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 BIRTHS¹
- SCD affects approximately 100,000 INDIVIDUALS¹
- Approximately 3,000,000 HAVE SICKLE CELL TRAIT¹

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.

## 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.

<table>
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<th>75%</th>
<th>Only 1 in 3</th>
<th>Treatment value</th>
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<td>of adults with SCD and frequent pain crises fail to get hydroxyurea, which is the recommended treatment.(^2)</td>
<td>children with SCD receive appropriate monitoring for stroke by age 2.(^3)</td>
<td>Children not treated with hydroxyurea accrue over $500,000 more in health care costs than those who receive this treatment.(^4)</td>
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### 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.

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**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.

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**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](http://www.hematology.org/SCD)

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