

SickleCell.org | Pregnancy and Family Planning

 sicklecelltrait.org/familyplan

HOW IS SICKLE CELL INHERITED?

There are several possibilities for children whose parents have sickle cell trait or sickle cell disease.

If one parent has sickle cell trait and the other parent has normal hemoglobin, the chances for each pregnancy are:

- 1 in 2 (50%) that the baby will have normal hemoglobin.
- 1 in 2 (50%) that the baby will have sickle cell trait.

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

- 1 in 4 (25%) that the baby will have normal hemoglobin.
- 2 in 4 (50%) that the baby will have sickle cell trait.
- 1 in 4 (25%) that the baby will have sickle cell disease.

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

- 1 in 2 (50%) that the baby will have sickle cell trait.
- 1 in 2 (50%) that the baby will have sickle cell disease.

If one parent has sickle cell disease and the other parent has normal hemoglobin, the chances for each pregnancy are:

- 4 in 4 (100%) that the baby will have sickle cell trait.

If both parents have sickle cell disease:

- 4 in 4 (100%) that the baby will have sickle cell disease.

WHAT IS SICKLE CELL TRAIT?

Sickle cell trait (SCT) is an inherited condition that affects the hemoglobin in red blood cells. Hemoglobin is the part of the red blood cell that carries oxygen from the lungs to other parts of the body. There are many different types of hemoglobin. The type of hemoglobin a person has depends on the genes passed down from both parents. Genes can determine things like gender or eye color.

Normal hemoglobin is called hemoglobin A and one type of abnormal hemoglobin is hemoglobin S. A person with sickle cell trait has inherited a normal hemoglobin A gene from one parent, and an abnormal hemoglobin S gene from the other parent.

Sickle cell trait is not a disease. Most people with sickle cell trait do not have any health problems. However, there are rare cases where individuals with sickle cell trait have experienced physical problems at high altitudes or in places where oxygen levels are low, like scuba diving.

There are several different types of abnormal hemoglobin genes. While hemoglobin S (sickle hemoglobin) is one of the most common types of abnormal hemoglobins, there is also hemoglobin C, beta-thalassemia, and others. So, it is possible to have a baby with sickle cell disease if only one parent has sickle cell trait, but the other parent has one of these other abnormal hemoglobins. This makes it important to talk to your healthcare provider

WHAT IS SICKLE CELL DISEASE?

Sickle cell disease (SCD) is the most common genetic, blood disorder in the United States. It is a serious, lifelong disease that can be life-threatening.

It is an inherited disorder that affects hemoglobin in red blood cells. Normal red blood cells are soft, round and can squeeze through blood vessels. Sickle cell disease causes the red blood cells to become stiff and sickle shaped (crescent shaped). This makes it difficult for the red blood cells to move through blood vessels. When sickled cells block blood vessels, less blood can reach that part of the body, and this can damage tissues and organs. This causes severe pain episodes.

Sickle cell disease is not contagious. You can only inherit it if both parents pass it on to you. If you were not born with sickle cell disease, you cannot get it later in life.

Sickle cell disease can be found in people of African, Asian, Caribbean, Indian, Mediterranean, Middle Eastern, South and Central American descent. About 1 in 400 African Americans have sickle cell disease.

In the United States, an estimated 100,000 people have sickle cell disease.

WHAT IS THE DIFFERENCE BETWEEN SCT & SCD?

Sickle cell trait is not sickle cell disease. Most people with sickle cell trait do not have any health problems because of sickle cell trait. People with sickle cell disease have serious medical complications.

WHY IS SCT IMPORTANT?

If you have trait, you are at risk of having a child with sickle cell disease. Knowing your trait status, as well as your partner's trait status is important for family planning.

WHO DOES SCT AFFECT?

Sickle cell trait can be found in people of African, Asian, Caribbean, Indian, Mediterranean, Middle Eastern, South and Central American descent. About 1 in 10 African Americans have sickle cell trait.

People with sickle cell trait will never get the disease, but they carry a gene that could affect their children.

HOW DO I GET TESTED?

A simple blood test called a hemoglobin electrophoresis can determine if a person has sickle cell trait or disease. A complete blood count (CBC) is also important when testing for sickle cell trait before planning for a pregnancy. Ask your health care provider for more information about testing and genetic counseling services.

If both parents know their trait status and are at risk of having a child with sickle cell disease, pre-implantation genetic diagnosis is a test that is available. In vitro fertilization (IVF) and pre-implantation genetic diagnosis can be used to identify embryos without sickle cell disease. Embryos that are not

affected with sickle cell disease can then be selected for implantation to establish a pregnancy. Talk to your obstetrician/gynecologist for more information about this option.

WHAT IS NEWBORN SCREENING?

Newborn screening is a blood test taken after a baby is born, and before leaving the hospital. A few drops of blood are taken from the baby's heel and sent to the state laboratory. Babies in all 50 states are tested for sickle cell disease, among other genetic, endocrine and metabolic disorders. In Ohio, babies are also tested for sickle cell trait.

Results will be sent to the newborn's healthcare provider, so it is important to make sure they have your correct address and phone number in case you need to be contacted. You should also ask about newborn screening results at the baby's first doctor's visit.

WHAT IF YOUR CHILD HAS SCT?

Knowing your child has sickle cell trait is important. You should make sure to write this information down and keep with your child's immunization or medical records, or their important family papers. Although having sickle cell trait should not cause any medical issues, you should make sure that all of your child's healthcare providers know that your child has sickle cell trait.

As your child becomes an adolescent, it is important to remind your child about sickle cell trait, and the possibilities of having a child with sickle cell disease.

If your child is planning to play college sports at a NCAA Division I, II or III school, your child may be asked to provide documentation of sickle cell trait status.