Sickle Cell Disease

FACT SHEET

Sickle cell disease is an inherited red blood cell disorder. Red blood cells become rigid and shaped like crescent moons. When this happens, oxygen cannot get to parts of the body. This can cause fatigue, severe pain, organ damage, or stroke.

Office of Minority Health and Health Equity

What is Sickle Cell Disease?

Sickle cell disease (SCD) is the most common inherited blood disorder in the U.S. It primarily affects African Americans (1 in 365) and Hispanic Americans (1 in 16,300). It is a chronic condition that can cause severe pain, organ damage, or even stroke.

Signs and Symptoms of SCD

All U.S. states including District of Columbia (DC) and U.S. territories require that all newborns get screened for SCD. If a baby test positive, parents are notified, but most infants do not start having symptoms until they are about 5 or 6 month old.

Early symptoms of SCD may include:

- **Painful swelling of the hands and feet (dactylitis)**
- **Fatigue or fussiness from anemia**
- **Yellowish color of the skin (jaundice)**
- **Yellowish color in white parts of the eye (icteris)**

The symptoms and complications of SCD will vary in severity from person to person and can change over time.

SCD Treatment Options

Current treatments for sickle cell disease are limited to preventing and managing a pain crisis, which is the most debilitating symptom of SCD.

- **L-glutamine Oral Powder**: Patients can take this oral medication to reduce acute complications in adults and children older than 5 years.
- **Hydroxyurea**: Patients can take this oral medication to help reduces the frequency of pain crises and the need for blood transfusions.
- **Voxelotor**: Patients can take this oral medication to increase their hemoglobin in adults and children 4 years of age and older.
- **Crizanlizumab**: Patients receive this medication by vein to reduce the frequency of vasoocclusive crises in adults and pediatric patients aged 16 years and older.
- **Pain Medications**: Patients can manage their pain with non-steroidal anti-inflammatory drugs (NSAIDs), opioids, antidepressants, and anticonvulsants.
- **Chronic Transfusion Therapy**: Patients can get regular blood transfusions to help prevent complications.
- **Bone Marrow or Stem Cell Transplants**: Younger patients with severe SCD can consider transplants, but they are expensive, require a suitable bone marrow or stem cell donor and have serious risks.

SCD and Clinical Trials

Clinical trials are very important to developing more and better treatments for sickle cell disease. Your participation is voluntary. There are laws that protect your safety and your information is kept confidential. If you think a clinical trial may be right for you, talk to your doctor. You can also search for clinical trials in your area at, **www.ClinicalTrials.gov**.

For more information on health equity go to **www.fda.gov/healthequity**.

To watch videos and view a list of questions to ask researchers go to **www.hhs.gov/about-research-participation**.