

Your baby's screening result: Haemoglobin E carrier

This leaflet provides information for parents whose baby's newborn bloodspot test shows that they are a haemoglobin E carrier (often referred to as having a 'trait').

What your baby's bloodspot test result means

The results of your baby's newborn bloodspot screening test show that your baby does not have a sickle cell disorder.

However, the results show your baby carries one unusual gene for haemoglobin, called haemoglobin E, and one usual gene. This is written as Hb AE and is known as being a carrier of haemoglobin E.

A carrier of haemoglobin E is healthy and will not need medical help to lead a normal life. Haemoglobin E is not the same as haemoglobin S (sickle cell). A carrier of haemoglobin E does not carry a sickle cell disorder.

Why it is important to know your baby is a haemoglobin E carrier

The blood cells of a baby who is a haemoglobin E carrier are often smaller than usual and their haemoglobin level is lower than normal. This is different to iron deficiency anaemia. Always tell your healthcare professional your baby is a haemoglobin E carrier so they can check your baby's iron levels before giving iron supplements.

Being a carrier of the haemoglobin E gene gives your child some protection against malaria during the first few years of life. However, if they travel to an area where malaria is a risk they should still take all recommended precautions. This includes taking anti-malaria medication.

As your child grows, it's important for them to know they are a haemoglobin E carrier. This knowledge will help them understand the risks involved in having children and how to minimise those risks. In the future, before considering a pregnancy, they may want their partner to be tested to see if they are also a carrier of an unusual haemoglobin gene. The

NHS offers counselling to explain the possible risks and available options.

Future pregnancies and your wider family

Your baby inherited the haemoglobin E gene from either you or the biological father of the baby. This means that one or both of you are likely to be carriers as well.

We recommend both you and the biological father get tested to find out who is a carrier, especially if this information was not provided during your pregnancy. This is particularly important if you plan to have more children, as there is a possibility that your next child could have a haemoglobin disorder if both parents are carriers. If you want to learn more about how it might affect future pregnancies, you can ask to be referred to the All Wales Medical Genomics Service (AWMGS). Your health visitor can help you with this.

Other family members, such as brothers and sisters, aunts, uncles and cousins, may want to consider getting tested before starting a family, as they could be carriers too. Sharing this information with them may be helpful.

