Sgrinio Cyn Geni Cymru
Antenatal Screening Wales

GIG CYMRU NHS WALES
Iechyd Cyhoeddus Cymru
Public Health Wales

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.

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.

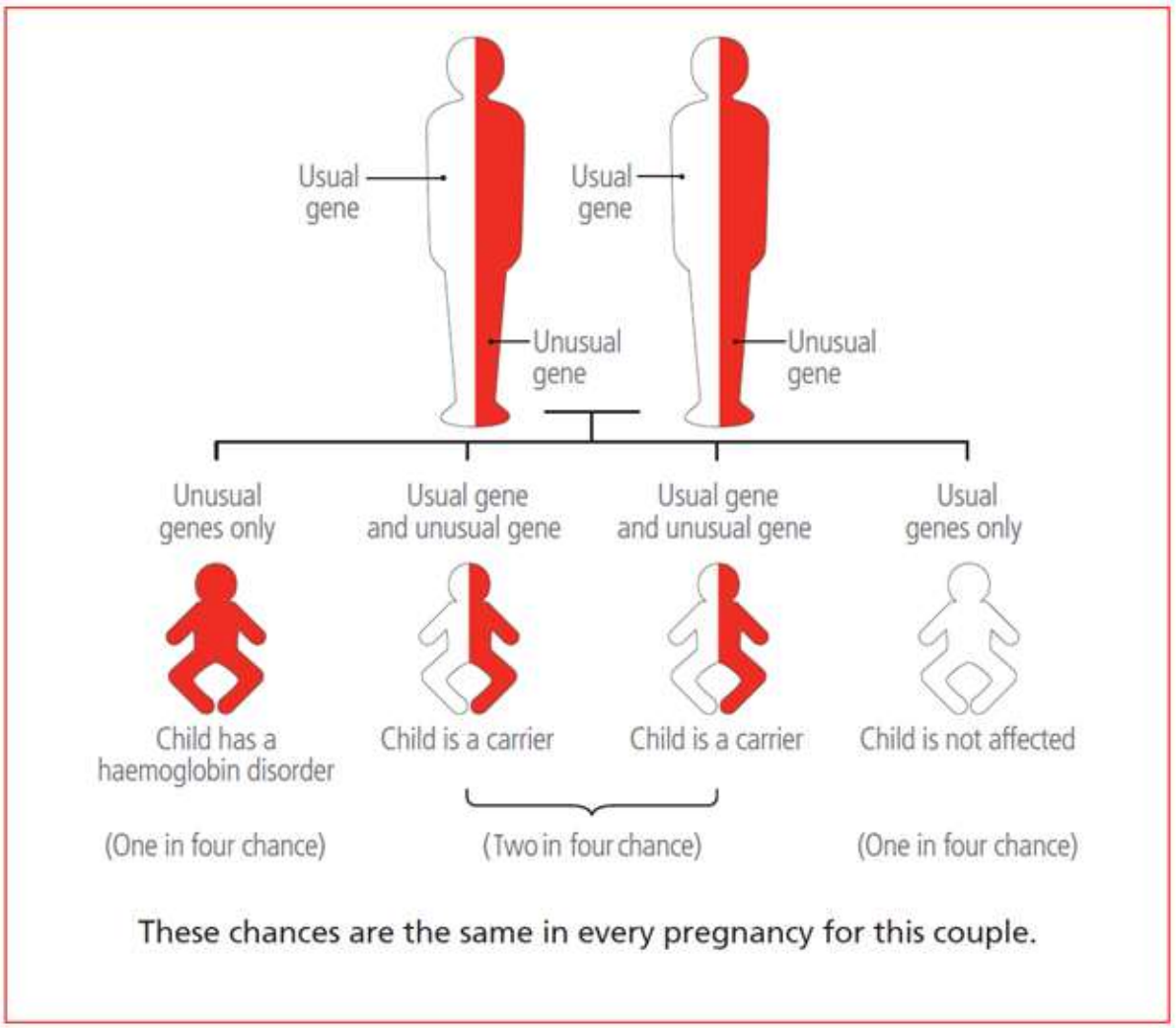
But, if a carrier has a baby with another person who is also a carrier, their baby has a 1 in 4 (25%) chance of having a haemoglobin disorder such as sickle cell disease or thalassaemia major.

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, we will offer a blood test for the baby within the first few days after birth. This will look for sickle cell and thalassaemia.

The next screening test that is offered to all babies is newborn bloodspot screening. This is offered to all newborn babies and tests for a number of rare but serious diseases including sickle cell disorders. The screening does not test for thalassaemia, but it may occasionally identify babies with this disorder. The test is done by taking a few drops of blood from your baby's heel, when they are 5 days old. If your baby is thought to have a sickle cell disorder you will usually be contacted before your baby is six weeks old. You will be told about the tests that will be needed to make the diagnosis, and will be given an appointment to see a specialist.

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.

More information and support

NHS Choices: www.nhs.uk/sct

Sickle Cell Society: www.sicklecellsociety.org
Phone: 0208 9617795
Email: info@sicklecellsociety.org

UK Thalassaemia Society: www.ukts.org
Phone: 0208 882 0011
Email: info@ukts.org

This leaflet is based on information developed by the NHS Screening Programmes within Public Health England

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Clarity approved by Plain English Campaign