My Baby Is a Carrier of a Hemoglobin Variant
What does this mean for my baby, me and my family?

Your baby's newborn screening test showed that he or she is a carrier of a hemoglobin variant. Babies who are carriers of hemoglobin variants are no more likely to get sick than any other baby. They do not need any special medical treatment. Hemoglobin variants will not change into a disease later on.

What causes hemoglobin variants?

Hemoglobin variants happen 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 who carry a hemoglobin variant have a second unusual type of hemoglobin, 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 who are carriers of a hemoglobin variant inherited one gene for hemoglobin A from one parent and one gene for a hemoglobin variant from the other parent.

Why is it important to understand that my baby carries a hemoglobin variant?

It is important to know so that you can tell your child later in life that he or she carries hemoglobin variant. His or her future partner can then choose to have testing. This information will tell them their chance to have a baby with a hemoglobin disease.

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

Since your baby carries a hemoglobin variant, this means that either you, or your partner, or both of you carry a hemoglobin variant. In almost all cases, ONLY ONE OF YOU will carry a variant.

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

IF ONLY ONE OF YOU CARRIES A HEMOGLOBIN VARIANT, 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 who carries a hemoglobin variant. This is harmless.

In the unlikely event that BOTH OF YOU CARRY A HEMOGLOBIN VARIANT *or* ONE OF YOU CARRY A HEMOGLOBIN VARIANT and the OTHER CARRIES ANOTHER TYPE OF UNUSUAL HEMOGLOBIN, the risk in the next pregnancy will depend on what type of variant or other unusual hemoglobin you and your partner has. In some cases, there may be a 25% chance in each pregnancy to have a baby with a serious hemoglobin disease. Your family doctor may refer you to a specialist for more information.

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

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Should my relatives be tested?

Any blood relative (for example, brother, sister, aunt or cousin) of a person with a hemoglobin variant may also carry a hemoglobin variant. 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.

How common are hemoglobin variants?

There are many different types of hemoglobin variants. Although anyone can carry a hemoglobin variant, it is more common among people and families who come from Africa, the Caribbean, the Middle East, Asia, the Mediterranean, India, and Central and South America.

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 Hospital 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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