ASH RESEARCH COLLABORATIVE®

COMMUNITY VOICES

SHAPING SICKLE CELL DISEASE RESEARCH

2026

A First Look at How Community Voices are Shaping SCD Research

Dear Sickle Cell Community Members, Researchers, and Friends,

We are pleased to share **Community Voices Shaping Sickle Cell Disease (SCD) Research**, the first community-facing report from the ASH Research Collaborative® (ASH RC) highlighting how lived experience is helping shape SCD research across the ASH RC SCD Research Network.

People living with sickle cell disease know what researchers need to understand: pain can be dismissed, care can feel unequal, trust must be earned, and daily life with SCD is more than what appears in a medical record.

This report shares how people with SCD, caregivers, advocates, and community partners are helping shape research across the ASH RC SCD Research Network. Through local Community Advisory Boards (CAB) and the National Community Advisory Board (NCAB), community members are helping researchers ask better questions, design studies that are easier to take part in, improve study materials, and focus on what matters most to people and families.

This report does not present final study results. Many studies are still underway. Instead, it shows something just as important: how community input is changing research while decisions are still being made.

Thank you to every CAB member, caregiver, advocate, research coordinator, investigator, and partner who has shared time, experience, questions, and trust. Your voice is helping build research that is more respectful, more useful, and more connected to real life with SCD.

We hope you are as proud as we are of the difference our CABs are making across the SCD Research Network. Their voices, leadership, and lived experience are helping shape research that is more practical, more respectful, and more connected to the needs of people living with SCD and their families. As we look ahead, we are excited to continue building this work together toward a stronger, more inclusive, and more hopeful future for the SCD community.

With deep appreciation,

Gary J. Schiller, MD
Chair, Board of Directors
ASH Research Collaborative

Charles Abrams, MD
Chair, SCD Research Network
ASH Research Collaborative

Titilope Fasipe, MD, PhD
Chair, SCD National Community Advisory Board
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Justine Nicholas, MS
Senior Manager, SCD Community Engagement
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ASH RC CAB Site: NYC Health + Hospitals; Taken by Rick Guidotti, Founder and Director of Positive Exposure.

> "Being on ASH RC means that my voice matters, and by sharing my perspectives through lived experience, it can make a difference in the research being done to help advance sickle cell for better, healthier outcomes."
>
> – James Griffin, SCD Warrior, NCAB Member

Community Voices at the Center

Community members connect with ASH RC because they want SCD research to reflect the realities of living with the disease, not only what is captured in a clinic visit, medical record, or study endpoint. Through CAB engagement, they bring context that data alone cannot provide, helping research teams understand what feels trustworthy, what may create burden, which questions matter, and how research can be useful beyond publication.

To CAB members, partnership in research means...

- Advancing research together
- Loyalty and respect for each other
- Building trust and equal opportunities
- Two-way communication between researchers and CAB members
- Working as a team to produce meaningful outcomes

From Insight to Action: Research Shaped With Community Voice

At ASH RC, impact means research made stronger through partnership. Our community engagement work brings the voices of people living with sickle cell disease into the research process, from shaping the earliest questions to sharing findings with the communities they are meant to serve.

In studies that are still underway, community input can make an impact before the study is complete. It can change how a research question is framed, whether participation feels realistic, how study materials are written, and how teams plan to keep participants and communities informed. That early influence gives patients, caregivers, and advocates a chance to shape the work before key decisions are locked in. It also gives researchers practical insight that can strengthen study design, feasibility, recruitment, retention, and return of results. The stories that follow show what this kind of impact can look like while studies are still moving toward later milestones.

Reducing SCD Stigma in Emergency Departments: A CAB-Directed Study

The CAB-Directed Study grew out of a practical question: what would it look like for CAB members to learn about research by helping lead a study themselves? Formally titled *Enhancing Clinical Trial Understanding through Experiential Learning: A CAB-Directed Study to Reduce SCD Stigma in Emergency Departments*, the study is co-led by Dr. Kenneth Rivlin of NYC Health + Hospitals and Dr. Tilicia Mayo-Gamble of Georgia Southern University. It was designed to build CAB members' understanding of clinical trials through direct experience while addressing stigma in emergency care.

For many people living with SCD, the emergency department is where pain, mistrust, and misunderstanding often collide. CAB members helped bring those realities into an educational intervention for residents, fellows, attending physicians, and nurses. As Dr. Rivlin explained, "Research needs to be done together, not independently."

The study, currently underway, connects research literacy with care improvement. CAB members are exploring clinical trial concepts and study design, helping refine the study intervention, and participating in provider education. **Dr. Mayo-Gamble described the approach as "teaching through leading," with CAB members helping clinicians understand how stigma, assumptions, and system-level pressures can shape emergency care.**

For CAB members, the study creates a pathway from naming a problem to testing an approach and using findings to support change. For participating sites, it offers a practical model for how community-led education can inform clinical training and strengthen the connection between research and care. In Dr. Rivlin's words, "The CABs want to learn. They also want to make a change."

Community Impact:

- Turned a concern raised by the CAB about stigma in emergency care **into a pilot research effort**.
- **Centered lived experience in clinician education** to show how stigma and assumptions can affect emergency pain care for people living with SCD.
- **Gave CAB members hands-on research experience** by involving them in study design, rollout, evaluation, and sharing results.
- **Used early findings to support discussions** with hospital leaders about incorporating the training effort into provider education.

> “Our voices helped providers see beyond the diagnosis and textbook information to better understand real-life experiences, challenges, and the needs of our community. When researchers and community members work together, research becomes more than data...it becomes a pathway to real change.”
>
> – Kiara Parker, CAB Chair, Augusta University

Think Zinc for Bone Health: Designing for Real-World Participation

Bone health is an important but often less visible complication of sickle cell disease. People living with SCD can experience low bone mass, fracture risk, avascular necrosis, chronic pain, and other bone-related complications that affect mobility, independence, and quality of life.

The Think Zinc for Bone Health study, led by Drs. Ellen Fung and Elliott Vichinsky at the University of California, San Francisco (UCSF), and Dr. Charles Abrams at the University of Pennsylvania, explores whether zinc supplementation could support bone health in people living with SCD and inform the design of a larger multi-site clinical trial. The study builds on a long-standing observation in the field. Dr. Fung noted, "Zinc was one of the first deficiencies noted in patients with sickle cell disease."

The study began with funding from ASH RC, which allowed the team to discuss the concept with the SCD community, gather pilot data, and develop the idea into a stronger proposal for federal funding. The project was later funded by the National Heart, Lung, and Blood Institute (NHLBI) as an R34 planning grant, a two-year award designed to work through key details before launching a larger trial.

Community members discussed how they think about bone health, what they knew about zinc, what would make the study feel worthwhile, and what barriers might make participation difficult. **Their feedback helped the team refine practical parts of the study, including scheduling, pill size, visit reminders, dosing instructions, and how study information should be written.**

Community conversations also helped the team respond to reviewer concerns about whether patients might be worried about radiation exposure from DEXA scans, a low-dose X-ray used to measure bone density. Dr. Abrams noted, "The feedback and the information we got was real. It helped us shape a better grant."

As the study continues, selected members of UCSF's local CAB will serve as Patient Research Advisors on the study team. These advisors will help the team think through recruitment, retention, follow-up, and communication with local CABs and the NCAB as the study moves forward. Dr. Fung reflected, "There is enthusiasm about wanting to participate in the research process, and not just be told, 'This is a research study, do you want to participate, yes or no?" As the study moves toward a larger multi-site trial, Patient Research Advisors will also help share progress with local CABs and the broader community, keeping the SCD community not just informed, but engaged in shaping the research as it grows.

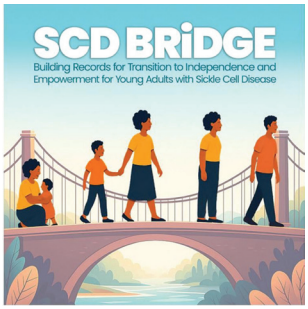
Community Impact:

- **Identified participation barriers early** and helped the study team design steps that are more practical for people living with SCD.
- **Reduced participant burden** by improving study materials and procedures, including scheduling, reminders, dosing instructions, and plain-language communication.
- **Strengthened readiness for a future multi-site study** by involving Patient Research Advisors in recruitment, participant retention, follow-up, and ongoing CAB communication.

> "There is enthusiasm about wanting to participate in the research process, and not just be told, 'This is a research study, do you want to participate, yes or no?"
>
> – Dr. Ellen Fung, ASH RC Investigator
> University of California, San Francisco

> "The transition metrics that are defined as important to providers are not what is defined as important to patients and caregivers."
>
> – Dr. Venée Tubman, ASH RC Investigator, Texas Children's Hospital / Baylor College of Medicine

SCD BRiDGE: Defining Transition Success Through Patient and Caregiver Experience



For young adults living with SCD, the move from pediatric to adult care can mean leaving a familiar care team while learning to manage appointments, insurance, symptoms, emergencies, and communication with new providers.

The SCD BRiDGE study, *Building Records for Transition to Independence and Empowerment for Young Adults with Sickle Cell Disease*, focuses on this critical point in care. Led by Dr. Venee Tubman at Texas Children's Hospital and Baylor College of Medicine, the study originally explored how an Epic-based Transition Navigator tool developed at Texas Children's could support young adults as they move into adult care.

The initial concept relied on health system measures such as visit timing, transfer of medical information, emergency care use, treatment patterns, and changes in health outcomes. When a transition goes poorly, young adults may disengage from care altogether, delaying or interrupting the regular treatment that people living with SCD depend on.

When the study team brought the concept to CAB members, they heard that successful transition also depends on trust, preparation, continuity, compassion, feeling known, and confidence that adult care will remain responsive. Dr. Tubman reflected, "The transition metrics that are defined as important to providers are not what is defined as important to patients and caregivers."

That feedback changed the study pathway. Rather than moving directly into testing an electronic medical record-based tool, the team created a "pre-SCD BRiDGE" study to first understand how young adults, caregivers, advocates, and community partners define successful transition. In Dr. Tubman's words, the team needed to "figure out what the community actually cares about" before finalizing the next phase of the work.

Through focus groups and interviews, the study team is building a broader understanding of transition success, one that includes both clinical continuity and the human experience of entering adult care. When the medical record intervention moves forward, community-defined concepts will help shape how the team evaluates whether the intervention is meaningful.

Community Impact:

- **Changed the study design by adding an early planning phase** before testing the transition tool, helping ensure it reflects patient and caregiver priorities from the start.
- **Expanded the definition of a successful transition** beyond health system measures to include trust, preparation, continuity, compassion, and feeling known by the adult care team.
- **Strengthened how the transition tool will be evaluated** by measuring not only whether young adults connect with adult care, but whether the transition feels supported, respectful, and meaningful.

> "We want to be looking at how the whole person is impacted by any of these treatment choices."
>
> – Dr. Patricia Steinert, Lead Investigator
> WARRIOR-SCD Study

WARRIOR-SCD: Shaping Long-Term Follow-Up Through Community Input

Led by the Center for International Blood & Marrow Transplant Research (CIBMTR) with support from NHLBI Cure Sickle Cell Initiative, the WARRIOR-SCD—*Whole-person Assessment of Response and Risk after transformative therapies: Investigating Outcomes and Resilience in Sickle Cell Disease*— is a long-term follow-up study focused on the impact of transformative therapies for SCD, including gene therapy and stem cell transplant, compared with standard care. The study looks beyond clinical outcomes alone, with attention to pain, organ function, quality of life, financial toxicity, and other patient-reported outcomes.

Study investigators Dr. Patricia Steinert and Dr. Amanda Brandow, at the Medical College of Wisconsin, emphasized the importance of looking beyond treatment response alone. As Dr. Steinert described, "We want to be looking at how the whole person is impacted by any of these treatment choices." WARRIOR-SCD therefore includes outcomes related to pain, organ function, fatigue, physical functioning, mental and emotional health, reproductive health, financial impact, and overall quality of life.

The study is currently in a pilot phase designed to demonstrate feasibility and strengthen the infrastructure needed for long-term follow-up. From the beginning, the study team recognized that sustained participation would require more than clinical data systems. People living with SCD needed a meaningful role in shaping how the study communicates, builds trust, and stays connected to participants over time.

Working alongside the WARRIOR-SCD study team, ASH RC created structured opportunities for NCAB members to inform the study during the planning phase. NCAB members advised on patient-facing communications, recruitment materials, and approaches for keeping the broader SCD community informed and connected over time. Their input also extended to the study's identity, including selection of the name WARRIOR-SCD, recognizing that language can influence how the community understands and connects with a long-term research effort.

CURE SICKLE CELL.

Dr. Brandow noted, "It's about them, and we don't want to create anything for them without their input." That input will continue through a small NCAB working group that advises the study team as implementation moves forward.

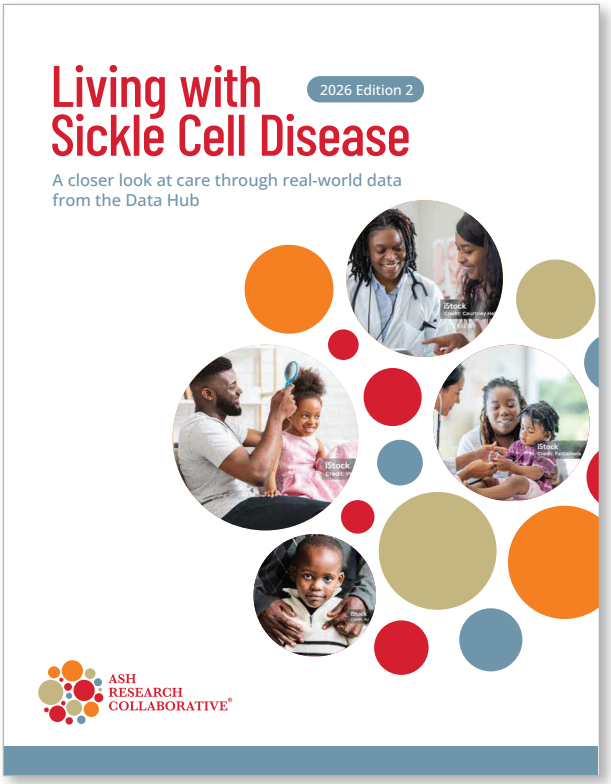
For WARRIOR-SCD, community guidance is part of feasibility: it helps the team think not only about whether participants enroll, but how they understand the study, receive updates, and remain connected over time.

Community Impact:

- **Strengthened the pilot phase of this national long-term follow-up study** by helping the study team refine its approach before broader implementation.
- **Improved recruitment and retention planning** by helping shape study materials, updates, and communication around what people living with SCD need to know and stay engaged.
- **Reinforced the importance of identity, language, and trust** by involving NCAB members in naming the study and shaping how it is introduced to the broader SCD community.

Community-Centered Research Education

Research education and data reports are most useful when community members can see how the information connects to their own questions and experiences. Through resources like the Clinical Trials Resource Library and the *Living with Sickle Cell Disease* Data Hub Report, CAB members helped shape materials that are accessible and useful for helping the SCD community engage more confidently with research and data.



Clinical Trials Resource Library

ASH RC's Clinical Trials Resource Library (ashresearchcollaborative.org/Library) was developed with the NCAB to help people living with SCD and their families better understand research participation. The plain-language videos and companion documents cover topics such as participant choice, privacy, research protections, bias in clinical research, and how clinical studies move from an idea to possible impact. NCAB members helped shape the topics, scripts, and character design, and the resources are available in English and Spanish.

Living With SCD: Data Hub Report

The *Living with Sickle Cell Disease Data Hub Report* (ashresearchcollaborative.org/data-hub-reports) shares insights from real-world health information contributed by participating SCD Research Network sites. The 2025 report included data from more than 13,000 people with SCD, and the 2026 edition builds on that work with a broader view of the Data Hub and additional questions raised by community partners. NCAB members helped identify meaningful findings, advise on plain-language explanations, and review how data and community context were presented.

> "As a Sickle Cell Caregiver and Advocate, collaborating with providers, researchers, and stakeholders via the ASH Community Advisory Board has been a rewarding experience. The CAB Impact Report demonstrates how the input of those with lived experience is valued and incorporated, greatly improving the outcomes for those affected by sickle cell."
>
> - Jaimee Roque, Mom and Caregiver to Two Sickle Cell Disease Warriors, NCAB Member

Looking Ahead

This first edition of *Community Voices Shaping Sickle Cell Disease Research* is a starting point. It shows how people living with SCD, caregivers, advocates, and community partners are already helping shape research across the ASH RC SCD Research Network, while pointing to the work still ahead. The next phase is about making this partnership stronger, more consistent, and easier to see, so community members help shape the questions researchers ask, the outcomes studies measure, and the way results are shared back.

A key part of this work is ASH RC's Patient-Centered Outcomes Research Institute (PCORI)-funded project, *Building Capacity to Engage in Patient-Centered Comparative Effectiveness Research on Sickle Cell Disease* (pcori.org/research-results/2025/building-capacity-engage-patient-centered-cer-sickle-cell-disease) (Award: EACB #45209). The project brings together site-based triads, a principal investigator, research coordinator, and CAB member, to learn together and develop research questions with community priorities at the center before study designs are finalized.

The project also uses the Patient-Led Research Scorecard (PLSC), which helps teams ask the questions that matter most: Are CAB members included early enough? Are their ideas changing the research? Is the work respectful of community members' time and lived experience? This work gives ASH RC a clearer way to see where engagement is working and where teams need support to involve community members earlier.

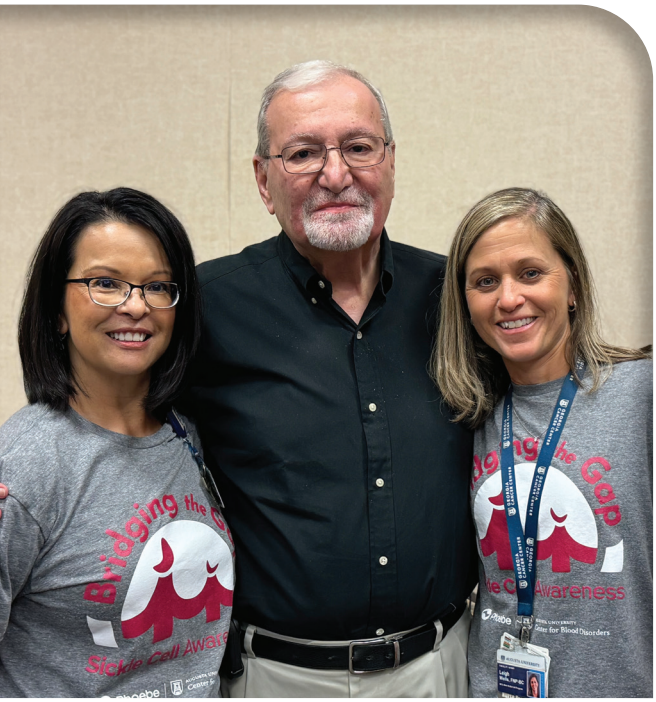
Over the next three years, ASH RC will focus on four connected priorities:

STRENGTHENING CAB infrastructure

EXPANDING Our community-centered research

SHARING Community impact

CULTIVATING CAB leadership and connection



> "The CAB Program reminds us that strong science and strong community engagement are not separate efforts; they are parts of the same process. We are building a foundation where people living with sickle cell disease and their families are not just participants in studies, but partners in deciding which questions we ask and how we answer them. Our goal is to make this kind of partnership the norm across the Network, not the exception."
>
> – Dr. Charles Abrams, Chair, ASH RC SCD Research Network

Appendix

A. ASH RC's Community Advisory Boards (CABs)

ASH RC's CAB Program provides an engagement infrastructure for integrating lived experience into the SCD Research Network. Across **28 local CABs and 418 members**, people living with SCD, caregivers, advocates, and community leaders work with investigators, research coordinators, and ASH RC staff to strengthen how research is developed, reviewed, and shared. Their input helps teams understand how studies may be experienced beyond the protocol, including whether language is clear, participation is realistic, trust is supported, and results are returned in ways that are useful to the community.

Local CABs are connected to participating SCD Research Network sites and serve as site-based Community partners. The NCAB brings representatives from local CABs into Network-wide research, education, protocol review, and patient engagement activities. Together, this structure creates a two-way feedback loop: local priorities can inform national discussions, and Network-wide opportunities can return to local CABs for review and practical guidance.

B. ASH RC SCD Research Network Sites

For a full list of SCD academic research centers connected in our Network, please visit Sickle Cell Disease Research Network - ASH Research Collaborative (https://www.ashresearchcollaborative.org/sickle-cell-disease-research-network).

C. How To Get Involved

How Potential Partners Can Engage

ASH RC welcomes collaboration with community organizations, clinicians, researchers, and industry partners who share the goal of improving the lives of people with SCD. Contact ASH RC to discuss how your questions or programs align with SCD Network priorities and community needs.

How Community Members Can Get Involved

If you are interested in getting involved or joining a CAB, you can reach out to us, and we will connect you with the site and CAB that are closest to where you live. By partnering with these advisory boards, we're able to ensure that community voices are not just heard, but truly shaping the direction of our research.

Contact us here (ashresearchcollaborative.org/contact-us)

D. Key Definitions

Term	Plain-language definition
Clinical comparative effectiveness research (CER)	Research that compares different health care options to better understand what works best, for whom, and in which circumstances.
Community Advisory Board (CAB)	A site-based group of people living with SCD, caregivers, advocates, and community partners who provide input on research priorities, study materials, engagement approaches, and plans for sharing results. See Appendix A.
National Community Advisory Board (NCAB)	A national advisory group made up of representatives from local CABs who bring community perspectives from across the SCD Research Network into Network-wide research, education, and engagement activities.
Patient-led Scorecard	A structured assessment tool developed by the Council of Medical Specialty Societies (CMSS) and the Patient-Led Research Collaborative (PLRC) to help patient groups and research partners evaluate the quality of collaboration. In ASH RC's PCORI-funded project, the PLSC helps assess areas such as governance, patient burden, integration of community input, and organizational readiness for research engagement.
Protocol	The detailed plan for a research study, including the study purpose, who can participate, what participants will be asked to do, what data will be collected, and how participants will be protected.
Real-world evidence (RWE)	Evidence drawn from routine health care settings, such as clinics, hospitals, electronic health records, or patient-reported information, to better understand how care and treatments work outside of a traditional clinical trial.
SCD Research Network	ASH RC's collaborative network of participating SCD centers working together to support research, strengthen data collection, and generate evidence that can inform care for people living with SCD.
Triad	A site-based team made up of a principal investigator, research coordinator, and CAB member. In ASH RC's PCORI-funded project, the triad model brings scientific, operational, and lived experience perspectives into research planning early.

About The ASH Research Collaborative

The ASH Research Collaborative (ASH RC) is a nonprofit organization established by the American Society of Hematology (ASH) to advance research that improves the lives of people affected by blood diseases. Through collaborative research programs, data infrastructure, and community engagement, ASH RC works with clinicians, investigators, patients, caregivers, and partners to support research that is scientifically rigorous, responsive to real-world needs, and connected to the communities most affected by the work.

About The SCD Community Advisory Board Program

The SCD CAB Program is ASH RC's primary structure for integrating community voice into SCD research. Through local CABs and the NCAB, people living with SCD, caregivers, advocates, and community partners work alongside investigators, research coordinators, and ASH RC staff to inform research ideas, study materials, education resources, engagement strategies, and plans for sharing results. This structure creates a consistent pathway for lived experience, local context, and practical guidance to shape research across the SCD Research Network.

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Washington, DC

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We also gratefully acknowledge **Hunter Carney, BS; Chris Dowd, MBA; Justine Nicholas, MS; Emily Semmel, MS; Kathleen Torres, DNP; and Shell Walser, BA, PMP**, for their programmatic support and coordination throughout the development of this report.

Most importantly, ASH RC is deeply grateful to the **local CAB members, National CAB members, research coordinators, investigators, and SCD Research Network sites** whose commitment to community engagement made this work possible.

For more information:

ASH Research Collaborative
ashrc.org

SCD Community Advisory Board
www.ashresearchcollaborative.org/sickle-cell-disease-research-network/sickle-cell-disease-community/community-advisory-boards/

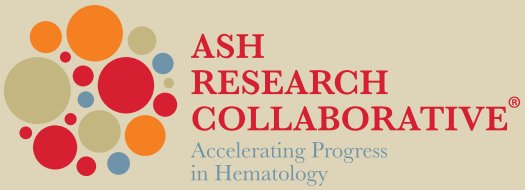
ASH's 10 Years of SCD Progress
www.hematology.org/ash-center-for-sickle-cell-disease-initiatives

ASH Clinical Practice Guidelines
www.hematology.org/education/clinicians/guidelines-and-quality-care/clinical-practice-guidelines/sickle-cell-disease-guidelines

SCD Coalition
www.scdcoalition.org

NHLBI Guidelines
www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease

Sickle Cell Disease Association of America (SCDAA)
www.sicklecelldisease.org



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