NEWBORN SCREENING BC

Information sheet

My Baby Has Sickle Cell Trait (Sickle Cell carrier)

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

Your baby had a newborn screen. This test was done on a blood sample collected by heel prick shortly after birth. This screen tests for a number of rare conditions like hemoglobin disorders. Knowing if your child has one of these conditions early in life is important because early diagnosis allows for early treatment and better health outcomes.

Your baby does **not** have a hemoglobin disorder but by chance the test picked up that your baby is a sickle cell carrier (also known as "sickle cell trait").

Sickle cell trait is NOT a disease and it will not change into a disease later in life. Many healthy people are sickle cell carriers. Babies with sickle cell trait do NOT need any special medical care.

What causes sickle cell trait?

Hemoglobin is an important protein found in our red blood cells. It picks up oxygen from our lungs and carries it to every part of our body. Hemoglobin is made in our cells by following a set of instructions (like a recipe) called a gene. This gene is called the beta globin gene. Normally we have two copies, one inherited from each parent. Changes in the beta globin gene cause hemoglobin variants like hemoglobin S.

Most people make a single type of hemoglobin called hemoglobin A. People with hemoglobin S trait make two types of hemoglobin: the usual hemoglobin A and the variant hemoglobin S. Since your baby is still making some hemoglobin A, they are able to transport oxygen efficiently and are **not** more likely to get sick than other babies.

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

Knowing about having sickle cell trait is usually only important when planning to have children. When both parents carry a beta globin gene variant then they may have an increased chance of having a baby with a hemoglobin disorder that could impact a baby's health.

For this reason, it is important to know about your child's sickle cell trait so that you can tell them about it later in life. Their future partner can then choose to be tested.

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 BC Children's Hospital website has more information about this.

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

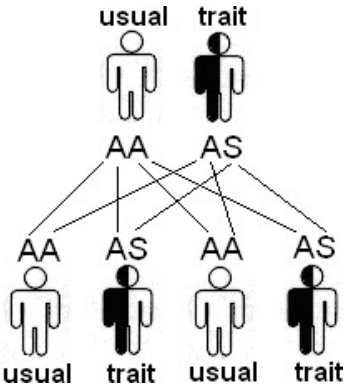
Most people do not know that they carry a hemoglobin variant because it does not typically effect their health. But now that your baby is known to have sickle cell trait, this means that either you or your partner or both of you have sickle cell trait. In most cases, ONLY ONE OF YOU will have a hemoglobin trait. To confirm this you and your partner have the option of being tested. Testing involves a blood test called "hemoglobin investigation". Ask your family doctor to arrange this test for you if you want to know your carrier status. This would be especially important to do if you plan on having more children.

If only one of you has sickle cell trait

In every pregnancy there will be a:

- 1 in 2 (50%) chance to have a baby with only hemoglobin A. This is normal.

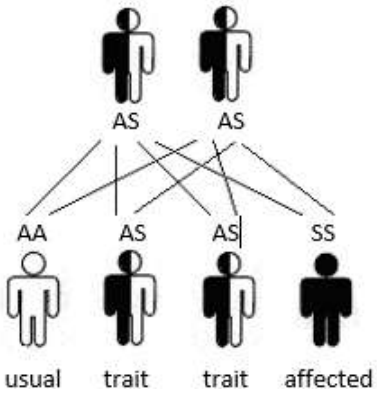
- 1 in 2 (50%) chance to have a baby with sickle cell trait, meaning the baby makes both hemoglobin A and hemoglobin S. This is harmless.



If both of you have sickle cell trait

In the unlikely event that both of you have sickle cell trait, in every pregnancy there will be a:

- 1 in 4 (25%) chance to have a baby with only 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 affected with sickle cell disease. In this case, the baby does not make any hemoglobin A.



What is sickle cell disease?

People with sickle cell disease have a genetic combination that causes the red blood cells to have a different shape (like a sickle or crescent moon) when oxygen levels in the blood are low. These red blood cells are called “sickle cells.” Sickle cells can become stuck in small blood vessels throughout the body, blocking the blood supply and causing pain and damage to the affected body tissues. Sickle cells also break down (hemolyse) more quickly than usual, causing significant anemia. Other issues people with sickle cell anemia may experience include jaundice, an increased chance of infections, and delayed growth. There is a lot of variability in how sickle cell disease can present.

What if ONE of us has sickle cell trait and the OTHER has another type of hemoglobin variant?

Depending on the other hemoglobin variant, there may be a 1 in 4 (25%) chance in each pregnancy to have a baby with a type of sickle cell disease. Hemoglobin variants that can result in this condition include hemoglobin C, D, E and beta thalassemia trait. Sickle cell disease is a serious hemoglobin disorder and it is important that babies with sickle cell disease to receive regular medical care.

Parents who have a chance of having a baby with sickle cell disease and are planning another pregnancy can be referred to a genetic counsellor by their doctor. The genetic counsellor will review all your testing options which include testing before, during or after a pregnancy.

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. It is usually recommended to delay the testing of other children until they can make their own decision about whether to be tested. However 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 or ONE OF YOU HAS SICKLE CELL TRAIT AND THE OTHER HAS ANOTHER HEMOGLOBIN VARIANT OR BETA THALASSEMIA TRAIT, your other children may be tested (a blood test) to make sure they do not have sickle cell disease. Your family doctor can arrange this testing.

Should my relatives be tested?

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

How common is sickle cell disease?

Although sickle cell disease occurs in all ethnic groups, it is more common in certain populations, such as the African, Mediterranean, Middle Eastern, and Asian communities.

How can I get more information?

Talk to your family doctor.

If you and your partner have a chance of having a baby with sickle cell disease, then genetic counselling is an option. Ask your family doctor to refer you to the Department of Medical Genetics at BC Children's and Women's Hospital or Vancouver Island Medical Genetics (at Victoria General Hospital) for genetic counselling.

Information about the BC Newborn Screening Program can be found at
www.newbornscreeningbc.ca

For more information on sickle cell trait please visit
www.bcchildrens.ca

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