Public Health England

NHS

# NHS Sickle Cell and Thalassaemia Screening Programme

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

# Who is this leaflet for?

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

The test gives information which 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 your partner's 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 have I 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 any risk for your baby.

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 does the test involve?

It is a simple 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 normal 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 does it mean if I am 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.

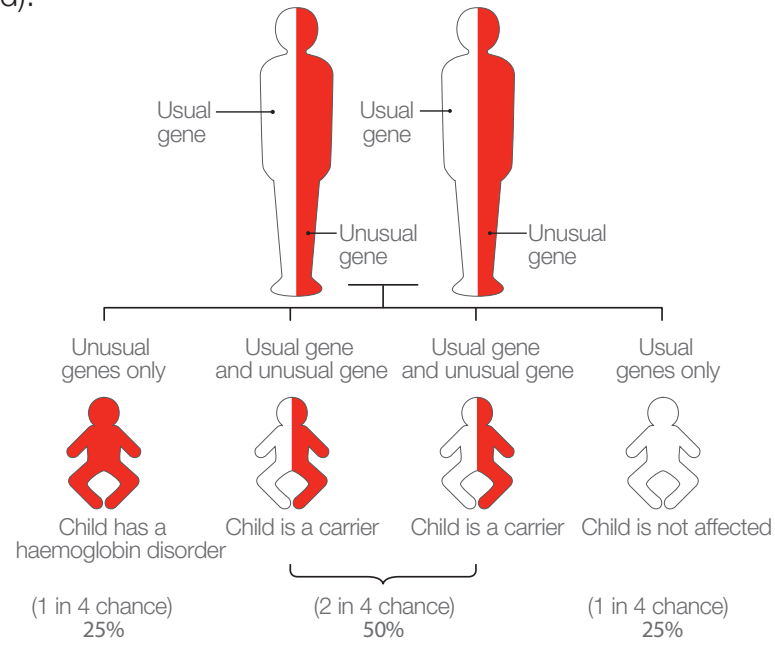
But, if a carrier has a baby with another person who is also a carrier, their baby has a 1 in 4 (25%) chance of having a haemoglobin disorder such as sickle cell disease or thalassaemia major.

# If we are both carriers, what are the risks for our baby?

There are 3 possibilities.

- Your baby could inherit a haemoglobin disorder such as sickle cell disease or thalassaemia major – 1 in 4 (25%) chance.
- Your baby could be a carrier – 2 in 4 (50%) chance.
- Your baby could be completely unaffected – neither having a condition nor being 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).



## What happens next if we 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.

## What if we don't 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 disorder. 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.

## If I am a carrier, will my own health be affected?

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 on www.GOV.UK for each type of carrier identified by screening.

**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 and support

**NHS Choices: www.nhs.uk/sct**

**Sickle Cell Society: www.sicklecellsociety.org**
E: info@sicklecellsociety.org T: 0208 9617795

**UK Thalassaemia Society: www.ukts.org**
E: info@ukts.org T: 0208 882 0011

Your local service is at:

For information on how NHS screening programmes use patient information safely and securely, visit
**www.gov.uk/phe/screening-data**

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**More information about sickle cell and thalassaemia screening:** www.nhs.uk/sct



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