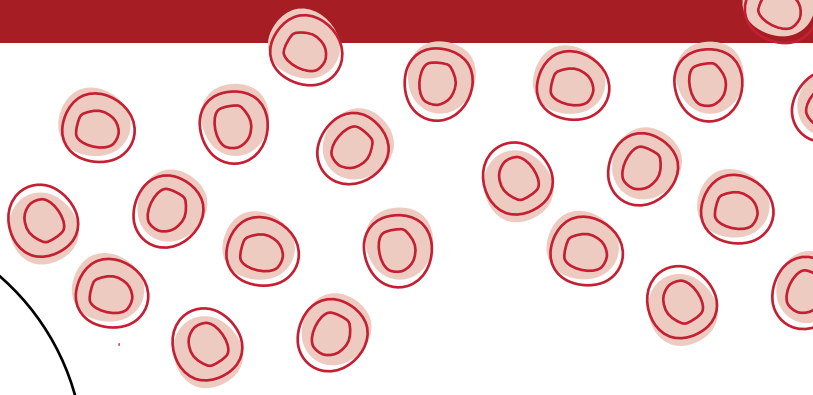
WHAT IS SICKLE CELL DISEASE (SCD)?

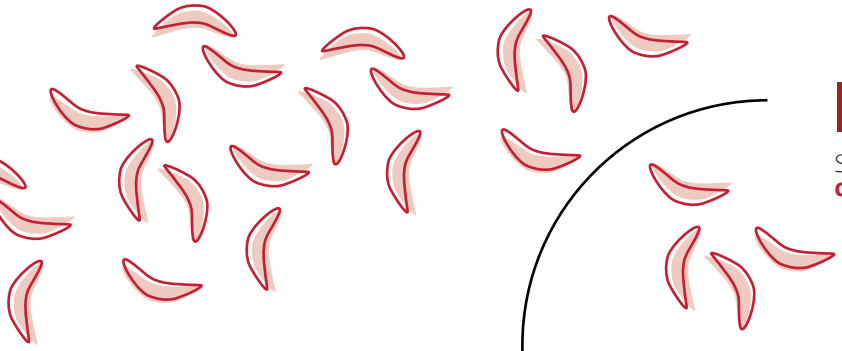
SCD is a blood disorder

SCD is an **inherited blood disorder** that affects red blood cells. Normal red blood cells are round and flexible, which lets them travel through small blood vessels to deliver oxygen to all parts of the body.



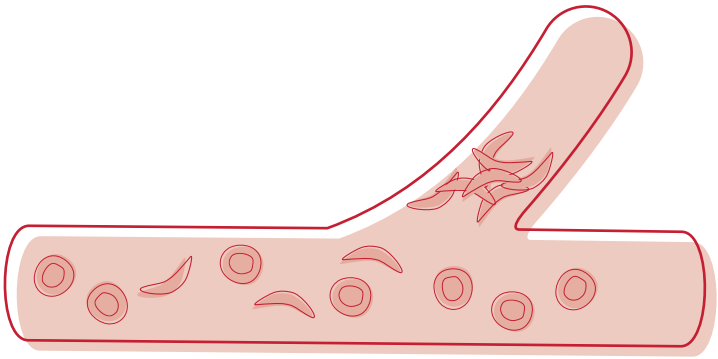
It causes misshapen blood cells

SCD causes red blood cells to **form into a crescent shape**, like a sickle.



And creates painful complications

The sickle-shaped red blood cells break apart easily, clump together, and stick to the walls of blood vessels, blocking the flow of blood which can cause a range of serious health issues.



In the United States, it is estimated that:

SCD occurs in
1 in 365
AFRICAN-AMERICAN BIRTHS[1]

SCD affects approximately
100,000
INDIVIDUALS[1]

Approximately
3,000,000
HAVE SICKLE CELL TRAIT[1]

The American Society of Hematology (ASH) represents more than 17,000 clinicians and scientists across the country committed to the study and treatment of blood and blood-related diseases. ASH members include clinicians who specialize in treating children and adults with SCD and researchers who investigate the causes and potential treatments of SCD manifestations. To learn about how ASH is working towards conquering sickle cell disease, visit www.hematology.org/scd.

1. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/sicklecell/data.html.

SCD Today:
Challenges and Opportunities

Though individuals with SCD are living longer, many are unable to access quality care and have limited treatment options to effectively address their condition.

75%

of adults with SCD and frequent pain crises fail to get hydroxyurea, which is the recommended treatment.[2]

Only 1 in 3

children with SCD receive appropriate monitoring for stroke by age 2.[3]

Treatment value

Children not treated with hydroxyurea accrue over $500,000 more in health care costs than those who receive this treatment.[4]

Only 2 treatment options:

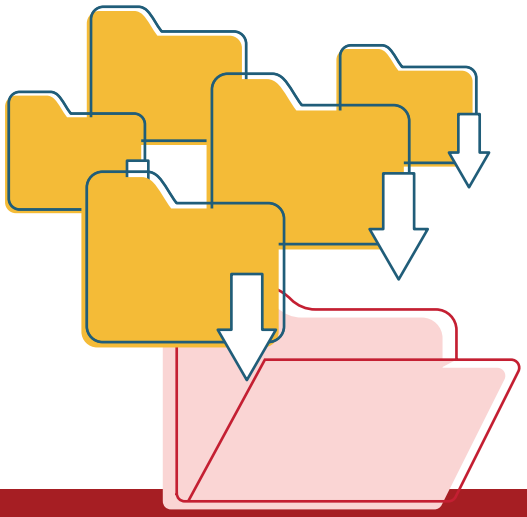
Hydroxyurea and L-glutamine are currently the only FDA-approved medications used to treat SCD. L-glutamine has been approved to treat patients 5 years and older.

90%

of people with SCD today live well into adulthood, which poses new issues and challenges.[5]

Bone marrow transplantation

is a cure for some individuals with SCD but may not be an option for everyone.



DATA COLLECTION

Data collection programs are necessary to understand the health outcomes and health care utilization patterns of individuals with SCD and to build cost-effective practices to improve and extend these patients' lives.

Currently, the CDC collects data on the incidence and treatment progress of individuals through funding provided by the CDC Foundation. As a result, data collection programs only occur in two states: California and Georgia. The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 authorizes an expansion of CDC's data collection efforts. Newly authorized data collection grants will need funding in 2020 and beyond.

OPPORTUNITIES

Strategic investments in research, training, and services can provide immediate, actionable opportunities that change the narrative for people living with SCD:

Increased funding

for regional grants improves care by providing genetic counseling and testing, training health professionals, and expanding continuity of care.

New, dedicated funding

to allow for the expansion of existing data collection programs across the U.S. SCD population increases evidence for public health programs to establish cost-effective practices that improve and extend the lives of people with SCD.

Development of education

and outreach efforts for the general public and medical community increases overall awareness of SCD and knowledge of health outcomes, helps audiences understand the effects of medical interventions, and informs best practices.

For more information, visit www.hematology.org/SCD

2. Nicolas Stettler, Colleen M. McKiernan, Court Q. Melin, Oluwkayode O. Adejoro and Nancy B. Walczak, "Proportion of Adults with Sickle Cell Anemia and Pain Crises Receiving Hydroxyurea," The Journal of the American Medical Association 313, no. 16 (April 2015): 1671-72.
3. Cindy E. Neunert, Robert W. Gibson, Peter A. Lane, Pragya Verma-Bhatnagar, Vaughn Barry, Mei Zhou and Angela Snyder, "Determining Adherence to Quality Indicators in Sickle Cell Anemia Using Multiple Data Sources," American Journal of Preventive Medicine 51, no. S1 (July 2016): S24-30.
4. Winfred C. Wang, Suzette O. Oyeku, Zhaoyu Luo, Sheree L. Boulet, Scott T. Miller, James F. Casella, Billie Fish, Bruce W. Thompson and Scott D. Grosee, "Hydroxyurea Is Associated With Lower Costs of Care of Young Children With Sickle Cell Anemia," Pediatrics 132, no. 4 (October 2013): 677-683.
5. Sunil Joshi K., "Disparities in Sickle Cell Disease Management: Quest for Global Protective Immunity," MOJ Cell Science & Report 2, no. 4 (October 2015): 36.