



## DID YOU KNOW?

The FDA recognizes that managing SCD is challenging for patients and their families and is committed to raising awareness of the disease and supporting the development of new treatments.

FDA encourages diverse participation in clinical trials.


If you think a clinical trial may be right for you, talk to your health care provider.

You can also search for clinical trials in your area at [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov).

### FOR MORE INFORMATION

 [www.fda.gov/HealthEquity](http://www.fda.gov/HealthEquity)

 [HealthEquity@fda.hhs.gov](mailto:HealthEquity@fda.hhs.gov)

 1-888-INFO-FDA  
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# SICKLE CELL DISEASE AND WHAT YOU NEED TO KNOW



FDA Office of Minority Health and Health Equity



## What is sickle cell disease?

Sickle cell disease (SCD) is an inherited blood disorder that causes red blood cells to change into a “C” shape that resembles a farm tool called a sickle. Normal red blood cells are round and flexible and travel through blood vessels to carry oxygen to the body’s tissues. Sickled red blood cells are rigid and can clog the blood flow, starving parts of the body of oxygen. This blockage can cause pain.

Approximately 100,000 children and adults in the United States are living with SCD. It is a lifelong condition that worsens over time. More than 3 million people in the United States carry the gene for SCD, a condition called sickle cell trait (SCT), and can pass this gene along to their children.



## What are symptoms of sickle cell disease?

Symptoms of SCD usually appear around 5 months of age and may include:

- Painful swelling of the hands and feet (dactylitis)
- Fatigue or fussiness from a shortage of oxygen in the blood (anemia)
- Yellowish color of the skin (jaundice) or in the white parts of the eye (icterus)



The hallmark symptom of SCD in children and adults is a pain crisis. Pain crises commonly occur in the abdomen, chest, lower back, arms, and legs. They can affect more than one part of the body and last for any length of time.

Sickle cell disease raises the risk of acute chest syndrome (ACS), infections, heart and kidney damage, and stroke. The symptoms and complications of SCD vary in severity from person to person and may change over time.

## How is sickle cell disease diagnosed?

In the United States, all newborns are screened for SCD using a simple blood test. Adults can get screened for SCT to estimate the likelihood that their child will inherit SCD.



## How is sickle cell disease treated?

The only cure for SCD is a bone marrow or stem cell transplant, though research is being conducted to determine if gene therapy can cure SCD. Younger patients with severe SCD can consider transplants, but they are expensive, require a matching donor, and have serious risks. They are used only in cases of severe SCD for younger patients who have minimal organ damage.

Pain crises are the most common cause of hospitalization. They are managed with nonsteroidal anti-inflammatory drugs (NSAIDs), opioids, antidepressants, and anticonvulsants. Blood transfusions (receiving healthy blood from a donor) can help prevent complications or treat severe anemia. Four FDA-approved medications may help prevent the common complications of SCD in children and adults:

- Hydroxyurea
- L-glutamine oral powder
- Voxelotor
- Crizanlizumab-tmca

There is no single best treatment for SCD. Talk to your health care provider to find a treatment plan that is right for you or your child.

