

BC Newborn Screening Program

Information Sheet

My Baby Has Sickle Cell Trait

What does this mean for my baby, me and my family?

Your baby's newborn screening test showed that he or she has sickle cell trait (this is also referred to as being a "sickle cell carrier"). Babies who have sickle cell trait are no more likely to get sick than any other baby. They do not need any special medical treatment. Sickle cell trait will not change into a disease later on.

What causes sickle cell trait?

Sickle cell trait happens when the part of the red blood cell that carries oxygen throughout the body is changed. This part that is changed is called hemoglobin. Hemoglobin is important because it picks up oxygen in the lungs and carries it to the other parts of the body.

People usually have one type of hemoglobin. This is called hemoglobin A. Babies with sickle cell trait have an unusual type of hemoglobin called hemoglobin S, as well as the usual hemoglobin A.

The type of hemoglobin a baby has depends on the genes that they inherited from their parents. Babies with sickle cell trait inherited one gene for hemoglobin A from one parent and one gene for hemoglobin S from the other parent.

Why is it important to understand that my baby has sickle cell trait?

It is important to know so that you can tell your child later in life that he or she has sickle cell trait. His or her future partner can then choose to have sickle cell testing. This information will tell them their chance to have a baby with sickle cell anemia (also known as sickle cell disease).

Most adults with sickle cell trait are healthy. Rarely, an adult with sickle cell trait will have health problems when they go through extreme stress or do hard physical work. This is another reason to tell your child that they have sickle cell trait later in life. The newborn screening website has more information about this.

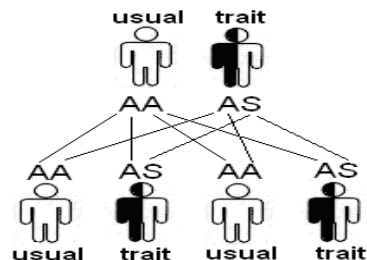
What does having a baby with sickle cell trait mean for me, my partner and for future pregnancies?

Since your baby has sickle cell trait, this means that either you or your partner, or both of you have sickle cell trait. In almost all cases, **ONLY ONE OF YOU** will have sickle cell trait.

Most people do not know that they have sickle cell trait. Now that your baby is known to have sickle cell trait, both you and your partner have the option of being tested. Testing involves a blood test.

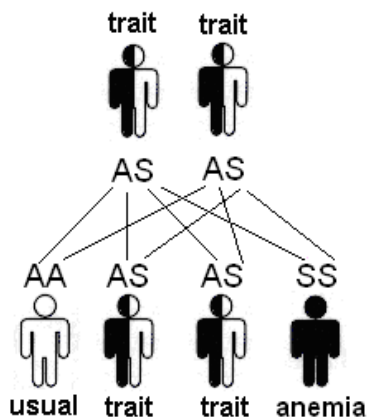
IF ONLY ONE OF YOU HAS SICKLE CELL TRAIT, in every pregnancy there is a:

- 1 in 2 (50%) chance to have a baby with only the usual hemoglobin A. This is normal.
- 1 in 2 (50%) chance to have a baby that has sickle cell trait. This is harmless.



In the unlikely event that **BOTH OF YOU HAVE SICKLE CELL TRAIT**, in every pregnancy there is a:

- 1 in 4 (25%) chance to have a baby with only the usual hemoglobin A. This is normal.
- 1 in 2 (50%) chance to have a baby with sickle cell trait. This is harmless.
- 1 in 4 (25%) chance to have a baby with sickle cell anemia.



If both of you have sickle cell trait and you become pregnant in the future, you will have the option of having your baby tested during pregnancy through prenatal diagnosis or after birth through newborn screening.

Should my other children be tested?

IF ONLY ONE OF YOU HAS SICKLE CELL TRAIT, it is suggested that you discuss the testing of your other children with your family doctor. While it is usually recommended to delay the testing of other children until they can make their own decision about whether to be tested, some parents may choose to have their child tested before this because of the small risk of health problems when the child goes through extreme stress or does hard physical work.

IF BOTH OF YOU HAVE SICKLE CELL TRAIT, your other children may be tested (a blood test) to make sure they do not have

sickle cell anemia. Your family doctor can arrange the testing.

Should my relatives be tested?

Any blood relative (for example, brother, sister, aunt or cousin) of a person with sickle cell trait may also have sickle cell trait. Your relatives may have questions about their chance of having a baby with sickle cell anemia. We suggest they talk to their family doctor who may offer them testing.

What is sickle cell anemia?

People with sickle cell anemia get two genes for hemoglobin S. These genes cause the blood cells to have a different shape when oxygen levels in your blood are low. They look like a sickle. The sickled red blood cells can become stuck in small blood vessels, block the blood supply and cause pain and damage in that part of the body. They also cause a low blood count that makes the person tired and short of breath. This is called anemia and it does not go away. It is important for babies with sickle cell anemia to receive regular medical care.

How common is sickle cell anemia?

Sickle cell anemia affects both males and females. It is common among people and families of African, Caribbean, Middle Eastern, Asian, Mediterranean, Indian and Central and South American descent. This is because malaria is common in these regions. People with sickle cell trait do better when infected with malaria than people who do not have sickle cell trait. In other words, it is an advantage in these parts of the world to have sickle cell trait. In British Columbia, sickle cell anemia is found in 1 or 2 babies each year.

How can I get more information?

Talk to your family doctor.

You may also want to think about talking to an expert about how family traits are passed on. This is called genetic counselling. You can also talk about your testing options and get more details on how these traits may affect other family members. You can get genetic counselling through the Department of Medical Genetics at BC Children's and Women's Health Centre or Vancouver Island Medical Genetics (at Victoria General Hospital). Ask your family doctor to refer you.

www.newbornscreeningbc.ca gives more information about newborn screening in British Columbia.

This fact sheet provides basic information only. It does not take the place of medical advice, diagnosis or treatment. Always talk to a healthcare professional about specific health concerns.

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