



Center for
**Sickle
Cell Disease**
Initiatives

10 YEARS OF PROGRESS IN SICKLE CELL DISEASE

The American Society of Hematology (ASH) has advanced a sustained commitment to improving the lives of individuals living with sickle cell disease (SCD). What began as a call to action in 2015 has grown into a globally recognized initiative spanning clinical care, research, workforce development, policy advocacy, and international collaboration.

Guided by the needs of patients and providers, ASH has served as a convener, catalyst, and champion—mobilizing stakeholders, shaping systems, and delivering tools that make measurable change possible.



By the Numbers: A Decade of Impact

6 clinical
guidelines
published,
with **70,000+**
implementation
tools downloaded



160,000+
newborns
screened and SCD care
programs implemented in
**7 Sub-Saharan
countries**



130+
SCD-focused projects
funded, totaling over
\$18 million
in investment



Over 16,000
patient records
collected
through the
ASH Research Collaborative



90+
organizations united
to support **federal
SCD legislation**



102 SCD Coalition members,
advancing a
shared agenda
across disciplines



EXECUTIVE SUMMARY

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ASH's Impact Focuses on **Three Strategic Areas**



QUALITY CARE

- Developed and implemented evidence-based clinical practice guidelines
- Implemented the Sickle Cell Disease Coalition that connects stakeholders to address key challenges in quality care
- Created decision-making tools, educational resources, and emergency care standards
- Advocated for policy change, including the SCD Comprehensive Care Act
- Supported quality improvement and workforce training through 58 care institutions



RESEARCH

- Established the ASH Research Collaborative and SCD Clinical Research Network
- Led critical conversations with the FDA to accelerate drug approvals
- Launched updated research priorities in 2024 to guide the next five years
- Funded innovative investigator-initiated studies and data-driven analyses



GLOBAL ACTION

- Launched and supported the Consortium on Newborn Screening in Africa (CONSA)
- Expanded provider training through the Visitor Training Program
- Co-founded the World Coalition on SCD to align global strategy
- Shared ASH-developed tools and models across low-resource settings

Looking ahead, ASH's newly launched Center for Sickle Cell Disease Initiatives and SCD Task Force will lead strategy through 2031, building on the foundation of the past decade to shape what comes next.

ASH, in collaboration with partners across the globe, remains committed to creating a future where individuals with SCD have access to the care, treatments, and better health outcomes they deserve.

[HEMATOLOGY.ORG/SCD](https://hematology.org/scd)



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