AMERICAN SOCIETY OF HEMATOLOGY ®

Center for
Sickle
Cell Disease
Initiatives

10 YEARS OF
SICKLE CELL DISEASE PROGRESS

This report reflects on a decade of dedicated effort and investment by the American Society of Hematology to strengthen the global response to sickle cell disease—convening partners, supporting progress, and helping to advance care, research, and better health outcomes for individuals living with SCD.

• HEMATOLOGY.ORG/SCD •

As a hematologist, I have been actively involved in the fight against the medical and social impacts of hematologic disorders, including SCD.

SCD is a global health challenge that has been overlooked for far too long. I've witnessed the burden this disease places on patients and families around the world. During my tenure as ASH President, I've had the opportunity to attend the Global Congress on SCD in Abuja, Nigeria, collaborate with the Consortium on Newborn Screening in Africa, and participate in key discussions that underscore the importance of ASH's leadership in this field.

Belinda Avalos, MD

As 2018 ASH President, and now as Chair of the SCD Task Force, I have seen the growth in ASH's efforts to effectively respond to SCD through guidelines, educational resources, advocacy, and research. The reconstitution of the SCD Task Force in 2024, aligned with the launch of the ASH Center for SCD Initiatives, are important steps to amplify ASH's achievements and define a future strategy in collaboration with our partners.

Alexis Thompson, MD, MPH

We've Come a Long Way.
The Journey Must Continue.

Dear Colleagues,

We are pleased to present this report highlighting the past 10 years of the American Society of Hematology's (ASH) initiatives to address sickle cell disease (SCD). As the 2025 ASH President and the Chair of the ASH SCD Task Force, we are proud to lead this charge and witness the important work being carried out to support hematologists, clinicians, federal partners, community-based organizations, and the global community in responding to SCD.

ASH launched the SCD Initiative in 2015 to expand its commitment—working with global stakeholders to identify and implement interventions that improve outcomes for those living with SCD. From facilitating access to care and expanding education and training to advancing research, a new chapter in SCD health care is emerging.

We invite you to join us in this effort, through partnership, collaboration, and action, as we work toward a better future for all affected by SCD. Thank you for reviewing this report, and we look forward to your continued engagement in this vital work.

Sincerely,

BELINDA AVALOS, MD
ASH President, 2025

ALEXIS THOMPSON, MD, MPH
SCD Task Force Chair

Convening the SCD Community:
A Journey in Action

The story of sickle cell disease is one of resilience and relentless pursuit—by those who live with it and those working to change its outcome. First documented in 1846, SCD has challenged generations of clinicians, researchers, and advocates to better understand and address its complex impact.

From scientific discovery to global action, ASH has stood at the center of progress. ASH has worked to elevate SCD as a public health priority—driven by urgency, a need for better outcomes, and a deep commitment to lasting impact. Recognizing this, ASH has been willing to challenge itself and the SCD scientific community to achieve even more.

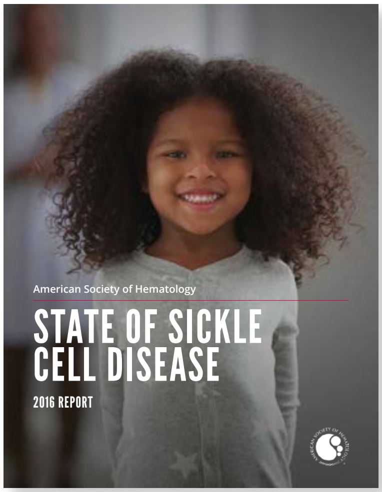
1846 WHERE IT ALL BEGINS: First case of SCD documented.

2015 ASH convenes the first Sickle Cell Disease Summit.

By 2015, ASH had helped catalyze a series of foundational steps, including the Society's first-ever Sickle Cell Disease Summit. Gathering more than 80 cross-sector stakeholders, from researchers and clinicians to advocates and policymakers, the Summit identified urgent priorities in access, research, and global care for SCD. The following year, ASH released the inaugural *State* *of Sickle Cell Disease Report* and launched the SCD Coalition, now a network of more than 100 organizations united to transform outcomes for individuals living with SCD.

This Summit represented more than a shift in ASH's strategy; it signaled a turning point in the field and a commitment from ASH to address this long-ignored disease. ASH stepped into a unique role: not just responding to a crisis but also helping to drive a coordinated, multi-front effort. By aligning science, policy, and community voice, ASH positioned itself as a convener of action and a partner in lasting change.

2016 ASH launches the SCD Coalition **(100+ members strong).**


American Society of Hematology

STATE OF SICKLE CELL DISEASE

2016 REPORT

2016 ASH publishes the inaugural *State of Sickle Cell Disease Report.*

The timeline that follows captures this evolution: a decade marked by collaborative milestones, measurable gains, and bold commitments to reimagine what's possible in SCD care research and SCD warrior leadership.

> **'You don't have to reinvent the wheel for SCD educational resources if it's already there,' Dr. Boateng notes. Coalition engagement has expanded our work—helping us leverage social media and creative online tools to better serve the sickle cell community.**

Dr. Stephen Boateng – Sickle Cell Disease Coalition Member

Sickle Cell 101

SICKLE CELL DISEASE COALITION

Founder of the No One Behind Foundation and head of research at Sickle Cell 101, Dr. Stephen Boateng leads efforts to advance education, research, and advocacy for sickle cell disease (SCD) and sickle cell trait (SCT) worldwide. Through his organization's participation in the Sickle Cell Disease Coalition, Dr. Boateng has seen stronger community engagement, deeper collaboration with research partners, and broader reach for Sickle Cell 101's educational resources.

SCD Progress Led by ASH

2011-2014

ASH addresses sickle cell trait in athletics and helps promote and disseminate National Heart, Lung & Blood Institute (NHLBI) SCD Guidelines.

2015

ASH hosts the ASH SCD Summit: A Call to Action.

2016

State of Sickle Cell Disease Report is released by ASH and other stakeholder groups, and the Sickle Cell Disease Coalition is launched.

SICKLE CELL
DISEASE
COALITION

2018

ASH and FDA Co-Host Clinical Endpoints Workshop in SCD.

ASH launches the ASH Research Collaborative (ASH RC) with SCD as its first disease area.

2019

ASH hosts the first annual SCD Adult Care Centers Workshop.

2020

Practice-changing data on CRISPR-based gene editing for SCD is presented at the 2020 ASH Annual Meeting.

2021

ASH launches Consortium on Newborn Screening in Africa (CONSA).

2024

ASH launches Center for SCD Initiatives and forms SCD Task Force.

2025

Updated ASH position statement affirms sickle cell trait is not a primary cause of sudden death.

Pivotal Moments in SCD Care

1998

The U.S. Food and Drug Administration (FDA) approves hydroxyurea as the first-ever drug proven to be effective in the treatment of adults with SCD.

2001

Gene therapy successfully cures a mouse with sickle cell.

2014

NHLBI releases guidelines for managing SCD.

2018

Congress passes legislation to establish the Centers for Disease Control and Prevention (CDC)'s Sickle Cell Disease Data Collection program.

NHLBI launches the Cure Sickle Cell Initiative to accelerate the development of gene therapies to cure SCD.

2020

National Academies of Sciences, Engineering, and Medicine (NASEM) releases "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action."

2021

Congress introduces the Sickle Cell Disease Comprehensive Care Act.

2023

FDA approves two gene therapies for SCD.

Improving Access to Care:

Sickle Cell Disease Doesn't Follow a Formula

Many providers have faced barriers to delivering timely, effective treatment. ASH responded by developing six clinical practice guidelines on pain, cardiopulmonary and kidney complications, transfusion, cerebrovascular disease, and stem cell transplantation, with a hydroxyurea guideline expected in 2025.

But developing guidelines is only part of the solution. ASH has driven sustained adoption through accessible, practical tools:

SHARED DECISION-MAKING (SDM) TOOL FOR STEM CELL TRANSPLANTATION:

Over **2,000** users and **more than 4,600** views.

SCD TEACHING SLIDES:

25,584 downloads.

SCD SNAPSHOTS:

25,302 downloads.

SCD INFOGRAPHICS:

21,003 downloads.

IN TOTAL, THESE SCD GUIDELINE IMPLEMENTATION TOOLS HAVE BEEN DOWNLOADED OVER 70,000 TIMES.

Stats as of September 2025.

ASH is also pushing for systemic change. In 2024, ASH partnered with the Health Services Advisory Group, Inc. (HSAG) to submit an electronic clinical quality measure (eCQM) to the Centers for Medicare & Medicaid Services (CMS), aimed at improving timely pain management for individuals with vas-occlusive episodes, a commonly reported challenge for patients. The measure was submitted for inclusion in the Hospital Outpatient Quality Reporting Program. While not yet adopted, ASH remains committed to advancing this standard in emergency care.

> ❝ ASH led the charge for the development of this new quality measure, meant to reduce disparities in care, and promote achievable ways hospitals can more quickly work to relieve patients dealing with SCD crisis. We will continue to work to see this measure integrated into all SCD pain management efforts.
>
> **Dr. Titilope Fasipe**

Accelerating Research to Mobilize SCD Care

In 2018, ASH launched the **ASH Research Collaborative (ASH RC)**, a bold step to bridge research and real-world care. Through the creation of the ASH RC, ASH has created one of the largest sources of aggregated, community-informed SCD data in the country, now covering nearly **16,000 patient records across 37 U.S. pediatric and adult hospital centers.** For more information on these data, see the ASH RC Sickle Cell Disease Data Hub Report.

The idea for a SCD Research Network emerged from ASH's 2015 Sickle Cell Disease Summit and its subsequent *State of Sickle Cell Disease Report*, which emphasized the urgent need to build infrastructure for studying individuals in clinical and community-based settings. In response, ASH mobilized by hosting community engagement workshops, launched the SCD Research Network and Data Hub, and established a national and local Community Advisory Board model, now with over 350 lived experience experts shaping how research is designed and implemented.

ASH RESEARCH COLLABORATIVE®
Accelerating Progress in Hematology

Sickle Cell Disease
Data Hub Report 2025

Since 2024, ASH RC has supported:

- 8 Investigator-Initiated Protocol Concept Grants
- 11 retrospective, observational analyses using data from the SCD Data Hub

To improve the scientific foundation of SCD trials, ASH also partnered with the U.S. Food and Drug Administration (FDA) in 2018 to co-convene a Clinical Endpoints Workshop.

While more details on these efforts are outlined in the following Advocacy section, two resulting papers, published in *Blood Advances*, rank among the top 25% of research outputs globally (according to Altmetric)—evidence of the field's growing influence and visibility.

Ronisha Edwards-Elliott—National Community Advisory Board, ASH RC

Diagnosed at birth with sickle cell disease, Ronisha Edwards-Elliott has channeled her lived experience into guiding others living with SCD. As a licensed medical social worker, she helps pediatric patients navigate the critical transition to adult care—building their understanding of the disease, their ability to work within the health care system, and their confidence as self-advocates.

Through her service on the ASH Research Collaborative National Community Advisory Board (NCAB), Ronisha ensures the patient perspective is embedded in national research and care improvement efforts. She champions resources and policies that center around lived experience, with a focus on transitions of care and patient empowerment.

> **Being a part of the NCAB has been life-changing. As Illinois' representative, I've had the chance to help shape protocols and projects that are transforming clinical research in SCD. Connecting with the national SCD community, I've grown as both a researcher and patient advocate in a space where the patient voice is truly valued. One of my proudest contributions has been collaborating on educational videos to help stakeholders understand the importance of clinical research. I am honored to be part of the NCAB and excited to see what lies ahead.**

In 2024, ASH released a set of research priorities to guide future innovation. These priorities confront critical gaps and focus on elevating both the quality and equity of research and care. **The seven focus areas include:**

SEVEN KEY RESEARCH PRIORITIES

1. ADVANCE understanding of disease progression through improved assessment, prevention, and treatment of organ dysfunction.
2. ENHANCE pain research to develop targeted, patient-informed therapies.
3. REFINE existing treatments–hydroxyurea, transfusions, and approved pharmacological therapies–for more personalized care.
4. DEVELOP new therapies, including combination and organ-protective approaches.
5. STRENGTHEN curative options, especially partial-matched transplants and long-term outcomes.
6. EVALUATE guideline distribution and use to improve adoption of evidence-based practices.
7. EXPAND sickle cell trait research, focusing on reproductive counseling and community impact.

These priorities were developed in close collaboration with researchers, clinicians, and stakeholders, ensuring that ASH's strategy is grounded in real-world needs and poised to drive impact. They build on the original 2014 framework and will be re-evaluated in 2029 to respond to new developments and opportunities.

ASH's impact in research isn't just about how much it does; it's about advancing research that sets the standard. More than 4,280 SCD-related papers have been published in ASH journals since 1946, and cited over 43,000 times, advancing science one insight at a time.

10 Years of Advocacy:
Powering Progress in Policy

Over the last decade, ASH has played a critical role in advancing policy solutions that address the systemic barriers faced by individuals living with sickle cell disease. As a trusted voice on Capitol Hill and a collaborative partner to several federal agencies, ASH has worked to shape legislation, inform regulatory processes, and expand federal investment in research, care infrastructure, and data collection.

LEADING FEDERAL LEGISLATION

The Sickle Cell Disease Comprehensive Care Act

ASH has led advocacy for the Sickle Cell Disease Comprehensive Care Act, a bipartisan, bicameral bill designed to ensure that individuals with SCD have access to coordinated, high-quality outpatient care. The legislation would allow states to establish Medicaid Health Homes with SCD as the single qualifying condition—an important step in supporting clinical, mental health, and support services for this population. ASH has built a coalition of more than 90 organizations, driven letter-writing campaigns, organized meetings on Capitol Hill, and raised national awareness to support the bill's introduction and reintroduction.

SHAPING FEDERAL AGENCY ACTION

USCDI Standards

When U.S. Department of Health and Human Services (HHS) administrators look to take action on SCD, they often turn to ASH. In 2024, ASH co-convened a series of SCD Data Registry Leaders' Roundtables with the Office of the Assistant Secretary for Health. These efforts helped catalyze the launch of the U.S. Core Data for Interoperability (USCDI) standards initiative focused on SCD—setting the stage for more unified data collection across states and health systems.

CDC'S SICKLE CELL DISEASE DATA COLLECTION (SCDC)

ASH also played a key role in establishing the Centers for Disease Control and Prevention (CDC)'s Sickle Cell Disease Data Collection (SCDC) program, beginning with two states in Georgia and California and growing to reach at least 50% of the SCD population in the U.S. ASH's advocacy helped secure funding through the 2018 Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act (P.L. 115–327) and through ongoing federal budget negotiations. The program now spans 16 states, providing critical insights into care patterns, complications, and outcomes.

In addition to surveillance, ASH has worked with the CDC to develop educational resources on topics such as SCD and pregnancy and sickle cell trait, extending its advocacy into clinical practice and public awareness.

ACCELERATING DRUG DEVELOPMENT THROUGH POLICY

FDA-ASH Clinical Endpoints Workshop

In partnership with the U.S. Food and Drug Administration (FDA), ASH co-led the 2018 FDA-ASH Clinical Endpoints Workshop to address a longstanding barrier in SCD drug development: the lack of standardized, validated clinical endpoints. The workshop helped set a foundation for regulatory clarity at a critical time as ASH continues to advocate for the SCD drug pipeline to grow. Since then, multiple therapies have gained approval, expanding treatment options for patients after years of stagnation.

> **'If you're even considering going for an ASH award, go for it,' Dr. Oyedeji says. The RTAF didn't just fund my research—it opened doors to mentors, collaborators, and a vibrant community committed to sickle cell disease. ASH gave me the foundation to build a career in research, and it can do the same for you.**

Dr. Charity Oyedeji – Advancing Research on Aging and SCD

Dr. Oyedeji is breaking new ground at the intersection of aging and sickle cell disease—an area long underrepresented in hematology. In 2019, she received ASH's prestigious Research Training Award for Fellows (RTAF), which allowed her to dedicate focused time to research, publish foundational work, and deepen her mentorship network. The award also set the stage for her first NIH grant through the GEMSSTAR program, leading to a coveted NIH career development ("K") award.

Now a faculty member at Duke University, Dr. Oyedeji continues to lead efforts to improve quality of life for adults aging with SCD.

Broadening Expertise to Meet SCD Needs

The future of SCD care depends on the people delivering it. ASH has made long-term, strategic partnerships to grow the next generation of clinicians, researchers, and institutional leaders working to improve the lives of individuals living with SCD.

Since 2013, ASH has supported more than 130 SCD-focused projects through fellowships, research funding, and physician training pathways—totaling over $18 million in direct investment. These efforts are not only training individual leaders but also building a deeper, more sustainable bench of SCD expertise across all stages of care and research.

One standout initiative, the SCD Away Elective, offers hematology fellows a month-long, immersive rotation in real-world SCD care settings. This hands-on experience equips rising clinicians with the practical knowledge needed to treat a condition shaped by complex clinical and social factors.

ASH has also worked to strengthen institutional capacity. Since 2021, the ASH SCD Centers Workshop has convened multidisciplinary teams from 58 hospitals across North America to advance the development of comprehensive care centers.

Dr. Éliane Gluckman, recipient of the 2024 Wallace H. Coulter Award for Lifetime Achievement in Hematology, is currently leading an effort to identify immunogenetic markers that may predict donor matches for stem cell transplant in people with SCD. Her leadership has trained many investigators and helped establish transplant units worldwide, advancing curative options in places where they are most needed.

These workshops foster peer learning, tackle operational barriers, and support long-term strategies to improve care delivery across the lifespan. The result is a growing network of institutions that view SCD not as a subspecialty—but as a strategic priority.

TRAINING AWARDS

Clinical Research Training Institute: 44 SCD participants (2013–2024)

Visitor Training Program: 19 SCD awardees (2014–2024)

African Visitor Training Program Stossel Award: 8 awardees (since 2024)

PROJECTS FUNDED

Scholar Award: 27 SCD-related projects funded since 2013 ($2.7–$4 million)

Hematology Inclusion Pathway: 44 SCD-related projects funded since 2020 ($1.4 million)

Global Research: 5 SCD projects funded since 2020 ($500,000)

Research Training Award for Fellows: 7 SCD-related projects funded since 2020 ($490,000)

Bridge Grant: 3 SCD-related projects awarded since 2019 ($145,000)

Physician Scientist: 3 SCD-related projects funded since 2020 ($126,000)

HONORS: 19 SCD projects funded since 2020 ($95,000)

ASH Graduate Hematology Award: 2 SCD-related projects funded since 2020 ($80,000)

For more information on these awards, go to: www.hematology.org/awards

A Global Call to Action

Sickle cell disease remains one of the world's most neglected health challenges, particularly in regions where the burden is highest. As highlighted by the *2023 Lancet Haematology Commission*, SCD imposes a profound and persistent toll on families and health systems across the globe. Nowhere is this more urgent than in sub-Saharan Africa, where the majority of children born with SCD still die before the age of five due to lack of access to diagnosis, treatment, and comprehensive care.

This reality exists despite the availability of cost-effective interventions that have significantly reduced SCD-related mortality in high-income countries. The gap is not only scientific—it is also systemic. Deep inequities in infrastructure, investment, and prioritization continue to leave millions behind, even as advanced therapies like gene editing emerge on the global stage.

ASH understands that addressing the SCD burden in low resource settings requires more than raising awareness—it requires sustained, coordinated effort. Drawing on its strengths in research, workforce training, policy, and convening, ASH has taken deliberate steps to extend its leadership beyond borders and into communities where the need is greatest.

CONSA INITIATIVE

One such effort is the Consortium on Newborn Screening in Africa (CONSA), a pioneering initiative launched in 2020 that supports early diagnosis and intervention in sub-Saharan Africa. As of July 2025, more than **160,000 newborns** have been screened across seven countries, resulting in the diagnosis of over 2,000 children with SCD. But CONSA's work extends beyond screening: ASH has helped strengthen clinical infrastructure, and those models are now being adopted in other regions.

> **The newborn screening by CONSA has created awareness and stirred interest in SCD by both state and non-state actors in Kenya.**
>
> **Dr. Bernard Awuonda, National Coordinator of CONSA Kenya Site**

VISITOR TRAINING PROGRAM

Building local capacity is equally vital. Through its Visitor Training Program (VTP), ASH connects clinicians in low-resourced settings with experts globally to support mutual learning and skill development. In 2025, this effort expanded with the launch of the African Visitor Training Program (AVTP)—Stossel Award, which focuses on building specialized SCD diagnostic and care capacity at two pilot centers in Abuja, Nigeria, and Cairo, Egypt.

WORLD COALITION ON SCD

As a founding member of the World Coalition on SCD, ASH collaborates with international partners to elevate SCD on national and global health agendas—sharing data, aligning advocacy strategies, and advancing resource mobilization efforts. Together, these efforts reflect ASH's deep investment in sustainable, scalable solutions that transcend borders and transform lives.

Looking Ahead

In 2024, the ASH launched the Center for Sickle Cell Disease Initiatives–a strategic hub designed to unify and elevate ASH's efforts under one cohesive vision. Alongside it, ASH convened a dedicated SCD Task Force to assess outcomes of the first 10 years and to set future-facing priorities through 2031. This expert group will guide ASH's next phase of work by identifying gaps, fostering innovation, and helping shape the systems needed to drive lasting change.

These efforts mark a shift from developing/managing individual programs to leading a transformation. ASH's long-term vision centers on three strategic goals:

1. Expanding the SCD workforce
2. Accelerating research
3. Ensuring individuals with sickle cell disease have access to high-quality care at every stage of life.

By investing in strategic leadership and infrastructure today, ASH is laying the groundwork for sustained progress and better outcomes for people living with SCD.

The journey isn't over—but the future is in focus.

> “ASH has been a catalyst for change in sickle cell disease, driving research and improving outcomes for decades. Despite significant advancements, current treatments and care models fall short in addressing the complex challenges faced by individuals with SCD, particularly in marginalized communities. Our new research priorities aim to be a guide for future research and comprehensive care, ensuring better access and equity for all patients.

Mohandas Narla, DSc, ASH President, 2024

10 Years and Counting. Your Role Matters More Than Ever.

- **SHARE ASH SCD tools and resources with your networks.**
- **DONATE to the ASH Foundation to advance the mission.**
- **VOLUNTEER your expertise to shape programs and advocacy efforts.**

ACKNOWLEDGEMENTS

ASH recognizes that the work to support SCD efforts requires collaboration, and we acknowledge the following organizations in advancing this work.

SCD WARRIORS

We recognize the leadership of individuals living with SCD, caregivers, and community-based organizations.

ASH MEMBERS

Our members are pioneering research and care practices to best meet the needs of individuals living with SCD.

SICKLE CELL DISEASE COALITION MEMBERS

Diverse organizations spanning the world that have come together to conquer SCD.

INDUSTRY PARTNERS

Organizations leading research into new drug therapies, diagnostic tools, and interventions to support individuals with SCD.

- Agios Pharmaceuticals
- AstraZeneca
- Bristol Myers Squibb
- Beam Therapeutics
- bluebird bio
- Cellarity
- Chiesi
- CSL Behring
- Disc Medicine
- Emmaus Life Sciences, Inc.
- Genentech
- Koneksa Health
- Miltenyi Biotech
- Novartis
- Novo Nordisk
- Pfizer
- Revvity
- Sanofi
- Terumo BCT
- Vertex Pharmaceuticals