Newborn screening: your baby carries a gene for Haemoglobin C

Public Health England (PHE) created this information on behalf of the NHS. In this information, the word ‘we’ refers to the NHS service that provides screening.

This guidance is for parents of babies found to carry gene for Haemoglobin C following their newborn blood spot screening test.

Your baby had a blood test (also called the heel-prick test) about a week after they were born. The test is to check for rare diseases and is offered to all babies.

One of these tests is to check for sickle cell disease and thalassaemia. Your baby has neither condition.

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

This is common. Every year in England, about 90,000 babies are born with a gene for an unusual haemoglobin.

Haemoglobin AC occurs in 1 in 570 births.

Haemoglobin is the substance in the blood that carries oxygen around the body.

This information explains what being a carrier of an unusual haemoglobin gene means for your baby, you and your wider family.

Your baby

A carrier of Haemoglobin C is healthy and no medical help will be needed to lead a normal life.

Haemoglobin C is not the same as Haemoglobin S (sickle cell). A carrier of Haemoglobin C does not carry sickle cell.

However, it’s important that your baby grows up knowing about being a Haemoglobin C carrier and understands the risks involved if they want to have a family.

If they have a baby with someone who is a Haemoglobin S carrier there would be a 1 in 4 (25%) chance that their baby would have haemoglobin SC disease which is a sickle cell disorder and would require lifelong treatment.

When your baby grows up they can ask any future partner to have a test to see if they also carry an unusual haemoglobin gene. There is NHS counselling to explain the risks and choices involved.

Carriers of unusual haemoglobin genes

Babies inherit characteristics from their parents' genes. For example, genes control the colour of their skin, hair and eyes.

For each characteristic, your baby gets one gene from their biological mother and one from their biological father. Genes also control the type of haemoglobin they inherit.

Your baby is a carrier because they inherited one gene that makes usual haemoglobin from one parent and one gene that makes unusual haemoglobin from the other parent.

Your baby will never develop a haemoglobin disorder because they inherited one usual gene, but they will always be a carrier.

Protection against malaria

There is some evidence that being a carrier of an unusual haemoglobin gene gives children some protection against malaria, but only during the first couple of years of their life.

It is important your child takes all the normal precautions if they are travelling to a country where there is a risk of malaria. This includes taking anti-malaria medication.

Future pregnancies and your wider family

Your baby inherited an unusual gene from either you or your partner. This means that you, your baby's father, or both of you are also carriers.

We recommend both you and your partner get a test to find out who is a carrier if you were not already given this information during pregnancy. This is particularly important if you are thinking of having another baby. If both of you are carriers, then your next baby could have a haemoglobin disorder.

The test is a simple blood test and takes just a few minutes. To arrange the test, you can ask your GP, visit your local sickle cell centre or contact a support organisation.

It may be a good idea to encourage other members of your family, such as brothers, sisters, aunts, uncles and cousins, to get a test before they start a family, in case they are carriers too. Showing them this information may help.

More information

More information and support is available from:

- the NHS.UK website at www.nhs.uk/sct
- Sickle Cell Society at www.sicklecellsociety.org Email info@sicklecellsociety.org or telephone 0208 9617795

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. Public Health England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

PHE supports the UN Sustainable Development Goals