NEWBORN SCREENING BC

Information sheet

My Baby Is a Carrier of a Hemoglobin Variant

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 is done to identify a number of rare but treatable conditions which usually do not have any symptoms early on. 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 carrier of a hemoglobin variant (also known as "trait").

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

What causes hemoglobin variants?

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.

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

Knowing about carrying a hemoglobin variant 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 variant so that you can tell them about it later in life. Their future partner can then choose to be tested.

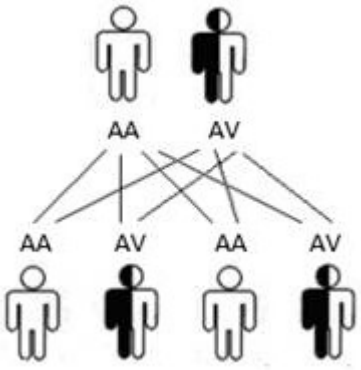
What does having a baby with a hemoglobin variant mean for me, my partner and for future pregnancies?

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 carry a hemoglobin variant, this means that either you or your partner or both of you carry a hemoglobin variant. In most cases, ONLY ONE OF YOU will carry a hemoglobin variant. To confirm this you and your partner have the option of being tested. Testing involves a blood test called "hemoglobin investigation". Ask your primary care provider 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 carries a hemoglobin variant

In every pregnancy there will be a:

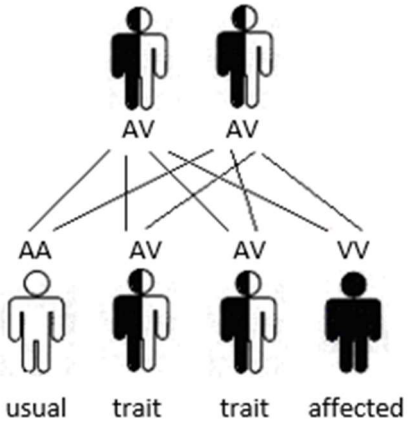
- 1 in 2 (50%) chance to have a baby with only hemoglobin A. This is normal.
- 1 in 2 (50%) chance to have a baby who carries a hemoglobin variant, meaning the baby makes both hemoglobin A and a hemoglobin variant. This is harmless.



If <u>both</u> of you have a hemoglobin variant

In the unlikely event that both of you carry a hemoglobin variant, 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 who carries a hemoglobin variant. This is harmless.
- 1 in 4 (25%) chance to have a baby with only hemoglobin variants, so the baby does not make any hemoglobin A. Depending on the variants involved, this may cause a serious hemoglobin disorder that requires special medical care. However some combinations cause no health problems.



Should my relatives be tested?

Any blood relative (for example, brother, sister, aunt, uncle or cousin) of a person who carries a hemoglobin variant may also carry a hemoglobin variant. Your relatives may have questions about their chance of having a baby with a hemoglobin disorder. We suggest they talk to their primary care provider 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 primary care provider.

If you and your partner both have a hemoglobin variant and you have a chance of having a baby with a serious hemoglobin disorder, then genetic counselling is an option. Ask your primary care provider 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.