

ABOUT THE SICKLE CELL DISEASE PARTNERSHIP

| a multi-sector policy and advocacy collaboration on sickle cell disease



ABOUT US

The Sickle Cell Disease Partnership - launched in early 2022 - is a multi-sector public policy and advocacy collaboration **committed to advancing actionable federal healthcare policies that will improve the lives of patients living with sickle cell disease** (SCD). The Partnership's work is grounded in the National Academies of Science, Engineering, and Medicine (NASEM) report released in 2020: "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action." The report outlines current guidelines and best practices for the care of patients with SCD and recommends priorities for programs and policies.

Our Mission

The Partnership's mission is to collaboratively achieve specific federal policy objectives, including regulatory and statutory changes, to ensure timely, sustained access to high-quality, equitable, coordinated, and comprehensive subspecialty, primary, and psychosocial care and access to existing and new disease-modifying and potentially curative therapies.

Our Vision

Our vision is a day when every individual with SCD in the United States lives to his or her fullest potential because the individual has timely, sustained access to high-quality, equitable, coordinated care and treatment.



ABOUT SICKLE CELL DISEASE

SCD is a rare, genetic blood disorder that primarily affects Black individuals. SCD is inherited when a child receives two sickle cell genes—one from each parent. Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In someone with SCD, the red blood cells become hard, sticky, and C-shaped. The sickle cells can easily get stuck and clog blood flow, which can cause **pain and other serious problems such as infection, acute chest syndrome, lung problems, severe pain, and stroke.**

100k

Americans are living with SCD

1 in 365

Black newborns will have SCD

\$1.6 m

The estimated lifetime medical expenses for SCD

LEARN MORE

To learn more about SCD, the Partnership's work, and recent progress, please visit us at sicklecellpartnership.org. If interested in joining the Partnership and helping to advance SCD-related policy priorities, please email us at Josh.Trent@LeavittPartners.com.