NEWBORN SCREENING BC

Information sheet

My Baby Has Hemoglobin C Trait (Hemoglobin C 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 hemoglobin C carrier (also known as "hemoglobin C trait").

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

What causes hemoglobin C 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 C.

Most people make a single type of hemoglobin called hemoglobin A. People with hemoglobin C trait make two types of hemoglobin: the usual hemoglobin A and the variant hemoglobin C. 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 hemoglobin C trait?

Knowing about having hemoglobin C 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 hemoglobin C trait so that you can tell them about it later in life. Their future partner can then choose to be tested.

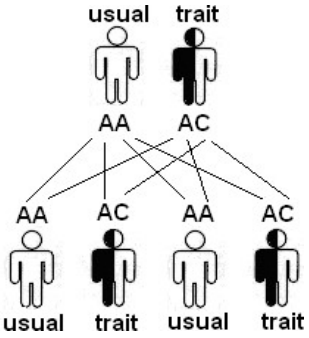
What does having a baby with hemoglobin C trait mean for me, my partner and for future pregnancies?

Most people do not know that they carry a hemoglobin variant because it does not typically affect their health. But now that your baby is known to have hemoglobin C trait, this means that either you or your partner or both of you have hemoglobin C 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 hemoglobin C 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 hemoglobin C trait, meaning the baby makes both hemoglobin A and hemoglobin C. This is harmless.



Provincial Health Services Authority

Newborn Screening BC is a collaboration of Provincial Lab Medicine Services, BC Children's Hospital and BC Women's Hospital and Health Centre, and Perinatal Services BC, all part of the Provincial Health Services Authority.

If both of you have hemoglobin C trait

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

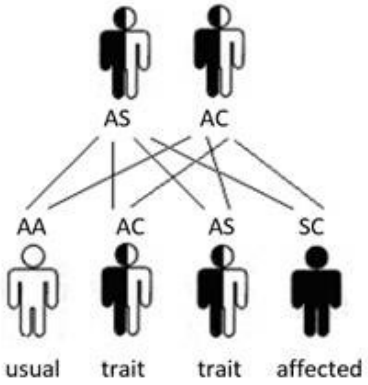
- 1 in 4 (25%) chance to have a baby with only hemoglobin A. This is normal.
- 1 in 2 (50%) chance to have a baby with hemoglobin C trait. This is harmless.
- 1 in 4 (25%) chance to have a baby with only hemoglobin C, so the baby does not make any hemoglobin A. This can cause a mild anemia and a slightly enlarged spleen, but otherwise does not cause health problems in most people.

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

The chance of this is low. If it were to happen, the seriousness would depend on the type of hemoglobin variant. Some hemoglobin variant combinations cause no health problems.

If one of you has hemoglobin C trait and the other has sickle cell trait

There is a 1 in 4 (25%) chance in each pregnancy to have a baby with a serious hemoglobin disorder called hemoglobin SC disease.



What is hemoglobin SC disease?

People with hemoglobin SC disease have one gene for hemoglobin S and one gene for hemoglobin C. This gene combination causes the blood cells to have a different shape (like a sickle or crescent moon) when oxygen levels in your blood are low. 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 called anemia. It is important for babies with hemoglobin SC disease to receive regular medical care.

Parents who have a chance of having a baby with hemoglobin SC 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 relatives be tested?

Any blood relative (for example, brother, sister, aunt, uncle or cousin) of a person with hemoglobin C trait may also have hemoglobin C 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 are hemoglobin variants?

There are many different types of hemoglobin variants. Although anyone can be a carrier of a hemoglobin variant, it is more common among people of African, Caribbean, Middle Eastern, Asian, Mediterranean, Indian and Central and South American descent.

How can I get more information?

Talk to your family doctor.

If you and your partner have a chance of having a baby with hemoglobin SC, 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

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.

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