Information for fathers invited for a screening test for sickle cell disease and thalassaemia major

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.

Who this information is for

This information is for fathers invited to have a screening test for haemoglobin conditions such as sickle cell disease and thalassaemia major.

The test gives information that may be important for the health of your unborn baby and any future children. We explain the test, why we offer it, what it might show and the choices you can make.

If you want the test, it is important to have it as soon as possible – the earlier in the pregnancy the better. Please make your appointment as soon as you can or, if you have already been offered one, confirm you will attend.

Why you have been invited for a test

Test results for the mother of your baby show she carries a gene for an unusual type of haemoglobin. Haemoglobin is the substance in the blood that carries oxygen and iron around our bodies. We now need to know if you also carry a gene for an unusual type of haemoglobin.

For every pregnancy we need to test both parents to see if there is a chance that your baby has one of the conditions.

If both parents are carriers of a gene for unusual haemoglobin, there is a 1 in 4 (25%) chance that your baby could inherit a haemoglobin disorder such as sickle cell disease or thalassaemia major. These are serious life-long health conditions.

What the test involves

It is a blood test which takes a few minutes. You should get your result within 3 to 5 days.

Possible results

The test will show whether you have usual haemoglobin or carry a gene for an unusual type of haemoglobin.

If you have a gene for unusual haemoglobin, you are a carrier. This is sometimes called having a ‘trait’.

For most people, the test will show they are not a carrier.

> “Knowing your status prepares you mentally for the road ahead in becoming a father. Depending on the knowledge of the man and the woman’s status, you will know what to expect when having a child and prepare yourself accordingly.” – Olufumi, a father who has sickle cell and whose son has inherited the trait

What it means if you are a carrier

To explain this, we must talk about genes.

Genes work in pairs. For each thing you inherit (for example, the colour of your skin, hair and eyes) you get one gene from your mother and one gene from your father.

People who are carriers have inherited one unusual gene for haemoglobin from one parent. Because they have also inherited one usual gene for haemoglobin from the other parent, they will never have a haemoglobin disorder themselves.

But, if a carrier has a baby with another person who is also a carrier, their baby has a 1 in 4 (25%) chance of having a haemoglobin condition such as sickle cell disease or thalassaemia major.

The risks for your baby if you are both carriers

There are 3 possibilities. Your baby could:

- inherit a haemoglobin condition such as sickle cell disease or thalassaemia major – 1 in 4 (25%) chance
- be a carrier – 2 in 4 (50%) chance
- neither have a condition nor be a carrier – 1 in 4 (25%) chance

These possibilities are shown in the diagram below. The chances are the same in every pregnancy you have with this partner. In the diagram below, the parents are both carriers. They are drawn in 2 colours to show they have one usual gene (white) and one unusual gene (red).

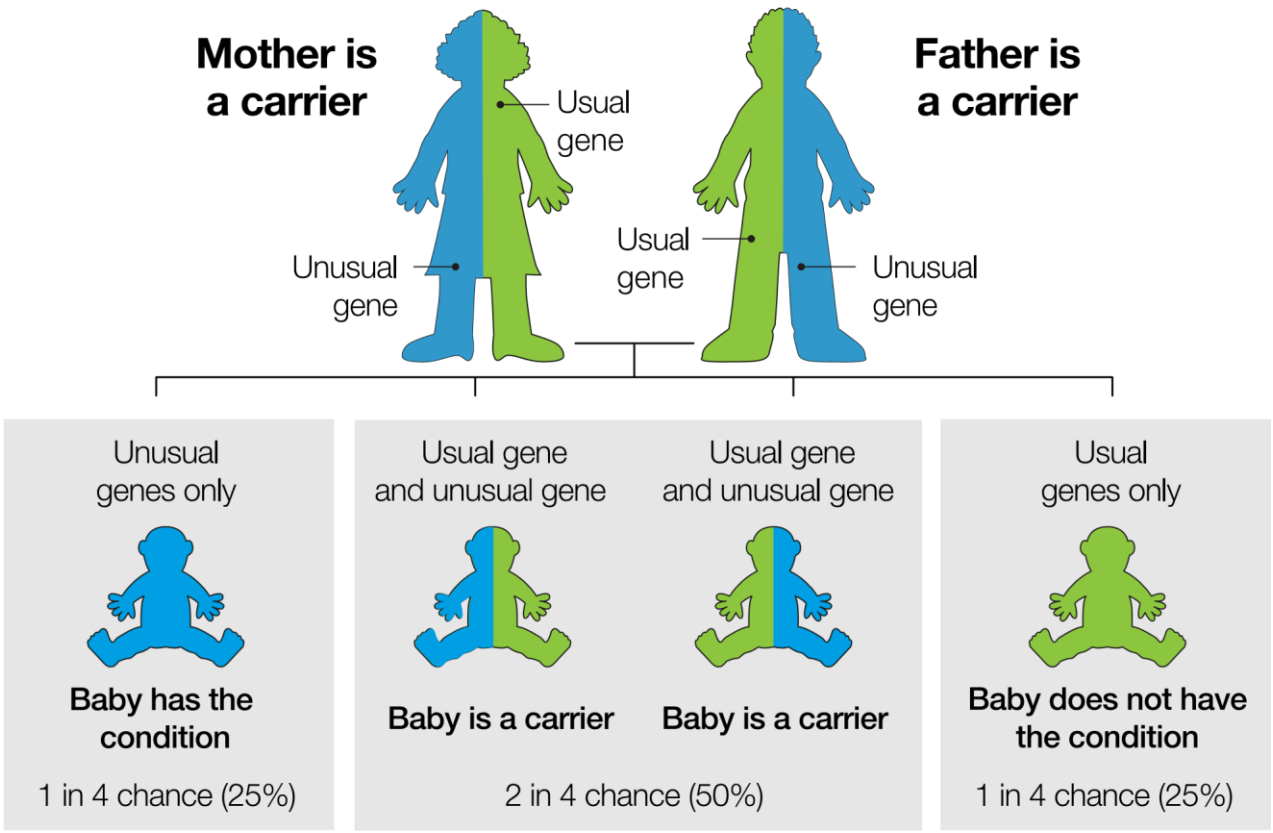

Illustration showing chances of baby inheriting condition from parents who are both carriers

What happens next if you are both carriers

We will offer you an appointment where a trained professional will explain more about being a carrier and about what condition your child could inherit. We will also offer a test for your baby called prenatal diagnosis (PND). It will show whether your baby has inherited any genes for unusual haemoglobin.

If you do not want any further tests during pregnancy

Parents can choose whether to have prenatal diagnosis or not. If not, the next test we will offer is when your baby is born. This will show if your baby has inherited a haemoglobin condition. The test is done by taking a few drops of blood from your baby's heel, when they are 5 days old. This test is called newborn blood spot screening.

Your health if you are a carrier

If the test shows you are a carrier, you should not worry about your own health. You do not have an illness and will never develop sickle cell disease or thalassaemia major. The NHS Sickle Cell and Thalassaemia Screening Programme has information for each type

of carrier identified by screening. See www.gov.uk/pregnancy-screening-info

> “I was very surprised to find out I was a thalassaemia carrier because there has never been any illness in our family – I was convinced the test would be negative. Our baby was born healthy, but my wife and I have learned a lot about thalassaemia in case we have more children. My brother has been tested since I found out and he is also a carrier.”
> – Mohammed Z, a father who carries the thalassaemia gene

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 E info@sicklecellsociety.org or tel 0208 9617795.
- UK Thalassaemia Society at ukts.org E info@ukts.org or tel 0208 882 0011.

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.

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