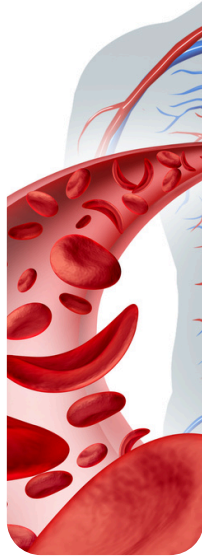




SICKLE CELL DISEASE IN ILLINOIS

01. Sickle Cell Disease: The Basics

Sickle cell disease (SCD) is a **group of inherited red blood cell disorders** affecting over 100,000 individuals in the U.S., including 1 in 365 Black or African Americans, and 1 in 16,000 Latino or Hispanic Americans. Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In someone who has SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle."



- People with SCD start to have signs of the disease during the first year of life, usually around 5 months of age.
- Symptoms and complications of SCD are different for each person and can range from mild to severe.
- The most common SCD complications are:
 - Pain crises (widespread pain in the body)
 - Acute chest syndrome
 - Stroke
 - Infection
 - Leg ulcers
- There are 3 FDA-Approved treatments for SCD
- Stem cell transplant & gene therapy are two curative options for SCD

SCD in IL 02.



In the U.S., 50-60% of individuals with SCD use Medicaid as their primary insurance. The proportion is higher in IL.



There are **5,000+** individuals living with SCD in IL, primarily in the Chicago area.



IL started newborn screening for SCD in 1989.



In Chicago, University of Illinois-Chicago, University of Chicago, and Rush University offer specialized care for adults with SCD.

03. Current IL Efforts Supporting SCD

HB 3916

Appropriates \$484,000 for the UIC Sickle Cell Clinic and \$1M for the Sickle Cell Chronic Disease Fund.

2025-2026 Appropriations

Public Act 102-0004

IDPH & IDHFS Publish the Sickle Cell Statewide Impact and Surveillance Program Report, as required in Public Act 102-0004.

03. Nat'l Support for SCD



Sickle Cell Disease Association of Illinois

Frontline services & advocacy



- The leading nonprofit in Illinois providing direct services for individuals with SCD and their families
- Hosts an annual "Advocacy Day" in Springfield
- HRSA Newborn Screening Grant Recipient (national)
- Sickle Cell Prevention, Care and Treatment Grant Recipient (Illinois)

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Sickle Cell Disease Association of America

National member organization



Sick Cells

National research and policy-focused nonprofit. Based in IL.