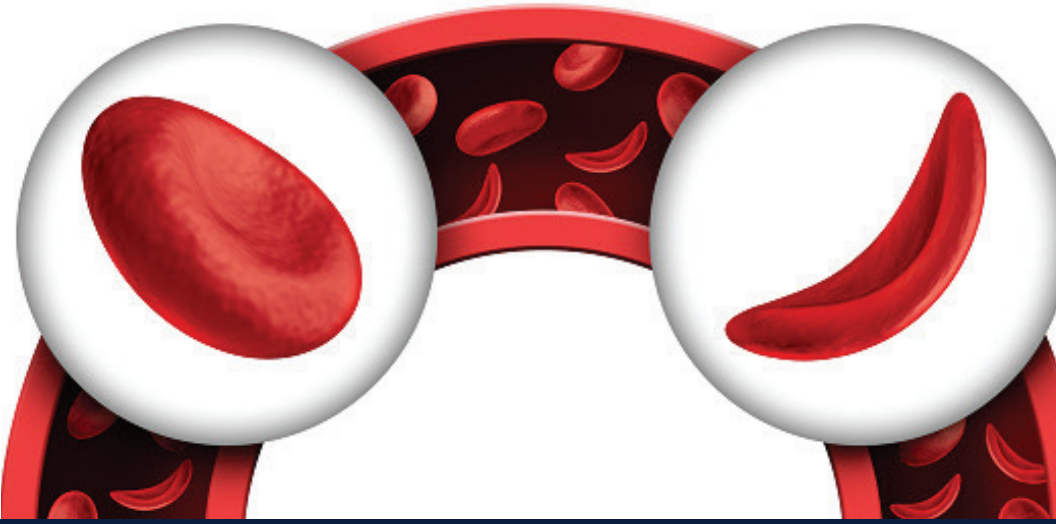
SICKLE CELL SERVICES FOR ADULTS



SOUTH CAROLINA
DEPARTMENT OF
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What problems are caused by Sickle Cell Disease?

Pain Episode or "Crisis": Sickle cells don't move easily through small blood vessels and can get stuck and clog blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.

Infection: People with SCD, especially infants and children, are more likely to experience harmful infections such as flu, meningitis, and hepatitis.

Hand-Foot Syndrome: Swelling in the hands and feet, often along with a fever, is caused by the sickle cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet.

Eye Disease: SCD can affect the blood vessels in the eye and lead to long term damage.

Acute Chest Syndrome (ACS): Blockage of the flow of blood to the lungs can cause acute chest syndrome. ACS is similar to pneumonia; symptoms include chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital.

Stroke: Sickle cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.

What complications are associated with Sickle Cell Trait?

Most people with sickle cell trait do not experience complications or have symptoms of SCD, but some people with SCT may experience these – very rare – complications. The following conditions could be harmful for people with SCT:

- Increased pressure in the atmosphere (e.g., experienced while scuba diving).
- Low oxygen levels in the air (e.g., when mountain climbing, exercising extremely hard in military boot camp, or training for an athletic competition). Due to this, the NCAA recommends that college athletics departments confirm the sickle cell trait status in all student-athletes.
- Dehydration (e.g., too little water in the body).
- High altitudes (e.g., when flying, mountain climbing, or visiting a city at a high altitude).

Is there a test for Sickle Cell Disease or Trait?

A simple blood test can show if you have sickle cell disease or trait. It is most often completed at birth during the routine Newborn Screening tests. Because of the risk and complications associated with SCD, early diagnosis and treatment are important. Currently, the only cure for SCD is bone marrow or stem cell transplant.

If you or someone you know is interested in being tested, you may contact your doctor, or a local community-based sickle cell organization.

What is Sickle Cell Trait?

When a person has sickle cell trait (SCT), they are a carrier of the sickle cell gene. This means a person with SCT, can pass the trait on to their children. It occurs when a person gets one sickle cell gene from one parent, and one normal red blood cell gene from the other parent. Someone who has SCT will not get SCD; sickle cell trait is not a disease and it cannot change into sickle cell disease. While persons with SCT usually live a normal life, sometimes problems may occur.

What is Sickle Cell Disease?

Sickle Cell Disease (SCD) is a group of inherited red blood cell disorders that is present from birth. Normal red blood cells are round and move easily through blood vessels. For someone who has SCD, the red blood cells become hard and sticky, and have a C-shape, like a farmer's sickle. These "sickled" cells become stuck in blood vessels and block the blood flow. Also, sickled cells die early which results in a constant shortage of red blood cells. This can cause pain, damage to body organs and anemia. SCD is inherited, which means it can run in families. It occurs when a person gets two sickle cell genes, one from each parent. A person cannot catch this disease from someone else. If you have sickle cell disease or trait, it is important to receive genetic counseling to know the chance of having a child with sickle cell disease or trait.

What are the facts?

- SCD affects approximately 100,000 Americans.
- SCD occurs among about 1 out of every 365 Black or African American births.
- SCD occurs among about 1 out of every 16,300 Hispanic-American births.
- About 1 in 13 Black or African American babies are born with sickle cell trait (SCT).
- If both parents have sickle cell disease, all their children will have sickle cell disease.

Who is affected by Sickle Cell Disease?

SCD is most common in people whose ancestors come from sub-Saharan Africa; Spanish-speaking areas of the world such as South America, the Caribbean, and Central America; India, Saudi Arabia and from Mediterranean areas, such as Turkey, Greece, and Italy. Other racial and ethnic groups can also be affected.

How is SCD and SCT inherited?

When one parent has sickle cell trait (AS), the other has regular hemoglobin (AA), the chances for each pregnancy are:

1 in 2 (50%) that the baby will have regular hemoglobin (AA)

1 in 2 (50%) that the baby will have sickle cell trait (AS)

When both parents have sickle cell trait, the chances for each pregnancy are:

1 in 4 (25%) that the baby's hemoglobin will be regular (AA)

2 in 4 (50%) that the baby will have sickle cell trait (AS)

1 in 4 (25%) that the baby will have sickle cell disease (SS)

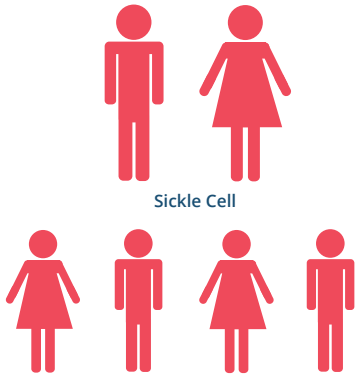
When one parent has sickle cell trait and the other has sickle cell disease, the chances for each pregnancy are:

1 in 2 (50%) that the baby will have the trait (AS)

1 in 2 (50%) that the baby will have the disease (SS)

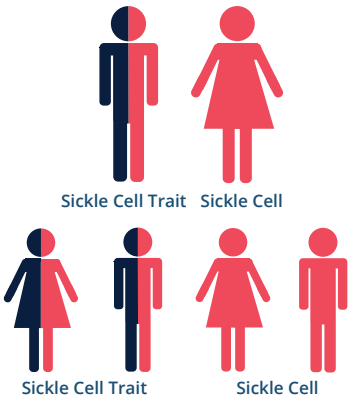
If both parents have sickle cell disease, all their children will have sickle cell disease

When both parents have Sickle Cell



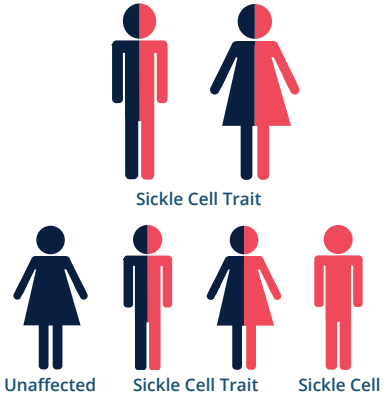
Risk for child to
Have Sickle Cell 100%
Have Sickle Cell Trait 0%

When one parent has Sickle Cell & another has the Sickle Cell Trait



Risk for child to
Have Sickle Cell 50%
Have Sickle Cell Trait 50%

When both parents have the Sickle Cell Trait



Risk for child to
Have Sickle Cell 25%
Have Sickle Cell Trait 50%

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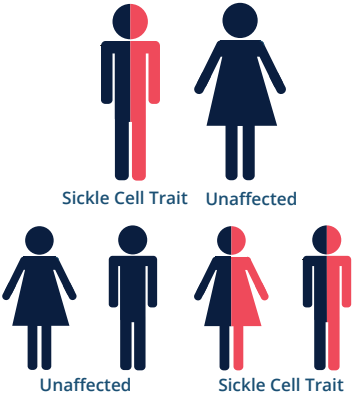
When one parent has the Sickle Cell Trait



Risk for child to
Have Sickle Cell 0%
Have Sickle Cell Trait 50%

LIVING WELL WITH SCD

A person with SCD can live a long and high-quality life. The following tips can help someone with SCD stay healthy as possible:

- Find medical care and get regular checkups or exams with your doctor
- Follow treatments as prescribed by your doctor, such as taking medications
- Prevent infections by taking simple steps including washing your hands
- Practicing healthy habits like drinking 8 to 10 glasses of water per day and eating healthy food

DPH SICKLE CELL PROGRAM

The DPH Sickle Cell Program works to increase public awareness on SCD related topics through education and client assistance.

In addition to education, the SCD program provides care coordination and payment assistance for medical services, supplies, equipment and medications for people with sickle cell disease. Care coordination is available to anyone referred to the program and this assists patients with obtaining needed services and supplies.

Who is eligible?

- U.S. citizenship or lawful permanent residency
- South Carolina residency
- Household income at or below 250%of the federal poverty level
- Physician diagnosed sickle cell disease or other congenital hemoglobinopathies

What client services are provided?

- Payment for outpatient medical services, supplies, equipment, and prescription medications related to treatment of sickle cell disease
- Care coordination as needed
- Nursing, nutrition, and/or social work consultation as needed (depending on regional resources)

SICKLE CELL COMMUNITY-BASED ORGANIZATIONS

There are four community-based organizations across the state that serve patients and families with sickle cell disease and trait. These organizations offer genetic counseling, education, sickle cell testing, and nurse case management for families.

COBRA Human Services Agency Sickle Cell Program

3962 Rivers Ave., Charleston SC 29405

Phone: (843) 225-4866

Fax: (843) 225-4869

Toll Free: (800) 354-4704

James R. Clark Memorial Sickle Cell Foundation

1420 Gregg St., Columbia SC 29201

Phone: (803) 765-9916

Fax: (803) 799-6471

Toll Free: (800) 506-1273

Orangeburg Area Sickle Cell Anemia Foundation

825 Summers Ave., Orangeburg SC 29115

Phone: (803) 534-1716

Fax: (803) 534-2422

Louvenia D. Barksdale Sickle Cell Anemia Foundation

645 S. Church St., Spartanburg SC 29306

Phone: (864) 582-9420

Fax: (864) 582-9421

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