# 2023 National SCD Policy Forum

# Opening & Welcome

11:00 - 11:10 am ET

**Ashley Valentine**
President & Co-Founder
Sick Cells

**Regina Hartfield**
Executive Director
Sickle Cell Disease Association of America, Inc. (SCDAA)

**Dr. Lakiea Bailey**
Executive Director
Sickle Cell Disease Community Consortium

# Today's Agenda

Scan to view the full program book:

## DAY 1 AGENDA | MARCH 21, 2023

**11:00-11:10am ET** — **Kick-Off & Welcome**

**11:10-11:20am ET** — **Keynote Address**

**Andy Lord**, Sickle 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**

# Thank you to our sponsors!

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| **Supporter Level** | editas MEDICINE; Pfizer |

# Keynote Address

11:10 - 11:20am ET

**Andy Lord**

Lobbyist, Sickle Cell Foundation of Georgia

# My Family's Experience

- Trait testing
- Newborn screening & Follow-up
- Advocating for your health & your family

# Turning Experience into Action

- Identifying **gaps**
  - What is missing in your state?
  - What efforts are currently underway?
  - Do they relate to federal efforts?
  - Can you look to another state's successes?

- Finding **Champions**
  - Connecting with legislators & staying in touch
  - Pairing your story with data & a plan

# Turning Experience into Action

- **Building** a state budget from $0
  - Establishing relationships
  - Making the request
  - Following up on the request

- **Implementing** the budget
  - Notable programs
  - Program reporting

Learn more about the Sickle Cell Foundation of Georgia at www.sicklecellga.org

# Panel Discussion

11:20am - 12:20pm ET

**Q&A**

12:05-12:20pm ET

# “Policy Efforts to Promote Comprehensive Care for Sickle Cell Disease”

| Time | Session Agenda |
|---|---|
| 10 mins | Topic Introduction & Defining Key Terms |
| 10 mins | Panel Introductions |
| 30 mins | Moderated Discussion |
| 10 mins | Questions from the Audience |

# Session Overview

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

This session will discuss:

1. What components of comprehensive care are needed to deliver quality care to individuals and families living with SCD?
2. What are SCD care centers, and how are the criteria determined?
3. What actions are needed at local, state, and federal levels to overcome barriers to establishing SCD care centers?
4. What strategies are clinics and policymakers using to address provider shortages in SCD?

# Definitions

Let’s start with defining key terms for the discussion…

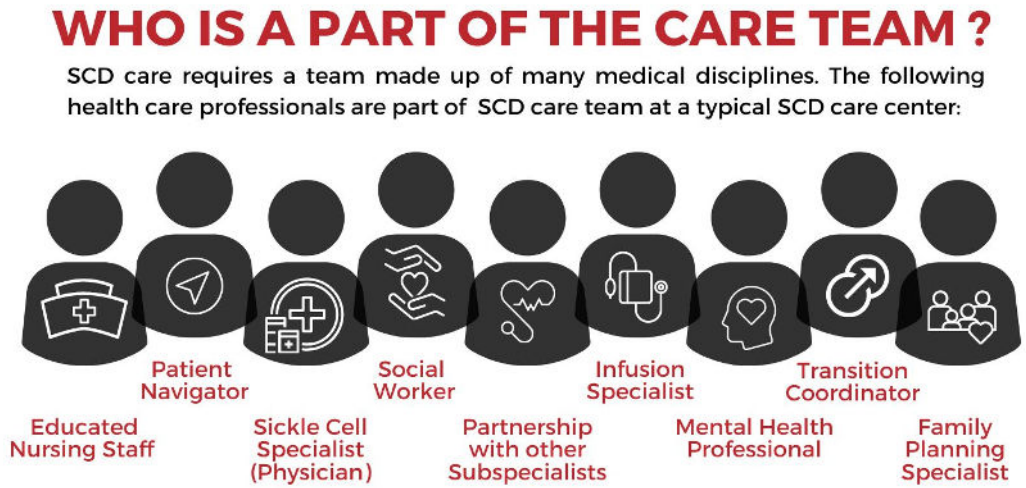
**Elodie Ontala**

Program Manager

Sick Cells

# What is Comprehensive Care for SCD?

Comprehensive care is **an approach that cares for the whole patient and all their needs.** Many professionals work together to co-manage a patient and ensure that **essential & support services** for SCD warriors are easily accessible.



# What is a Sickle Cell Specialist?

A **sickle cell specialist** is someone who is:

- knowledgeable of the **evidence-based guidelines** for SCD
- **trained in hydroxyurea** management and transfusions
- **trained on screening** for organ damage in SCD
- **aware of psychosocial** and cognitive issues in SCD
- **experienced working** with SCD patients
- trained **in pain management** and on SCD emergencies
- **attends SCD conferences** regularly
- **mentored by an SCD specialist**
- **continuing medical education** on SCD every 2 years

*Nine criteria defined by the NHLBI's SCD Implementation Consortium.

# What is a SCD care center?

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

- Specialized care centers are sometimes referred as "*centers of excellence*," however currently there is no established criteria to be called a centers of excellence for SCD.

The **National Alliance for Sickle Cell Centers** (NASCC) supports sickle cell disease centers by setting standards of care, promoting guideline adoption, and **recognizes SCD centers have the essential components** needed to provide full spectrum disease care in their respective geographic regions.

National Alliance of Sickle Cell Centers

NASCC

# How are clinical practice guidelines used in SCD care centers?

One of the benefits of a care center model is to **improve and standardize patient care** and **promote the adoption of treatment guidelines** that reflect the newest evidence.

The American Society of Hematology (ASH) and other national organizations work together to set guidelines and standards to define quality care for SCD. With these guidelines, accredited centers can then provide a standard of care for SCD.

ASH CLINICAL PRACTICE GUIDELINES
SICKLE CELL DISEASE (SCD)

# What are examples of comprehensive specialty care networks?

- Chronic genetic diseases such as **cystic fibrosis** and **hemophilia** have networks of comprehensive specialty care:
  - **130+ Cystic Fibrosis** Foundation-accredited care centers offer comprehensive, high-quality specialized care for cystic fibrosis.
  - **~141 federally-funded Hemophilia Treatment Centers (HTCs)** specialize in treating people with hemophilia across the country.

Although the population with SCD in the United States is over **double** that of hemophilia and triple that of cystic fibrosis, there is **no equivalent** system of care for SCD.

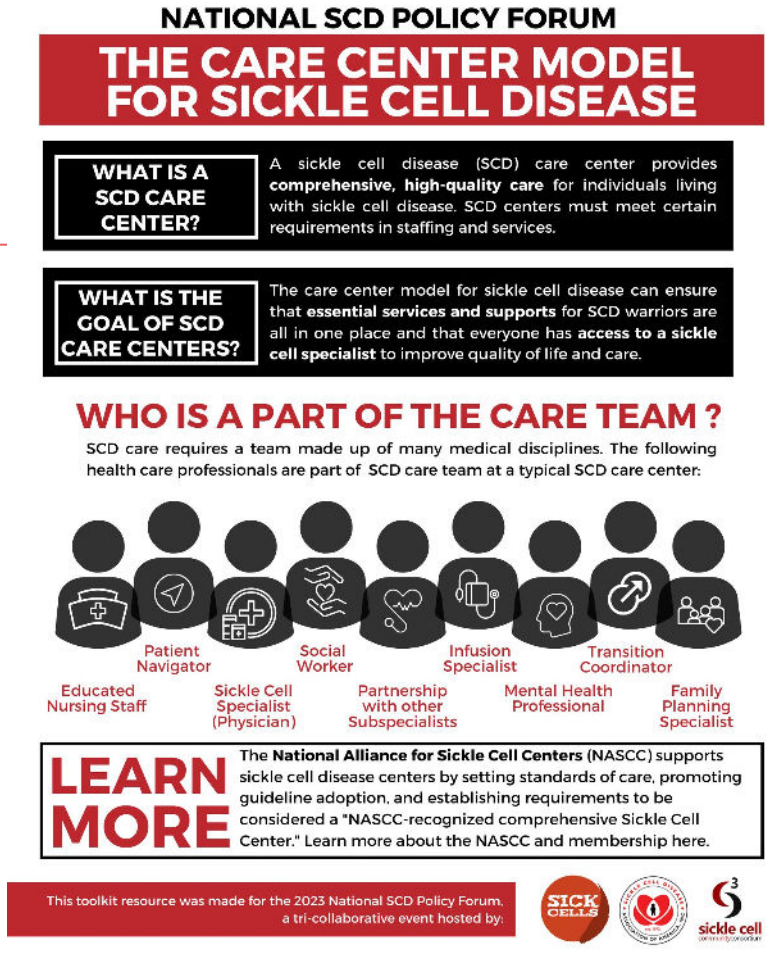
# What are current barriers to establishing SCD care centers?

Various barriers have been identified, including:

- The **underinvestment in federal funding** and attention has created challenges in establishing a network of SCD care centers.
- **SCD specialists** and providers specializing in nonmalignant hematology for adults **are rare**
- While most US urban areas have SCD pediatric **comprehensive care centers**, comprehensive care centers for adults living with sickle cell disease **are limited**
- Upon transitioning out of pediatric care, **adults encounter a lack of providers** knowledgeable in SCD and a fragmented healthcare system

# Program Book Resource

You can access The Comprehensive Care Model **toolkit** in your program books located on the event platform



# Panel Introductions

## SESSION SPONSOR

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**Christina Hartman | Moderator**

Christina Hartman is the Senior Director, Government Affairs & Alliance Development at bluebird bio. Christina is an external affairs professional with deep background in policy, government relations, alliance building and issue advocacy.

**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.

# Panel Introductions

Christina Hartman

Comprehensive Care at

bluebird bio

# Panel Introductions

Dr. Andrew Campbell

Comprehensive Care at
Children's National

Children's National

# Panel Introductions

Dr. Titilope Fasipe

Comprehensive Care at
Texas Children's

Texas Children's Hospital

# Panel Introductions

Gina Glass

Comprehensive Care at
Dreamsickle Kids

# Panel Introductions

Stephanie Kaplan

Comprehensive Care at

American Society of Hematology

# Q1

What **components** of comprehensive care are needed to **deliver quality care** to individuals and families living with SCD?

What kind of **expertise and roles** must the comprehensive care team represent?

# Q2

What are the **essential next steps** in establishing a national network of SCD centers to **provide comprehensive** and community-based care for all SCD warriors?

# Q&A

Please submit your questions for the panel using the “Comments & Questions” function on your screen

# 10-minute Guided Break

**Dr. Marjorie Dejoie-Brewer**

Medical Director & Strategist,
Global Medical Affairs

Vertex Pharmaceuticals

# 10-min Free Break

We will resume at 12:40pm ET

*(11:40am CT)*

*(9:40 am PT)*

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# Hill Day Training

12:40-1:10pm ET

**John Otsuki**

Government Relations Manager

SCDAA

**Emma Andelson**

Senior Program Manager

Sick Cells

| Time | Session Agenda |
| --- | --- |
| 30 mins | Federal Priorities Training |
| 20 mins | Meeting Platform Training |
| 20 mins | Mock Meetings |
| 50 mins | Breakout Room Practice Session |

# Key Terms

**Legislator** is someone who makes laws.

- Other names include member of Congress, a policymaker, or a lawmaker.

The primary function of **Congress** is to create and modify legislation.

- Legislation is introduced as bills.
- If approved, it becomes a law.

**Legislative staff** (or staffers) are staff hired by legislative offices to conduct research, draft legislation, give advice, and make recommendations.

A **constituent** is someone who lives in a particular constituency, especially someone who is able to vote in an election.

# U.S. Government 101

## The Senate

- **“Senators”**
- 100 members with two Senators per state
- 6-year terms
- Represent their entire state (two senators per state)

## The House of Representatives

- “**Representatives**,” “Congressmen,” Congresswomen” or ”Members of Congress”
- 435 members with varying members per state
- 2-year terms
- Represent a congressional district (number of districts differ in each state)

# NEW: Legislative Request

The **Sickle Cell Disease Comprehensive Care Act** will be re-introduced today.

**Sponsors:** Representatives Danny Davis (D-IL) and Michael Burgess (R-TX) and Senators Cory Booker (D-NJ) and Tim Scott (R-SC)

- Establishes a demonstration program through the Centers for Medicare and Medicaid services (CMS) to improve access to quality care for SCD Warriors enrolled in Medicaid.
- Identical to the version introduced in December of 2021.

# NEW: Legislative Request

The **Sickle Cell Disease Comprehensive Care Act** directs CMS to create a demonstration program in up to 10 states to improve access to comprehensive, high-quality, outpatient care for SCD Warriors enrolled in Medicaid.

- Improve patient access to clinical, mental health, and ancillary and support services
- Promote coordination through multidisciplinary teams
- Provide support to community-based organizations, community health centers, hospitals, and academic health centers
- Develop infrastructure to recruit providers and provide specialized training
- **Appropriations: $25M (planning grants) & $50M (CMS)**

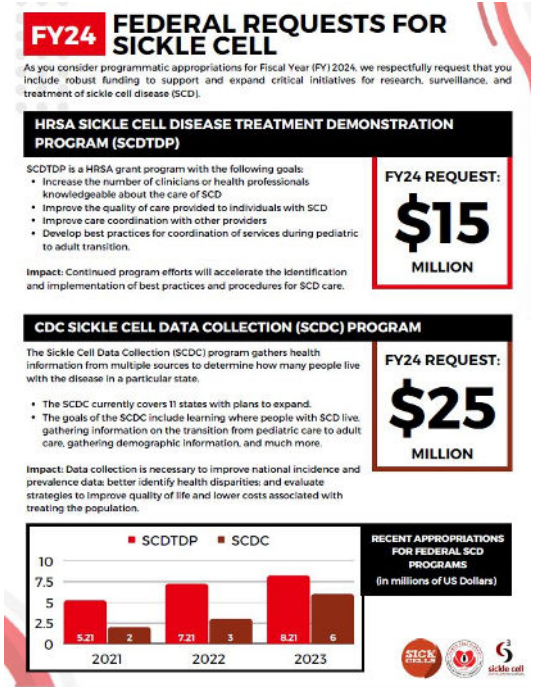
# This Year's Asks

All asks this year will be referred to as **FY24 asks**, because they are for the federal government's NEXT fiscal year.

- Appropriate **$25M** for the **CDC Data Collection Program**

- Appropriate **$15M** for the **HRSA Demonstration Program**

# 2023 (FY24) “Leave Behind”



**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**

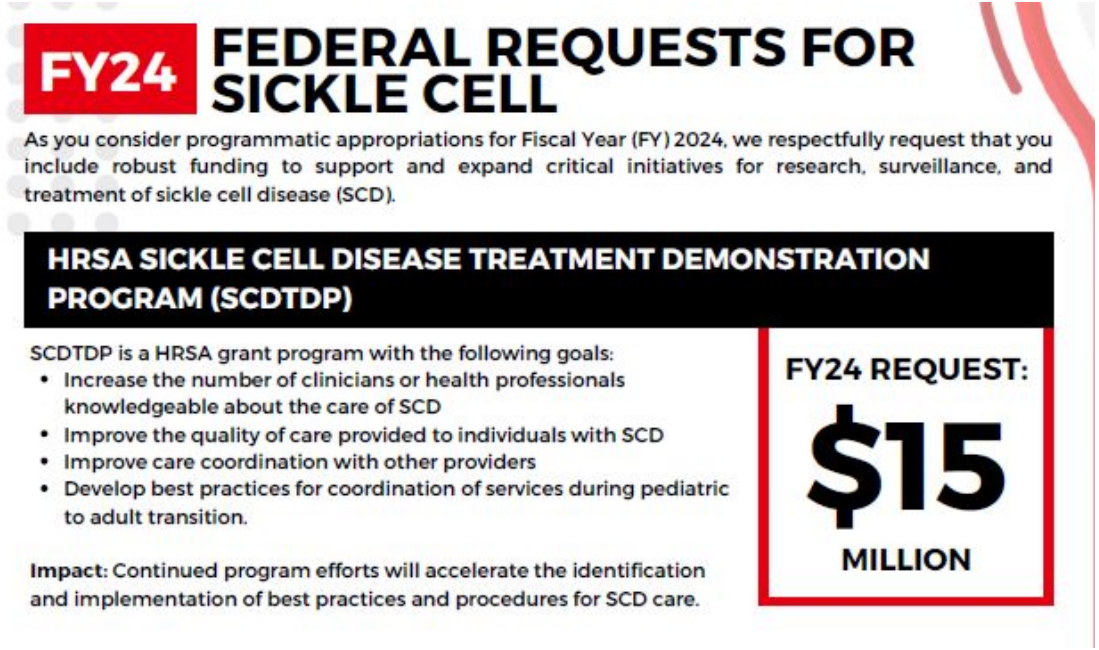


**RECENT APPROPRIATIONS FOR FEDERAL SCD PROGRAMS (in millions of US Dollars)**

**FY24 Federal Requests Leave-Behind**

*Walk through*

# FY24 Leave-Behind (Pt 1)



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**FY24 REQUEST:**

**$15**

**MILLION**

**HRSA =**
Health Resources & Services Administration

**SCD =**
Sickle cell disease

**TDP =**
Treatment demonstration program

# FY24 Leave-Behind (Pt 1)

## CDC SICKLE CELL DATA COLLECTION (SCDC) PROGRAM

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**FY24 REQUEST:**

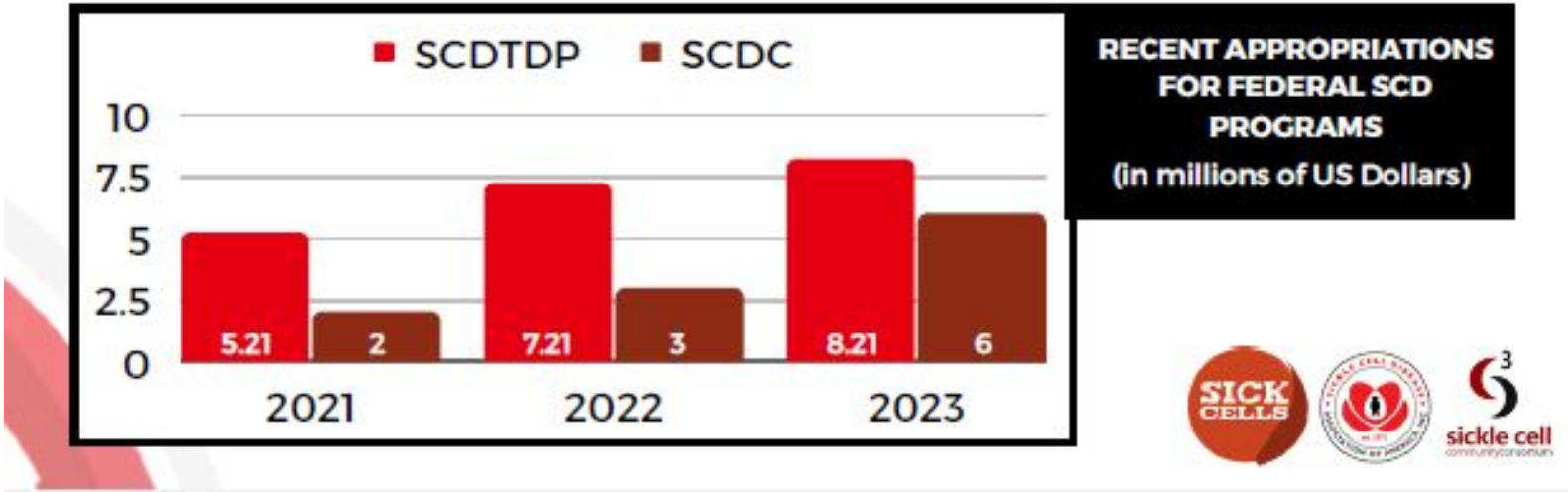
**$25**

**MILLION**

**CDC =** Centers for Disease Control & Prevention

**SCDC =** Sickle Cell Data Collection

# FY24 Leave-Behind (Pt 1)

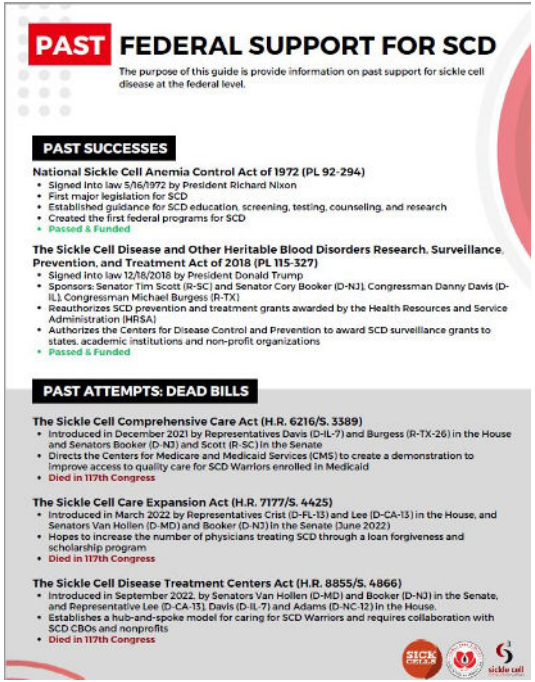



Funding has increased since 2021, but needed levels of funding have not been met.

# 2023 (FY24) “Leave Behind”

**FY24 Federal Requests Leave-Behind**

*Page 2*



**PAST** FEDERAL SUPPORT FOR SCD

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
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# FY24 Leave-Behind (Pt 2)

**PAST** **FEDERAL SUPPORT FOR SCD**

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- Authorizes the Centers for Disease Control and Prevention to award SCD surveillance grants to states, academic institutions and non-profit organizations
- **Passed & Funded**

This section highlights two important sickle cell-specific bills that were passed & funded at the federal level.

# Past Legislation

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

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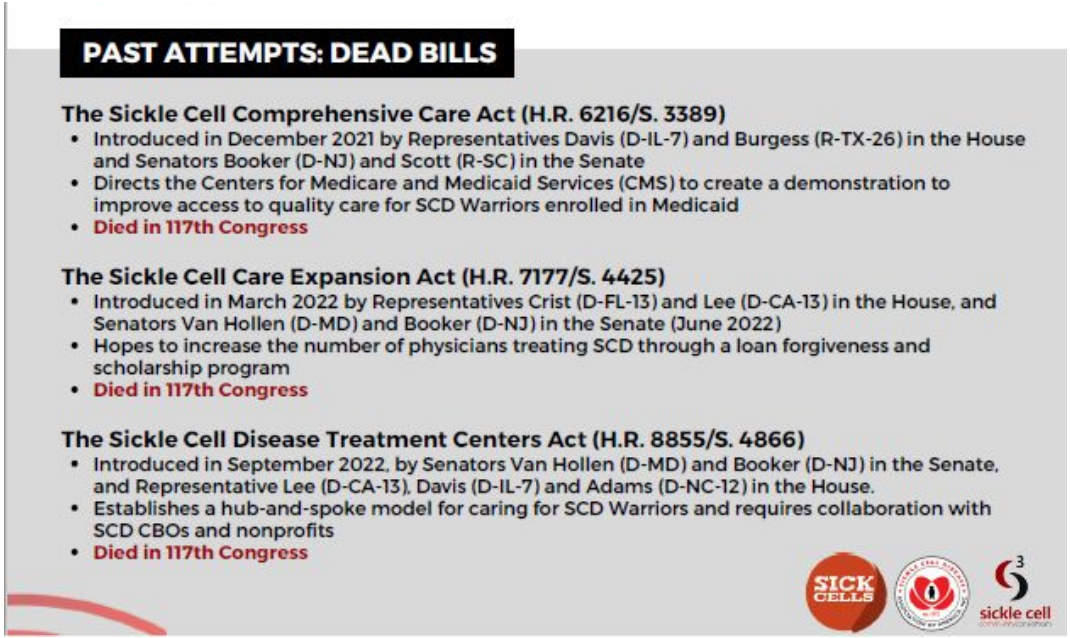
**Passed & Funded**

# FY24 Leave-Behind (Pt 2)




This section highlights three important sickle cell-specific bills that were introduced in the 117th Congress (last year) but died in Congress.

If a bill dies, it means it was not enacted during the term is was introduced. Bills can be re-introduced in the next session.

# Past Legislation

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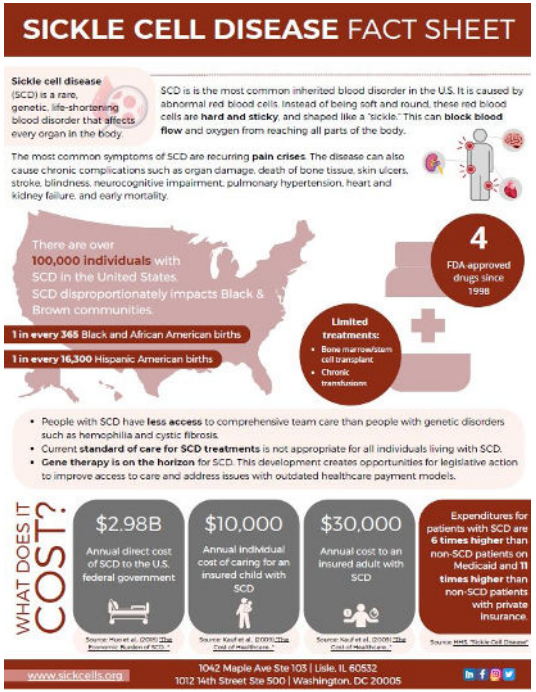
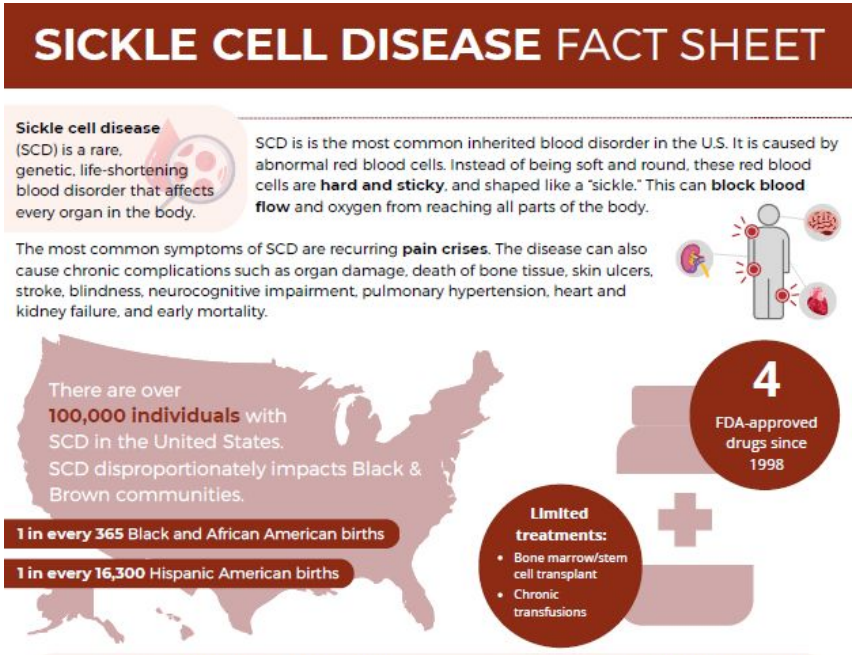
# 2023 (FY24) “Leave Behind”

**Sickle Cell Disease Fact Sheet**

*Page 3*



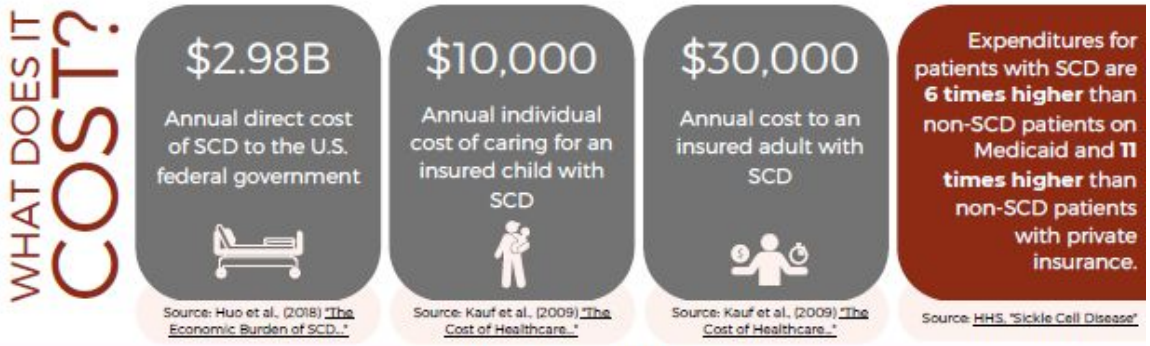
# FY24 Leave-Behind (Pt 3)




This section provides a basic description of SCD and notable facts about prevalence and treatments.

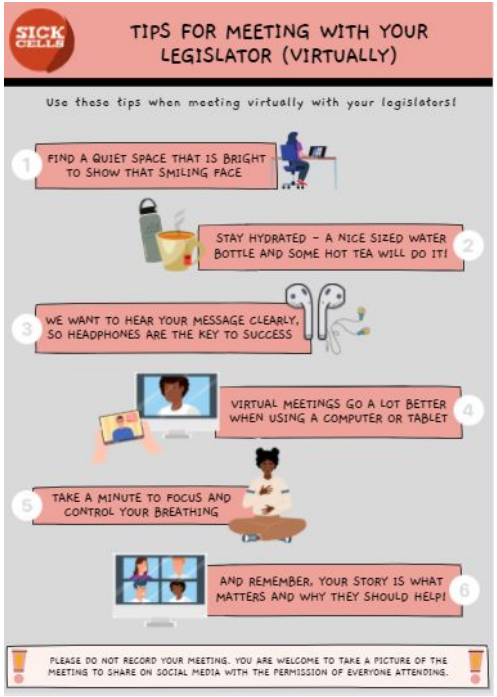
# FY24 Leave-Behind (Pt 3)

- People with SCD have **less access** to comprehensive team care than people with genetic disorders such as hemophilia and cystic fibrosis.
- Current **standard of care for SCD treatments** is not appropriate for all individuals living with SCD.
- **Gene therapy is on the horizon** for SCD. This development creates opportunities for legislative action to improve access to care and address issues with outdated healthcare payment models.




This section highlights a few more facts and the cost of SCD.

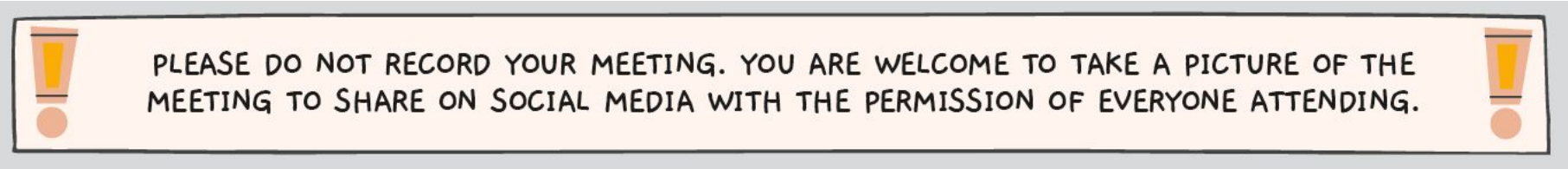
# Support Materials



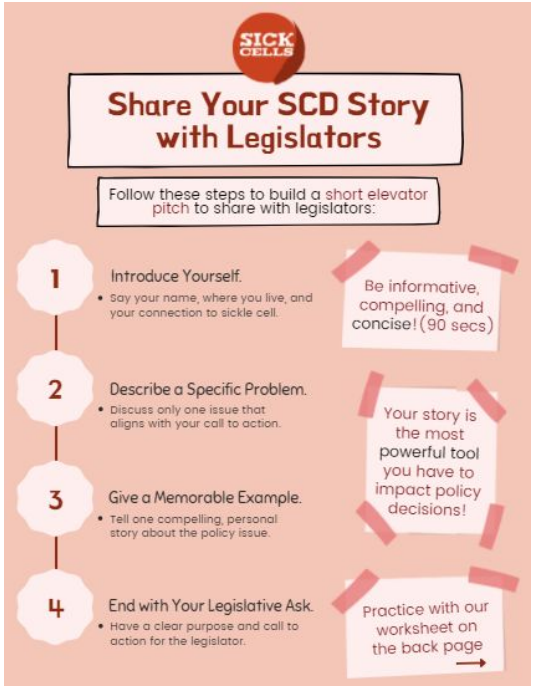

Tips for virtual meetings:

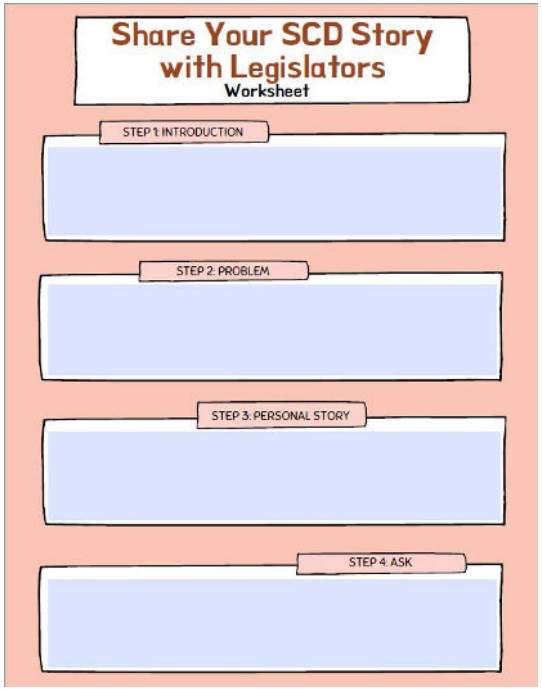
- Audio
- Video
- Centering yourself

# Support Materials



# Support Materials




This is a guide to use to craft your story.

Follow these steps and you'll have what you need for Hill Day!

# Q&A

Are there any questions about this year's asks?

# Hill Day Platform

1:10-1:30pm ET

What you'll use on Day 2 (Virtual Hill Day)

*Relevant to those who signed up for Day 2*

# Logging In

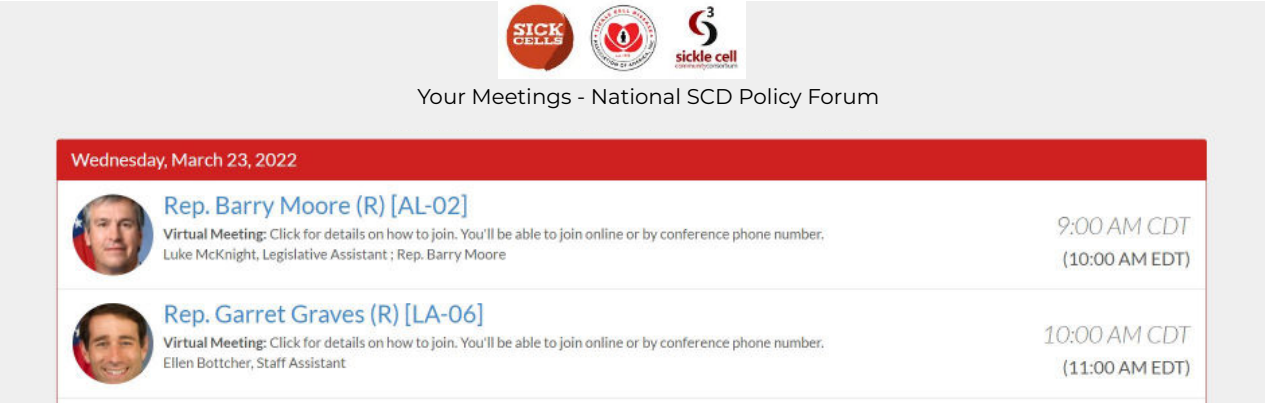
Everybody who registered for Hill Day meetings received an email from “Advocacy Day” (advocacyday@advocacyassociates.com) on Tuesday, March 14 at noon ET

To access your schedule, go to sc.constituentvoice.net

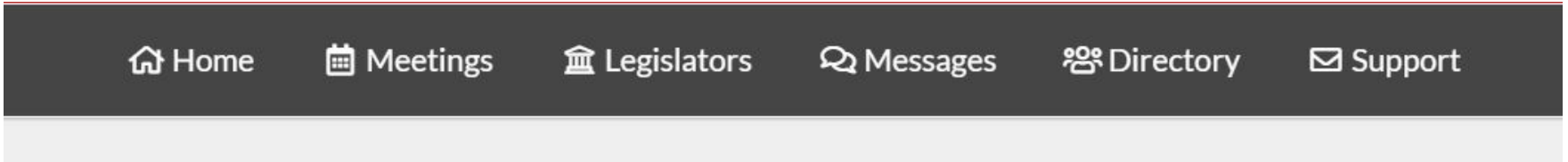
# Logging In

Go to [sc.constituentvoice.net](sc.constituentvoice.net)

- Username: The email you used to sign up
- Password: The password you chose

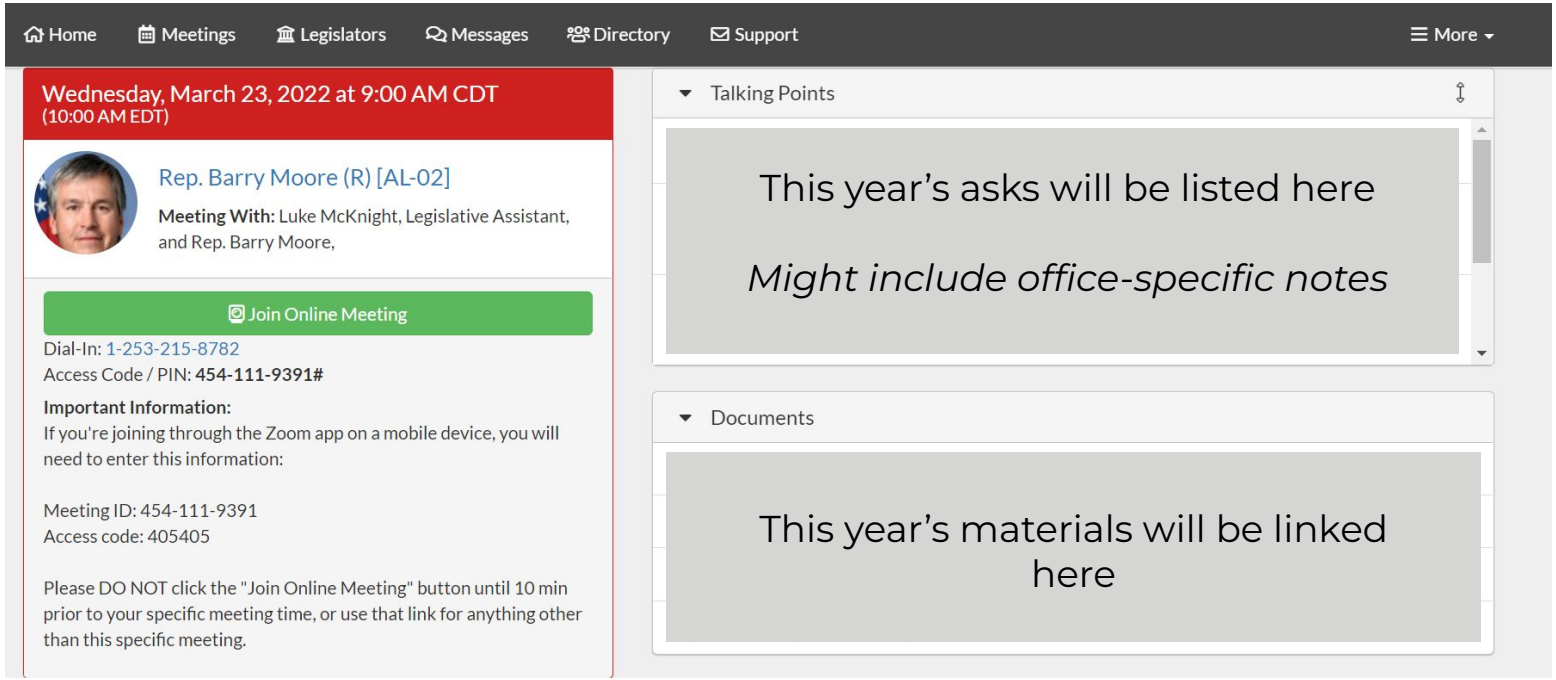


# Inside the Platform

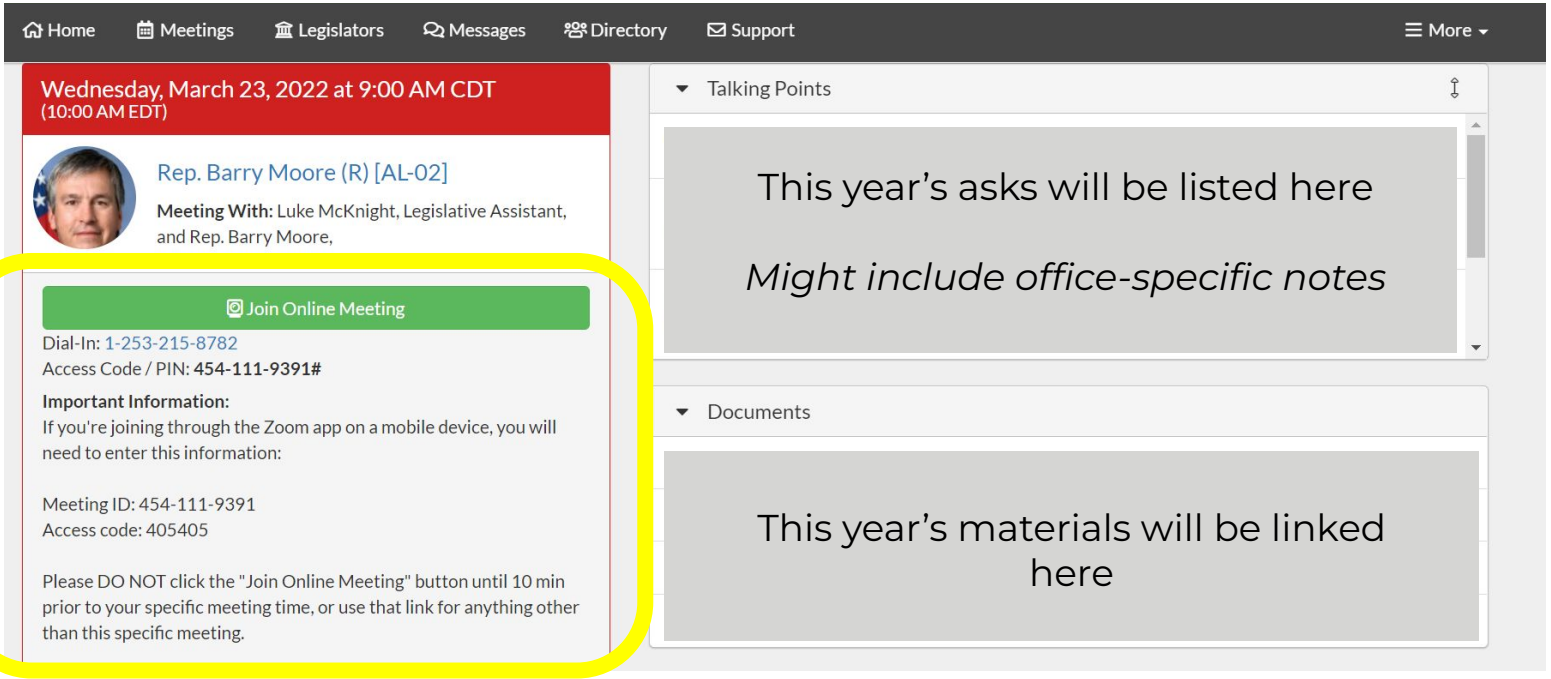



- **Home**: shows your full schedule
- **Meetings**: shows your full schedule (same screen as “Home”)
- **Legislators**: Gives you background information on all the offices/legislators you’re meeting with
- **Messages**: You’ll see relevant notices here
- **Directory**: Allows you to send messages to other advocates signed up for Hill Day
- **Support**: Technical support from Advocacy Associates - NOT from event staff

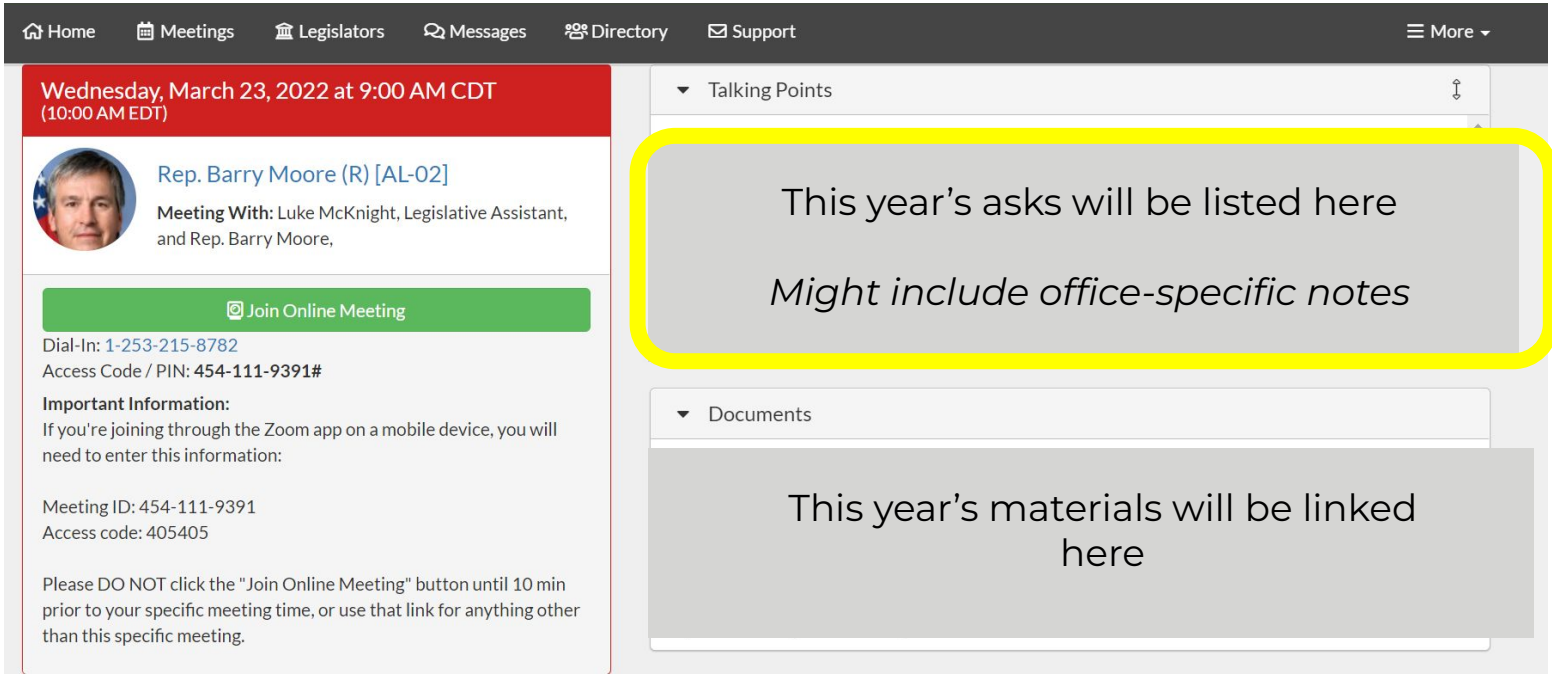
# Your Meetings



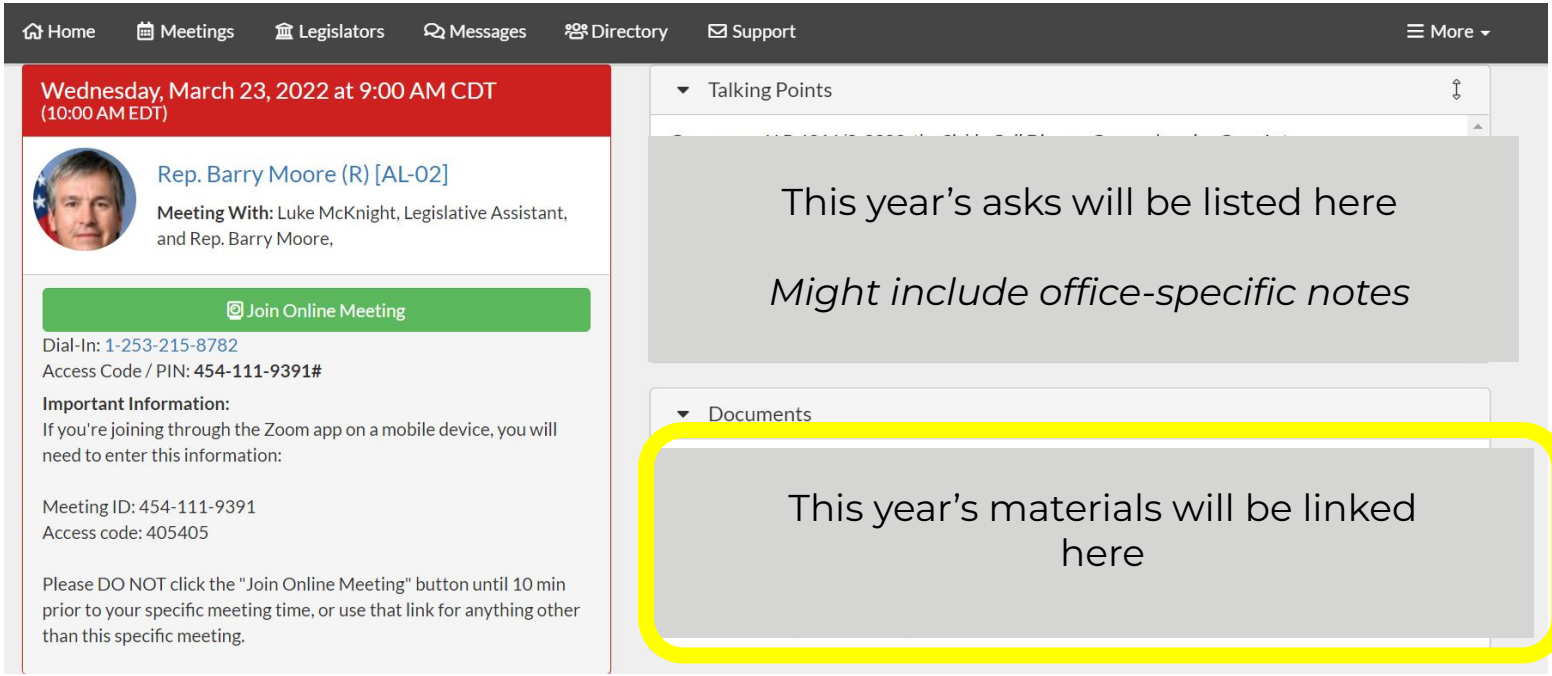
# Zoom Info


Home
Meetings
Legislators
Messages
Directory
Support
More
Wednesday, March 23, 2022 at 9:00 AM CDT
(10:00 AM EDT)
Rep. Barry Moore (R) [AL-02]
Meeting With: Luke McKnight, Legislative Assistant, and Rep. Barry Moore,
Join Online Meeting
Dial-In: 1-253-215-8782
Access Code / PIN: 454-111-9391#
Important Information:
If you're joining through the Zoom app on a mobile device, you will need to enter this information:
Meeting ID: 454-111-9391
Access code: 405405
Please DO NOT click the "Join Online Meeting" button until 10 min prior to your specific meeting time, or use that link for anything other than this specific meeting.
Talking Points
This year's asks will be listed here
Might include office-specific notes
Documents
This year's materials will be linked here

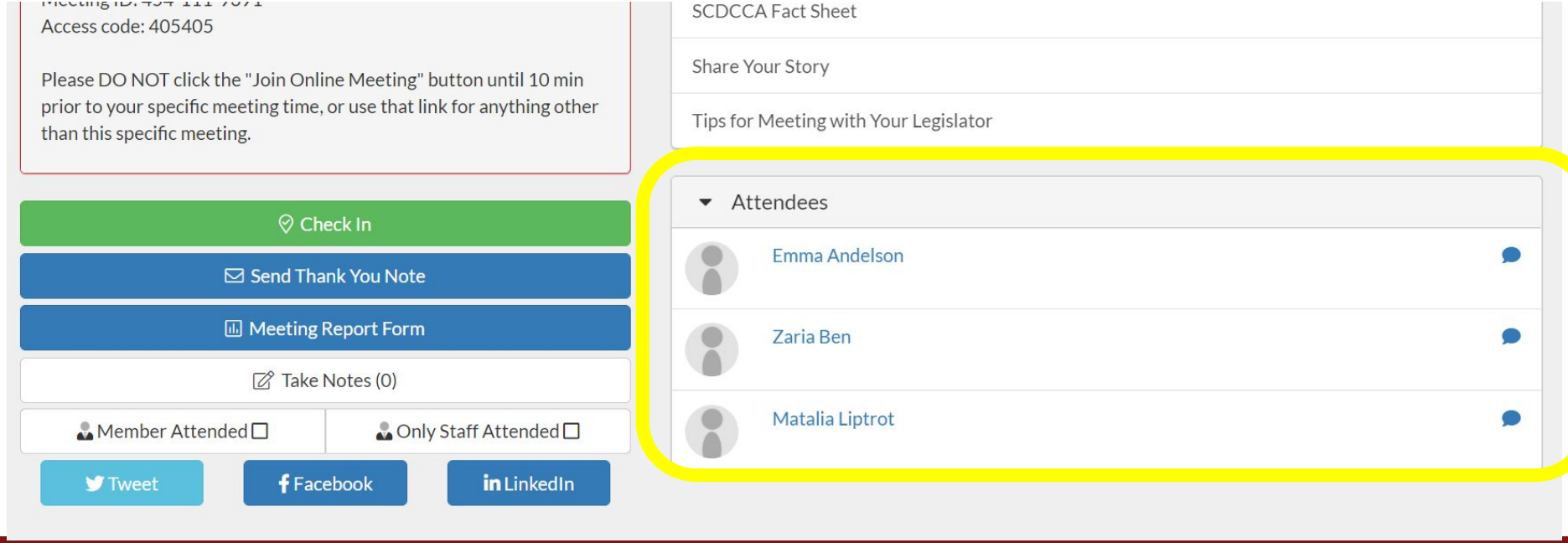
# Your Talking Points



# Meeting Documents



# Your Meeting Buddies



# Post-Meeting Actions

Copy & Paste our pre-written Thank You Note | Answer questions about how your meeting went

Access code: 405405

Please DO NOT click the "Join Online Meeting" button until 10 min prior to your specific meeting time, or use that link for anything other than this specific meeting.

Check In

Send Thank You Note

Meeting Report Form

Take Notes (0)

Member Attended ☐ | Only Staff Attended ☐

Tweet | Facebook | LinkedIn

SCDCCA Fact Sheet

Share Your Story

Tips for Meeting with Your Legislator

Attendees

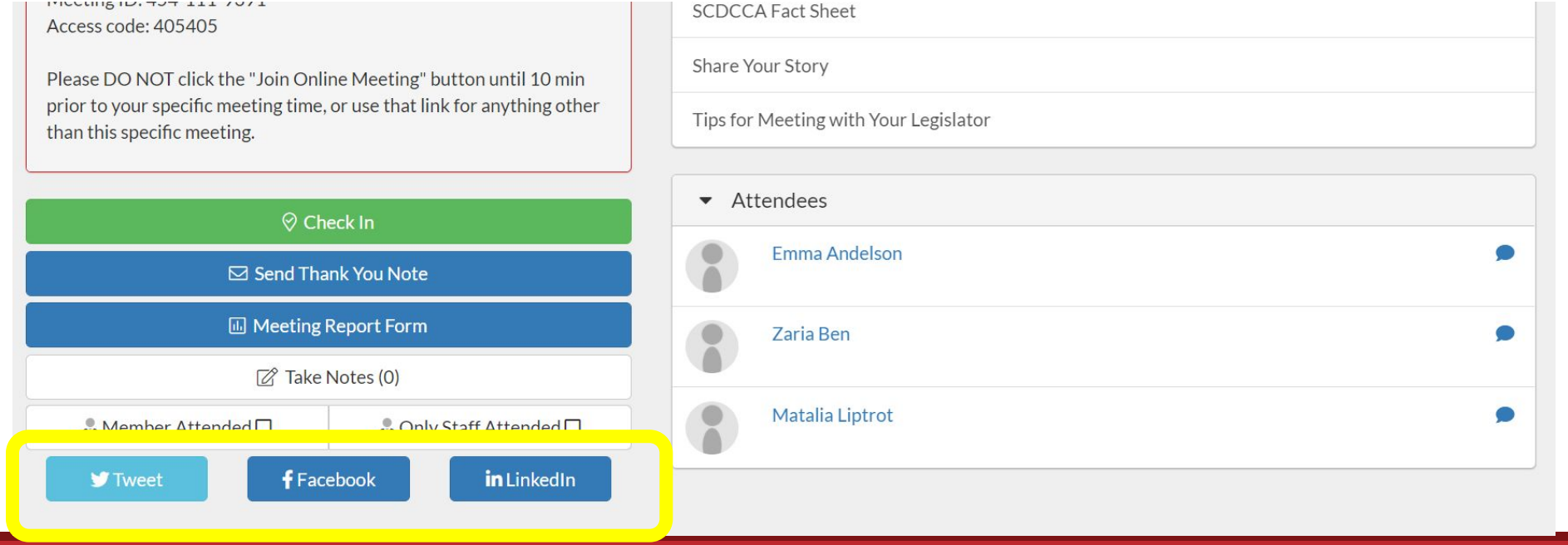
Emma Andelson

Zaria Ben

Matalia Liptrot

# Share on Socials

Copy & Paste our pre-written socials posts



# Questions on Hill Day

If you have **technical questions** (i.e. your portal has a bug, the platform isn't working, the staffer did not show) you can reach out to Advocacy Associates for immediate assistance:

- request "support" through the web portal
- Call their support staff directly: (301) 388-8107

If you have **questions about the Hill Day** (i.e. talking points, medical emergencies), please let event staff know by emailing

- Maggie Jalowsky: mjalowsky@sickcells.org
- Abby Tainter: atainter@sickcells.org
- Arielle Krahenbuhl: akrahenbuhl@sickcells.org

# Q&A

Are there any questions about the Hill Day meeting platform or viewing your schedule?

# Mock Meetings

1:30-1:50pm ET

Let’s Practice!

# Team Leads

Team Leads are in charge of **coordinating speaking roles** during their Hill meetings. They are in charge of:

- Managing their meetings
- Reporting meeting details to event staff
- Taking screenshots
- Engaging on social media with offices
- Following the Team Lead doc →

# Reminders for Meetings

- Do not repeat negatives
- Bridge to key messages (this year's asks)
- Stay confident
- Be clear
- It's okay to say "I don't know"

# Reminders for Meetings

## SIGNAL PHRASES TO HELP REDIRECT

When you're working with the media, you might encounter situations you don't feel prepared for. Here are some tips to help you maintain control of your story in any situation.

- "That's one view, but your readers would probably be interested to know that..."
- "I think what you're trying to say is..."
- "I don't think I have that information, but let me tell you who does..."
- "I'm not sure I'm the right person to answer that, but you could ask..."

**SIGNAL PHRASES CAN STOP THE CONVERSATION, REFRAME IT, AND BRING IT BACK TO WHERE YOU WANT SO YOU STAY IN CONTROL.**

# Meeting 1

Team Lead

Attendee

Legislator/Staffer

# Meeting 2

Team Lead

Attendee

Legislator/Staffer

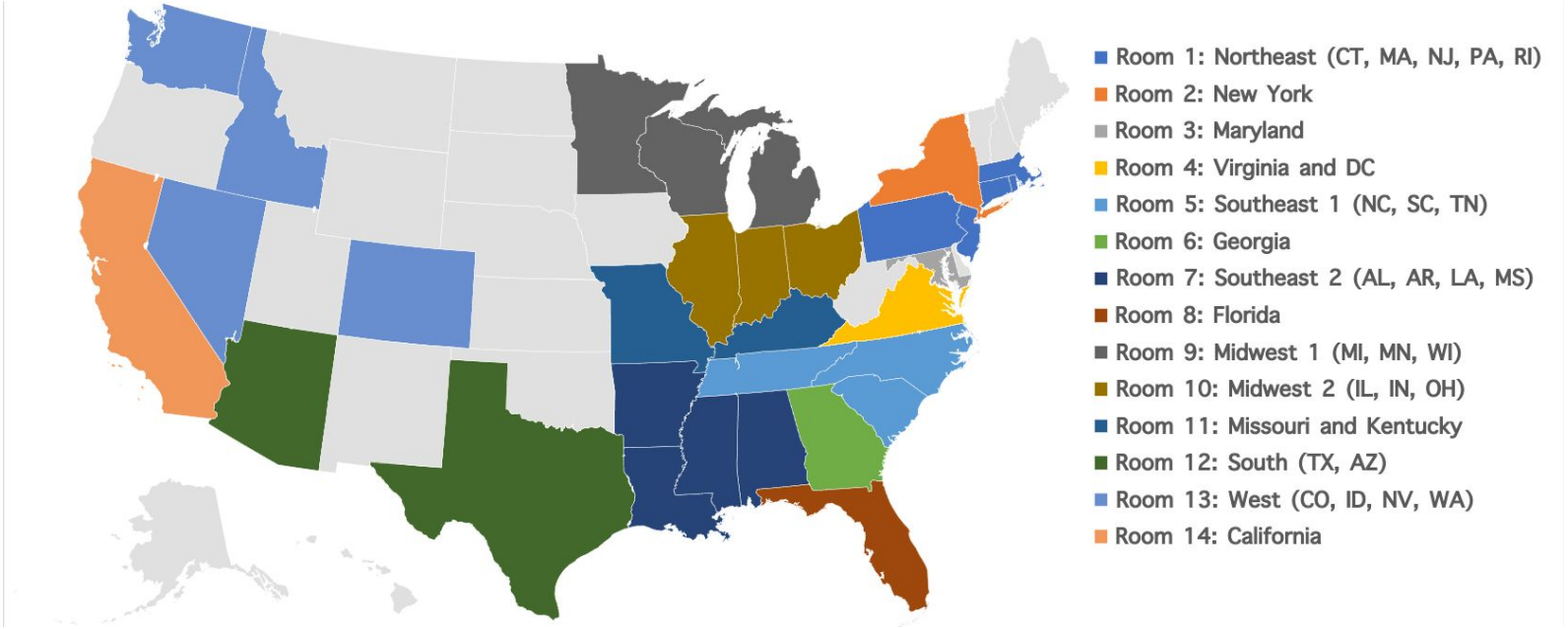
# Breakout Rooms!

1:50-2:40pm ET

Connect with your state team by heading to the “Session” relevant to you.

# Session Breakouts

There are **14 breakout rooms**, according to your state or geographic region:



# Session Breakouts

**5 states** will meet as independent breakout rooms:

- **New York (Room 2)**
- **Maryland (Room 3)**
- **Georgia (Room 6)**
- **Florida (Room 8)**
- **California (Room 14)**

# Session Breakouts

**9 regions** will meet in combination with other states:

- **Northeast (Room 1)**
  - Connecticut
  - Massachusetts
  - New Jersey
  - Pennsylvania
  - Rhode Island
- **Virginia & DC (Room 4)**
  - Virginia
  - District of Columbia
- **Southeast 1 (Room 5)**
  - North Carolina
  - South Carolina
  - Tennessee
- **Southeast 2 (Room 7)**
  - Alabama
  - Arkansas
  - Louisiana
  - Mississippi
- **Midwest 1 (Room 9)**
  - Michigan
  - Minnesota
  - Wisconsin
- **Midwest 2 (Room 10)**
  - Illinois
  - Indiana
  - Ohio
- **Missouri & Kentucky (Room 11)**
  - Missouri
  - Kentucky
- **Texas & Arizona (Room 12)**
  - Texas
  - Arizona
- **West (Room 13)**
  - Colorado
  - Idaho
  - Nevada

# Session Breakouts

Breakout **Goals**:

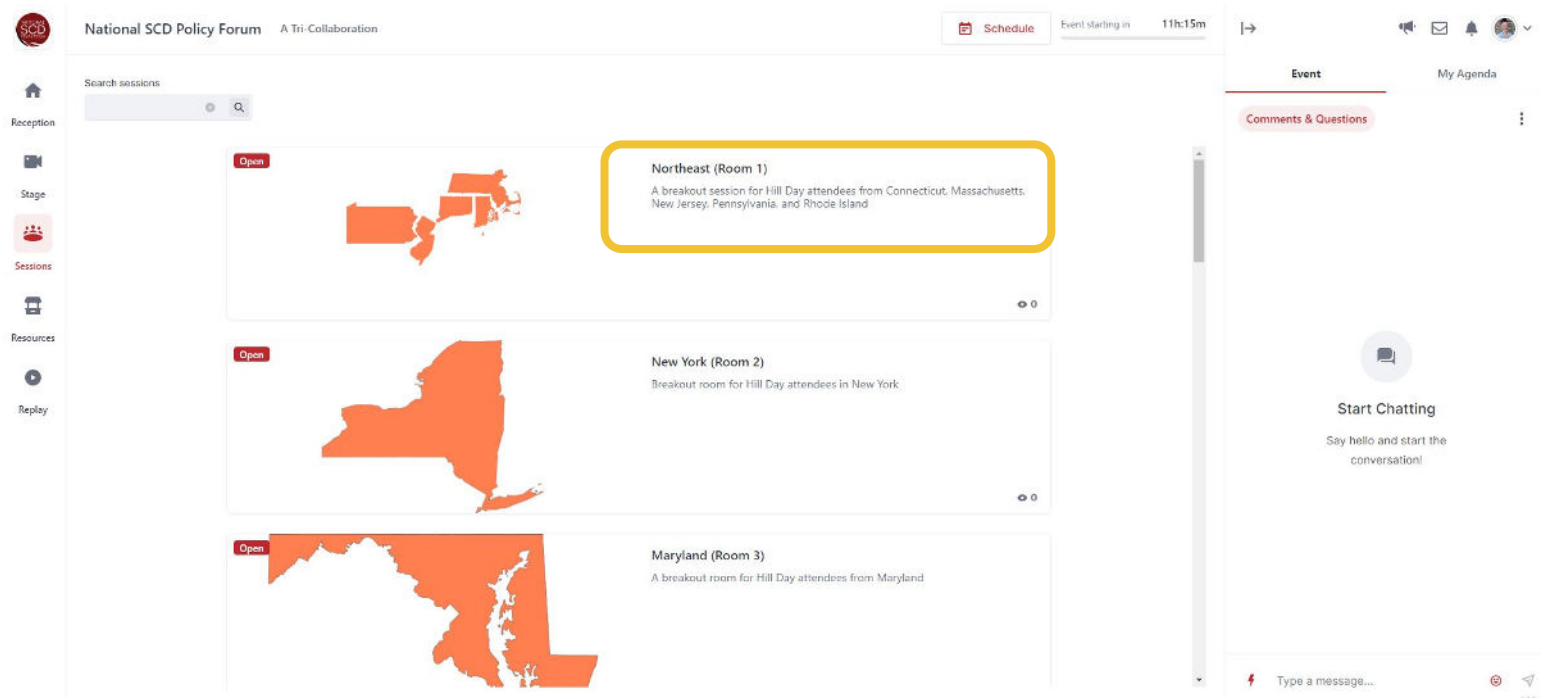
- Confirm Day 2 attendance
- Confirm Team Leads
- Check Hill Day schedules
- Establish speaking roles:
  - Team Lead
  - 2 personal stories *(flexible)*
  - 1 person per ask *(flexible)*
  - Non-speaking/observing roles

Session Breakouts are intended for those **participating in the Virtual Hill Day.**

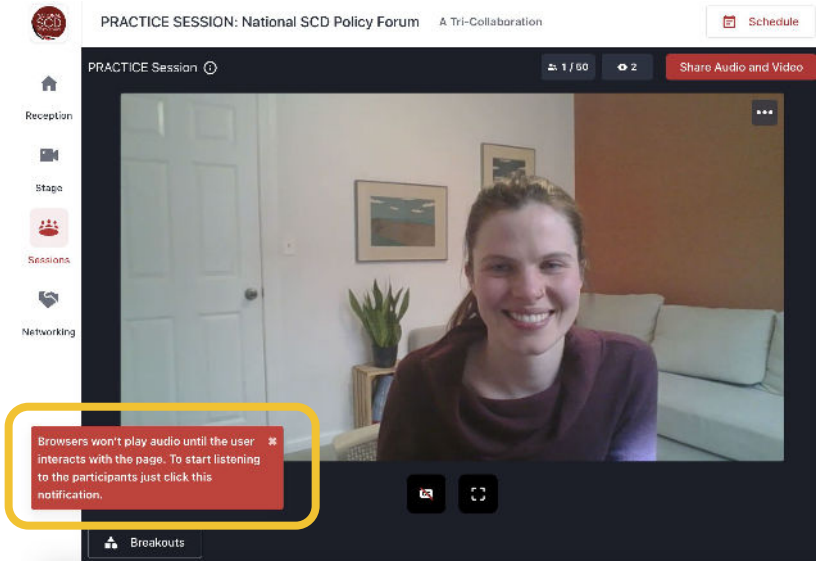
If you would like to observe but are NOT participating in the Hill Day, please remain a silent attendee.

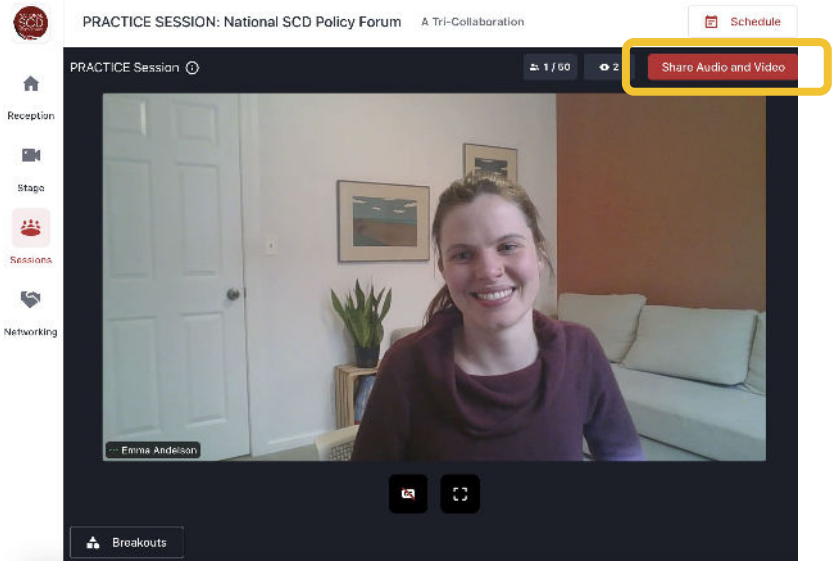
# Session Breakouts

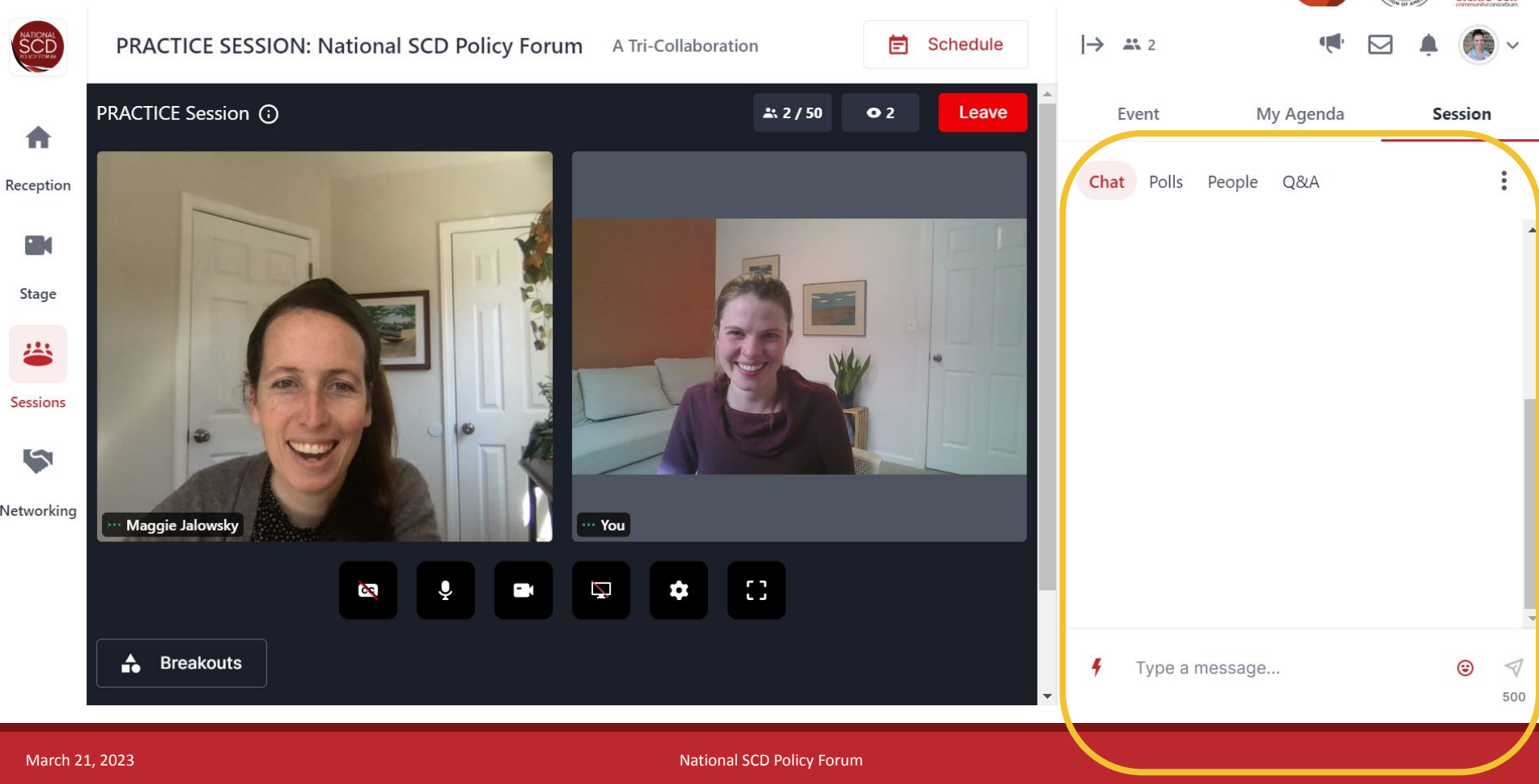
# Pick Your Session



# Enable Audio & Video




PRACTICE SESSION: National SCD Policy Forum
A Tri-Collaboration
Schedule
2
Reception
Stage
Sessions
Networking
PRACTICE Session
2 / 50
2
Leave
Maggie Jalowsky
You
Breakouts
Event
My Agenda
Session
Chat
Polls
People
Q&A
Type a message...
500

# Session Info

Sessions will stay open & accessible for two hours after the event in case your team wants to use them to coordinate and practice more.

*You are also welcome to practice with your team at tonight's Office Hours from 6-8pm ET*

# Breakout Rooms

1:50-2:40pm ET

Please join the “Session” based on your state or region

*Those not participating in Day 2 are welcome to observe silently or head out after watching the “Next Generation” message in “Booths”*

# Next Generation

2:40-2:45pm ET

A message from young SCD advocates across the U.S.

# Closing Remarks

2:45-3:00pm ET

**Ashley Valentine**

President & Co-Founder

Sick Cells

**Regina Hartfield**

Executive Director

Sickle Cell Disease Association of America, Inc. (SCDAA)

**Dr. Lakiea Bailey**

Executive Director

Sickle Cell Disease Community Consortium

# Thank you to our sponsors!

| | |
|---|---|
| **Gold Level** | bluebirdbio |
| **Silver Level** | VERTEX |
| **Supporter Level** | editas MEDICINE; Pfizer |

# Reminders

- View your Hill Day schedule
- Outline your SCD story
- Sleep well & prep for tomorrow!

## Questions?

- Come to Office Hours TONIGHT from 6-8pm ET
- Register at the link in the chat