting.



**Andy Lord | Keynote Speaker**

Andy is a lobbyist representing twelve non-profit organizations in Georgia. He began his lobbying career as the Director of Government Relations for the American Cancer Society in 2001. In 2006 he formed his own lobbying firm, Georgia Capitol Solutions, to work exclusively with non-profit organizations in Georgia. His firm specializes in state legislation for health care, education, insurance, and appropriations-related policy.

**Dr. Andrew Campbell | Panelist**

Dr. Campbell is the Director, Comprehensive Sickle Cell Disease Program at Children's National Hospital where has led their approaches to workforce diversity, health equity, and inclusion. He has lectured in and out of the U.S. on issues related to the care and healthcare system approach to patients and families dealing with the effects of SCD.

**Dr. Titilope Fasipe | Panelist**

Dr. Fasipe is the Co-Director, Sickle Cell & Thalassemia Program at Texas Children's Hospital and Assistant Professor, Department of Pediatrics, Section of Hematology-Oncology, Baylor College of Medicine. Dr. Fasipe's goals are shaped by her desire to help children facing the hardships of a blood disorder.

**Gina Glass | Panelist**

Georgene' "Gina" Glass is the founder and Executive Director of Dreamsickle Kids Foundation, Inc, the first sickle cell disease (SCD) organization in the state of Nevada, founded in 2018. Gina is the mother of two, including one SCD Warrior. Georgene' has worked extensively in state issues.

**Stephanie Kaplan | Panelist**

Stephanie Kaplan is the Deputy Director of Government Relations and Public Health at the American Society of Hematology (ASH). Stephanie leads the development of ASH's priorities, policies and programs focused on public health issues and oversees ASH's engagement with federal partners.

THE SPONSORS

This event is sponsored by the following organizations. Thank you for supporting our work.

GOLD



SILVER



SUPPORTER





EVENT RESOURCES



NATIONAL SCD POLICY FORUM

THE CARE CENTER MODEL FOR SICKLE CELL DISEASE

This is a companion toolkit to the National SCD Policy Forum Panel:
"Policy Efforts to Promote Comprehensive Care for SCD"

WHAT IS A SCD CARE CENTER?

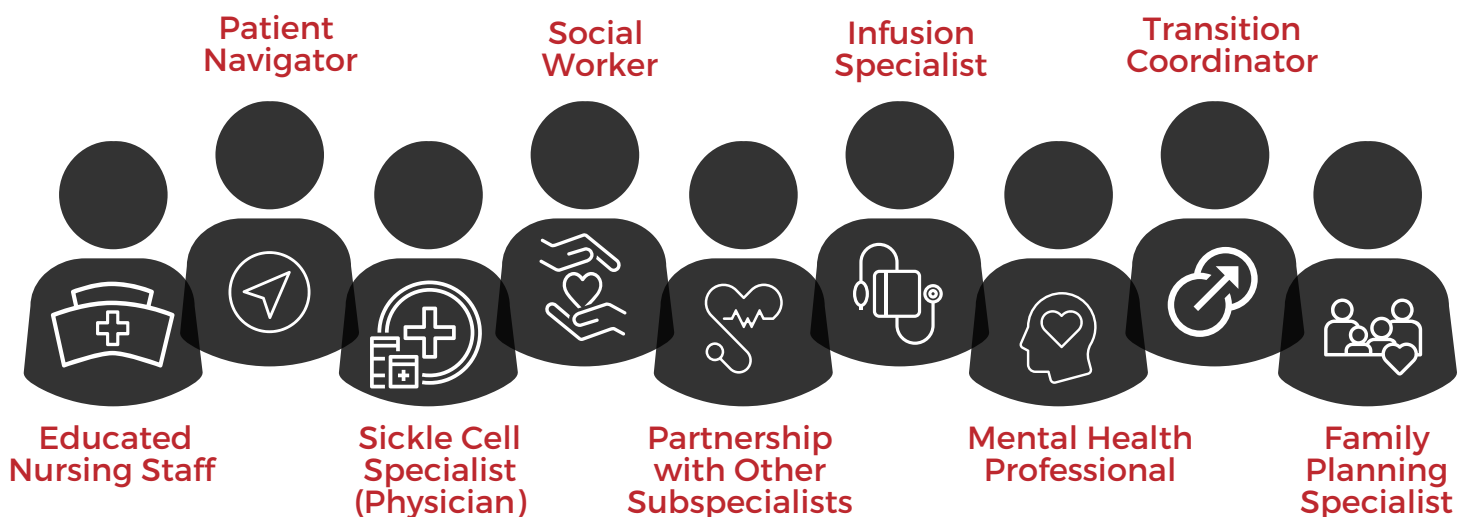
A sickle cell disease (SCD) care center provides **comprehensive, high-quality care** for individuals living with sickle cell disease. SCD centers must meet certain requirements in staffing and services.

WHAT IS THE GOAL OF SCD CARE CENTERS?

The care center model for sickle cell disease can ensure that **essential services and supports** for SCD warriors are all in one place and that everyone has **access to a sickle cell specialist** to improve quality of life and care.

WHO IS A PART OF THE CARE TEAM ?

SCD care requires a team made up of many medical disciplines. The following health care professionals are part of the SCD care team at a typical SCD care center:



LEARN MORE

The **National Alliance for Sickle Cell Centers (NASCC)** supports sickle cell disease centers by setting standards of care, promoting guideline adoption, and establishing requirements to be considered a "NASCC-recognized comprehensive Sickle Cell Center." Learn more about the NASCC and membership [here](#).

FY24

FEDERAL REQUESTS FOR SICKLE CELL

As you consider programmatic appropriations for Fiscal Year (FY) 2024, we respectfully request that you include robust funding to support and expand critical initiatives for research, surveillance, and treatment of sickle cell disease (SCD).

HRSA 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
- Improve care coordination with other providers
- Develop best practices for coordination of services during pediatric to adult transition.

Impact: Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care.

FY24 REQUEST:

\$15
MILLION

CDC SICKLE CELL DATA COLLECTION (SCDC) PROGRAM

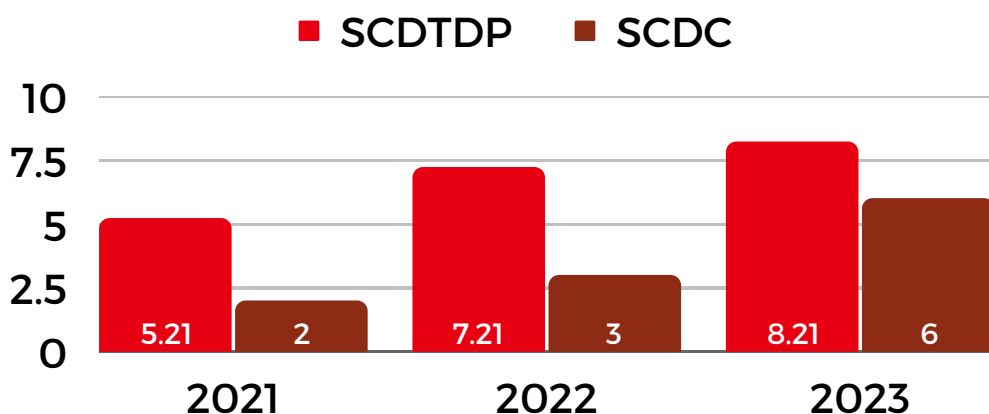
The Sickle Cell Data Collection (SCDC) program gathers health information from multiple sources to determine how many people live with the disease in a particular state.

- The SCDC currently covers 11 states 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.

Impact: 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.

FY24 REQUEST:

\$25
MILLION



RECENT APPROPRIATIONS FOR FEDERAL SCD PROGRAMS
(in millions of US Dollars)



The purpose of this guide is provide information on past support for sickle cell disease at the federal level.

PAST SUCCESSES

National Sickle Cell Anemia Control Act of 1972 (PL 92-294)

- Signed into law 5/16/1972 by President Richard Nixon
- First major legislation for SCD
- Established guidance for SCD education, screening, testing, counseling, and research
- Created the first federal programs for SCD
- **Passed & Funded**

The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (PL 115-327)

- Signed into law 12/18/2018 by President Donald Trump
- Sponsors: Senator Tim Scott (R-SC) and Senator Cory Booker (D-NJ), Congressman Danny Davis (D-IL), Congressman Michael Burgess (R-TX)
- Reauthorizes SCD prevention and treatment grants awarded by the Health Resources and Service Administration (HRSA)
- Authorizes the Centers for Disease Control and Prevention to award SCD surveillance grants to states, academic institutions and non-profit organizations
- **Passed & Funded**

PAST ATTEMPTS: DEAD BILLS

The Sickle Cell Comprehensive Care Act (H.R. 6216/S. 3389)

- Introduced in December 2021 by Representatives Davis (D-IL-7) and Burgess (R-TX-26) in the House and Senators Booker (D-NJ) and Scott (R-SC) in the Senate
- Directs the Centers for Medicare and Medicaid Services (CMS) to create a demonstration to improve access to quality care for SCD Warriors enrolled in Medicaid
- **Died in 117th Congress**

The Sickle Cell Care Expansion Act (H.R. 7177/S. 4425)

- Introduced in March 2022 by Representatives Crist (D-FL-13) and Lee (D-CA-13) in the House, and Senators Van Hollen (D-MD) and Booker (D-NJ) in the Senate (June 2022)
- Hopes to increase the number of physicians treating SCD through a loan forgiveness and scholarship program
- **Died in 117th Congress**

The Sickle Cell Disease Treatment Centers Act (H.R. 8855/S. 4866)

- Introduced in September 2022, by Senators Van Hollen (D-MD) and Booker (D-NJ) in the Senate, and Representative Lee (D-CA-13), Davis (D-IL-7) and Adams (D-NC-12) in the House.
- Establishes a hub-and-spoke model for caring for SCD Warriors and requires collaboration with SCD CBOs and nonprofits
- **Died in 117th Congress**

NO

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NO

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