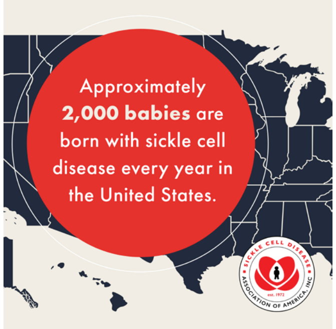
What is Sickle Cell Disease?

Advocacy Days, 2025

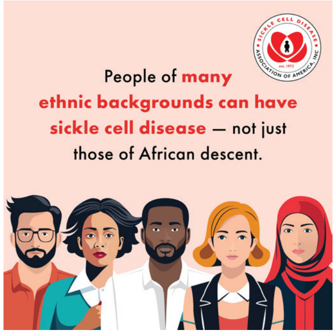
Sickle Cell Disease in the United States



Sickle cell disease (SCD) is a rare inherited red blood cell condition, which causes abnormal red blood cells that form into a crescent shape, break easily, clump together and block blood flow to organs and tissues. There is no universal cure.

Complications of SCD include strokes, anemia, periodic and severe acute pain episodes, decreased quality of life, fatigue and organ damage and other serious medical complications which can lead to a reduced life expectancy.

Early entry into evidence-based care including specialty care reduces complications, extends life expectancy for individuals living with SCD, and can lower costs for the health care system overall. While treatment options for SCD are still limited, in 2023, the U.S. Food and Drug Administration approved two gene therapies for the treatment of SCD. These therapies are the first of their kind and considered to be potentially curative. The goal of the Center for Medicare and Medicaid Innovation's (CMMI) Cell and Gene Therapy Access Model is to improve access to these gene therapies for individuals with SCD on Medicaid.



Sickle Cell Disease Association of America, Inc.

SCDAA is the national organization representing SCD community-based organizations (CBOs) and the sickle cell warriors they serve. SCDAA advocates for people affected by sickle cell conditions, works to educate and raise public awareness of the disease, and supports efforts to find a cure. SCDAA works in collaboration with its member organizations which include 57 CBOs in 30 states, which collectively serve over 500,000 individuals who are living with or are impacted by SCD.

What are Sickle Cell Disease Community-Based Organizations?

SCDAA's member organizations are 501(c)(3), community-based, not-for-profit organizations that provide services, education and support to individuals living with sickle cell disease and their families and caregivers. Community-based organizations:

- Support access to **clinical services,** such as testing for sickle cell trait, and facilitate connections to providers.
- Help provide access to **support services,** such as mental health groups and transition programs (to help teens with SCD transition from pediatric to adult health care).
- Provide access to **financial services** to help cover costs for critical needs, such as transportation, utilities and rent.

Community-based organizations are a trusted source of information and a lifeline to the SCD community.

For more information or for questions, please contact Regina Hartfield, SCDAA president and CEO, at rhartfield@sicklecelldisease.org.

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