Understanding the impact of Sickle Cell Disease

What is Sickle Cell Disease?

SCD is a blood disorder. Sickle Cell Disease (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.

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

Creating 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
- SCD affects approximately 100,000 INDIVIDUALS
- Approximately 3,000,000 HAVE SICKLE CELL TRAIT

Though individuals with SCD are living longer, many are unable to access quality care. There is also a lack of treatment options to effectively address their condition.

SCD Today

- 75%+ of adults with SCD and frequent pain crises fail to get hydroxyurea, which is the recommended treatment.
- Only 1 in 3 children with SCD receive appropriate monitoring for stroke by age 2.
- Treatment value: Children not treated with hydroxyurea accrue over $500,000 more in health care costs than those who receive this treatment.

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ACCESS TO CARE IN THE U.S.

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TRAINING AND EDUCATION

- 73% of family physicians believe that more education and support tools would help avoid complications in managing SCD.
- 69% of family physicians report that clinical decision support tools would be useful for treating SCD.
- Only 20% of family physicians report feeling comfortable treating people with SCD.

RESEARCH & CLINICAL TRIALS

- Only 1 treatment (hydroxyurea) is currently approved by the FDA to treat SCD in adults — it is often used off-label in children.
- Stem cell transplantation has shown success in curing some individuals with SCD, but it is not widely available.
- 90%+ of people with SCD today live well into adulthood, which poses new issues and challenges.

GLOBAL

- 90%+ of children with SCD do not survive to adulthood in resource-poor countries.
- Approx. 1,000 children are born with SCD in Africa every day, and more than half will die before the age of five.
- Growth in the number of people with SCD expected globally by 2050.

For a more detailed look at the state of SCD, and how a coalition of groups with an interest in SCD are working to improve care worldwide, visit scdcoalition.org.

REFERENCES

6. Ibid.
7. Ibid.