

BC Newborn Screening Program

Information Sheet

My Baby Has Hemoglobin D/Beta Thalassemia *What does this mean for my baby, me and my family?*

Your baby's newborn screening test showed that he or she has hemoglobin D/beta thalassemia. Babies who have hemoglobin D/beta thalassemia are no more likely to get sick than any other baby. They do not need any special medical treatment. Hemoglobin D/beta thalassemia will not change into a disease later on.

What causes hemoglobin D/beta thalassemia?

Hemoglobin D/beta thalassemia 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 two copies of one type of hemoglobin, called hemoglobin A. Babies with hemoglobin D/beta thalassemia have a reduced amount of hemoglobin A (called beta thalassemia) along with a different type of hemoglobin called hemoglobin D.

The type of hemoglobin a baby has depends on the genes that they inherited from their parents. Babies with hemoglobin D/beta thalassemia have inherited one gene for hemoglobin D from one parent and one gene for beta thalassemia from the other parent.

Why is it important to understand that my baby has hemoglobin D/beta thalassemia?

It is important to know so that you can tell your child later in life that he or she has hemoglobin D/beta thalassemia. 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.

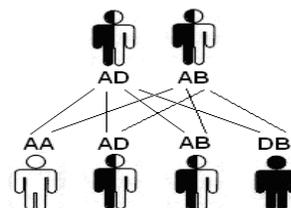
What does having a baby with hemoglobin D/beta thalassemia mean for me, my partner and for future pregnancies?

Since your baby has hemoglobin D/beta thalassemia, this means that you carry either hemoglobin D or beta thalassemia and your partner carries the other.

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

IF ONE OF YOU HAS HEMOGLOBIN D TRAIT AND THE OTHER HAS BETA THALASSEMIA 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 either hemoglobin D trait or beta thalassemia trait. This is harmless.
- 1 in 4 (25%) chance to have a baby with hemoglobin D/beta thalassemia. This too is harmless.



Should my relatives be tested?

Any blood relative (for example, brother, sister, aunt or cousin) of a person with hemoglobin D trait or beta thalassemia trait may also have hemoglobin D trait or beta thalassemia 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.

How common are unusual hemoglobins?

There are many different types of unusual hemoglobins. Although anyone can have an unusual type of hemoglobin, 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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