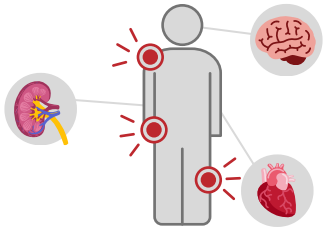
# SICKLE CELL DISEASE FACT SHEET

**Sickle cell disease** (SCD) is a rare, genetic, life-shortening blood disorder that affects every organ in the body.

SCD is is the most common inherited blood disorder in the U.S. It is caused by abnormal red blood cells. Instead of being soft and round, these red blood cells are **hard and sticky**, and shaped like a "sickle." This can **block blood flow** and oxygen from reaching all parts of the body.



The most common symptoms of SCD are recurring **pain crises**. The disease can also cause chronic complications such as organ damage, death of bone tissue, skin ulcers, stroke, blindness, neurocognitive impairment, pulmonary hypertension, heart and kidney failure, and early mortality.

There are over **100,000 individuals** with SCD in the United States.

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FDA-approved treatments

**Limited treatments:**

- Bone marrow/stem cell transplant
- Chronic transfusions
- Cell & Gene Therapy

- People with SCD have **less access** to comprehensive team care than people with genetic disorders such as hemophilia and cystic fibrosis.
- Current **standard of care for SCD treatments** is not appropriate for all individuals living with SCD.
- **Two gene therapy treatments were approved in 2024** for SCD. This development creates opportunities for legislative action to improve access to care and address issues with outdated healthcare payment models.

## WHAT DOES IT COST?

**$2.98B**

Annual direct cost of SCD to the U.S. federal government

Source: Huo et al., (2018) "The Economic Burden of SCD..."

**$10,000**

Annual individual cost of caring for an insured child with SCD

Source: Kauf et al., (2009) "The Cost of Healthcare..."

**$30,000**

Annual cost to an insured adult with SCD

Source: Kauf et al., (2009) "The Cost of Healthcare..."

Expenditures for patients with SCD are **6 times higher** than non-SCD patients on Medicaid and **11 times higher** than non-SCD patients with private insurance.

Source: HHS, "Sickle Cell Disease"