SICKLE CELL DISEASE

Fact Sheet

Sickle cell disease is an inherited blood disorder that can cause anemia, severe pain, infections, organ damage, and stroke. It is a lifelong condition that primarily affects Black or African American and Hispanic or Latino populations.

Office of Minority Health and Health Equity

What is sickle cell disease?

Healthy red blood cells are flexible and travel through your blood vessels to carry oxygen to your tissues. Sickle cell disease (SCD) is caused by a genetic mutation that changes the shape of red blood cells from round to C-shaped like a farm tool called a sickle. Sickled red blood cells are stiff and sticky and can get stuck in blood vessels and clog the blood flow, preventing oxygen from getting to parts of the body. This blockage can cause pain.

Who is affected by sickle cell disease?

Sickle cell disease is the most commonly inherited blood disorder in the United States. About 1 out of every 400 Black or African Americans and about 1 out of every 16,000 Hispanic or Latino Americans are born with SCD.

What are the symptoms of sickle cell disease?

The symptoms and complications of SCD vary in severity from person to person and may change over time. Early symptoms usually develop 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)

Adults and children living with SCD often experience pain crises, which are the most common cause of hospitalization. Sickle cell disease raises the risk of acute chest syndrome, infections, heart, kidney, and spleen damage, priapism, and stroke.

How is sickle cell disease diagnosed?

Since 2006, all U.S. states require newborn screening for SCD using a blood test. Adults can get screened to identify sickle cell trait (SCT), which is when a person carries the gene for SCD. Your health care provider can estimate your chances of passing the gene to your children.

How is sickle cell disease treated?

Patients may use pain medications to manage pain crises. 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

In 2023, the FDA approved two gene therapy products to treat SCD in patients 12 years and older, lovotibeglogene autotemcel and exagamglogene autotemcel. Patients who receive either SCD gene therapy product will take part in a long-term study to evaluate the safety and effectiveness of these gene therapy products.

Currently, the only cure for SCD is a bone marrow or stem cell transplant; however, more research is being done to determine if gene therapy can cure SCD. Younger patients with severe SCD can consider transplants, but they are expensive, require a matched donor, and have serious risks. Learn more about these FDA-approved gene therapies for the treatment of sickle cell disease.

Talk to your health care provider to find out if any of these medications or therapies are right for you or your child.

Sickle cell disease and clinical trials

The 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**.

For more information on health equity, visit **www.fda.gov/HealthEquity**.