

BC Newborn Screening Program

Information Sheet

My Baby Has Hemoglobin E Trait *What does this mean for my baby, me and my family?*

Your baby's newborn screening test showed that he or she has hemoglobin E trait (this is also referred to as being a "hemoglobin E carrier"). Babies who have hemoglobin E trait are no more likely to get sick than any other baby. They do not need any special medical treatment. Hemoglobin E trait will not change into a disease later on.

What causes hemoglobin E trait?

Hemoglobin E trait 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 one type of hemoglobin. This is called hemoglobin A. Babies with hemoglobin E trait have a second type of hemoglobin called hemoglobin E, 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 with hemoglobin E trait inherited one gene for hemoglobin A from one parent and one gene for hemoglobin E from the other parent.

Why is it important to understand that my baby has hemoglobin E trait?

It is important to know so that you can tell your child later in life that he or she has hemoglobin E trait. 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.

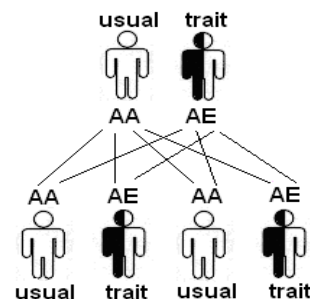
What does having a baby with hemoglobin E trait mean for me, my partner and for future pregnancies?

Since your baby has hemoglobin E trait, this means that either you or your partner or both of you have hemoglobin E trait. In almost all cases, only one of you will be a carrier.

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

IF ONLY ONE OF YOU HAS HEMOGLOBIN E TRAIT, 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 with hemoglobin E trait. This is harmless.



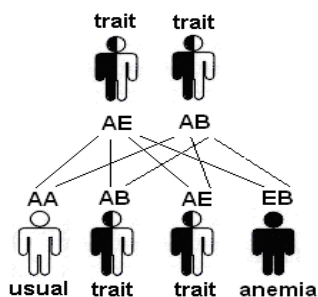
IN THE UNLIKELY EVENT THAT BOTH OF YOU HAVE HEMOGLOBIN E TRAIT, in every pregnancy there is a:

- 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 hemoglobin E trait. This is harmless.

- 1 in 4 (25%) chance to have a baby with only hemoglobin E (called homozygous hemoglobin E). This does not cause health problems in most people.

What if ONE OF US has hemoglobin E trait and the OTHER has another type of unusual hemoglobin?

It would depend on the type of unusual hemoglobin. If ONE OF YOU has hemoglobin E trait and the OTHER has beta thalassemia trait, there is a 1 in 4 (25%) chance in each pregnancy to have a baby with a serious form of anemia called hemoglobin E/beta thalassemia disease.



What is hemoglobin E/beta thalassemia disease?

People with hemoglobin E/Beta thalassemia disease cannot make hemoglobin normally and therefore cannot make normal red blood cells. Each red blood cell contains less hemoglobin than usual and there are fewer of them than usual. This is called anemia and it does not go away. It is important for babies with hemoglobin E/Beta thalassemia disease to receive regular medical care.

Parents who are at risk to have a baby with hemoglobin E/Beta thalassemia disease have the option of having their baby tested either during pregnancy through prenatal diagnosis or after birth through newborn screening.

Should my relatives be tested?

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

E 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 of African, Caribbean, Middle Eastern, Asian, Mediterranean, Indian and Central and South American descent. This is because malaria is common in these regions. People with hemoglobin E trait do better when infected with malaria than people who do not have hemoglobin E trait. In other words, it is an advantage in these parts of the world to have hemoglobin E trait.

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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