Sgrinio Cyn Geni Cymru
Antenatal Screening Wales

Newborn Bloodspot
Screening Wales
Sgrinio Smotyn Gwaed
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Information for adult haemoglobinopathy carriers
You are a **haemoglobin Lepore carrier**
Your test result shows: Hb A Lepore

What is my test result?

The substance in your blood that carries oxygen around your body is called haemoglobin. You had a blood test recently to check your haemoglobin type. **The test result shows that you are healthy** – there is no need to worry about being unwell.

But the result shows that you are a haemoglobin Lepore carrier (some people call it 'having a trait').

This leaflet gives you information about being a carrier, and what this means for you and your family.

What is a haemoglobin Lepore carrier?

For everything that you inherit, you get one gene from your biological mother and one gene from your biological father. For example, your genes control the colour of your skin, hair and eyes.

Your genes also control the type of haemoglobin you inherit. The usual type is called 'A'.

You have inherited the usual haemoglobin A from one of your parents, and a gene that makes unusual haemoglobin (in your case haemoglobin Lepore) from the other parent. We call this being a haemoglobin Lepore carrier.

Because you have inherited usual haemoglobin A from one parent, you are healthy. You will never develop a haemoglobin disorder. But there is a chance that you could pass on haemoglobin Lepore to your children.

How is my test result written?

The type of haemoglobin you have inherited is written **Hb A Lepore (or haemoglobin Lepore carrier)**.

The letters 'Hb' stand for haemoglobin.

The letter 'A' shows your usual type of haemoglobin.

'Lepore' is the name of the unusual haemoglobin that you carry.

What does this result mean for me?

Being a haemoglobin Lepore carrier will not generally cause you any health problems.

The reason why you need to understand about being a haemoglobin Lepore carrier is because you could pass the gene to your children. We explain this below.

What could my result mean for my children?

As a carrier, there is a chance that you could pass on the gene for haemoglobin Lepore to any children that you have. Only the biological parents can pass this genetic information on to their child.

If you have a child with a partner who has the usual haemoglobin AA, there is a 2 in 4 (50%) chance that your child could be a carrier (like you).

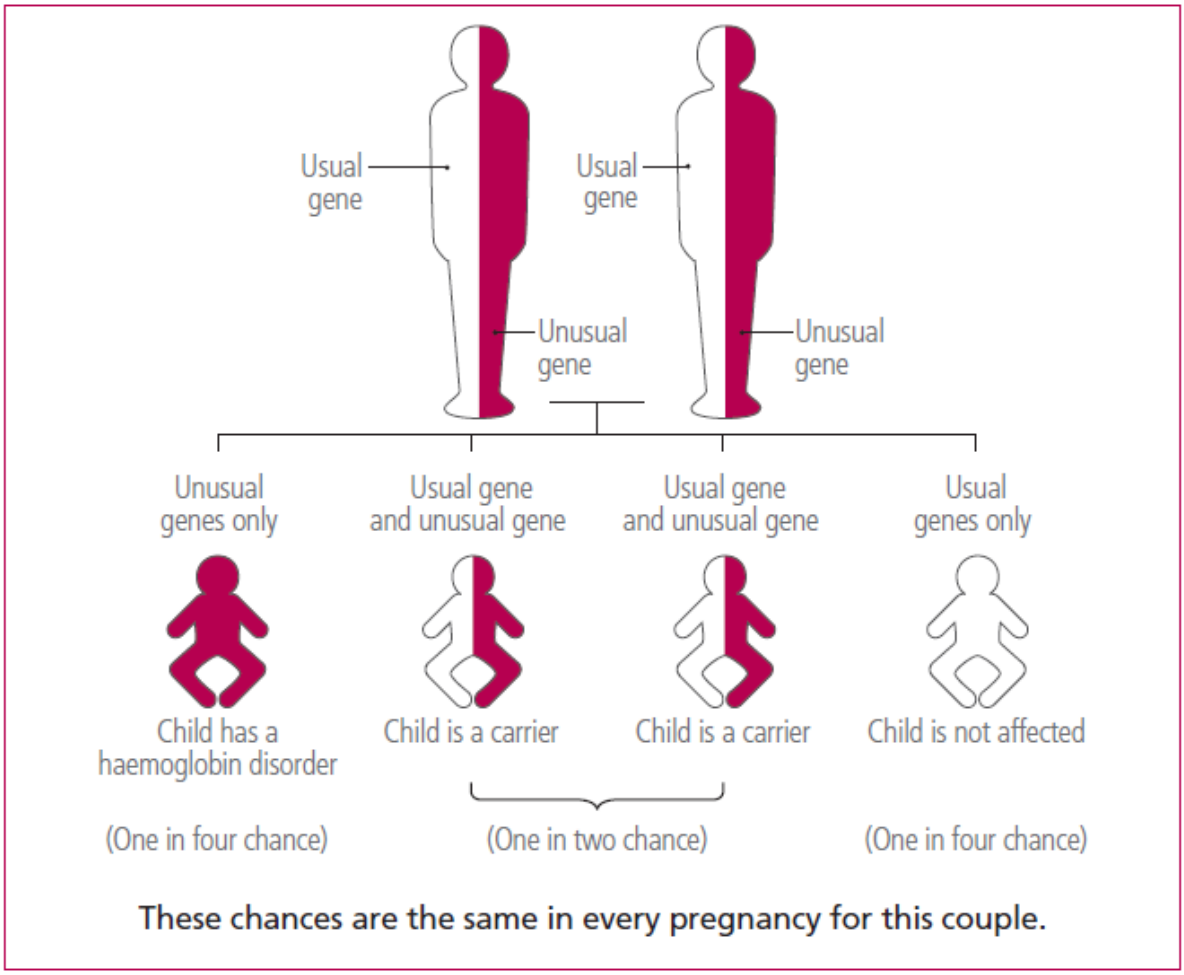
If you have a child with a partner who is a **beta thalassaemia carrier**, there is a 1 in 4 (25%) chance that your child could inherit thalassaemia major. This is a serious health condition which is explained in the following pages.

If you have a child with a partner who carries a gene for **any other type of unusual haemoglobin**, there is a 1 in 4 (25%) chance that your child could inherit unusual haemoglobin from both parents. The type of disorder depends on which genes are inherited.

Your partner will only know they are a carrier if they have had a specific blood test to check their status. Fathers-to-be will be offered this test when antenatal screening shows the mother is a carrier. But both men and women can ask for a test at any time from their family doctor (GP) or from their nearest specialist sickle cell and thalassaemia centre.

Below is a diagram showing an example of how haemoglobin inheritance works.

The parents are both carriers. They are drawn in two colours to show that they have one usual haemoglobin gene (white) and one unusual gene (red).



What kind of disorder could my child inherit?

There are a number of haemoglobin disorders. Some are more serious than others. The most serious disorders are called sickle cell disease and thalassaemia major. People who have these conditions will need specialist care throughout their lives.

The type of disorder your child could inherit will depend on what types of haemoglobin both biological parents have. The chart opposite shows a combination of different carriers and the condition your child could inherit. We have only shown the most common types of carrier in England and the more significant conditions. The most serious conditions are shaded red.

You are a haemoglobin Lepore carrier.

If your partner is a carrier of beta thalassaemia (β thalassaemia carrier)	There is a 25% (1 in 4) chance your child could inherit haemoglobin Lepore/beta thalassaemia.	This is a type of thalassaemia major. It is usually serious and needs regular treatment.
	There is a 25% (1 in 4) chance your child could inherit thalassaemia intermedia.	It is usually moderate or mild.
If your partner is a carrier of delta beta thalassaemia (δβ thalassaemia carrier)	There is a 25% (1 in 4) chance your child could inherit haemoglobin Lepore/delta beta thalassaemia.	This is a type of thalassaemia major. It is usually serious and needs regular treatment.
If your partner is a carrier of haemoglobin Lepore (Hb A Lepore)	There is a 25% (1 in 4) chance your child could inherit haemoglobin Lepore/ haemoglobin Lepore.	This is a type of thalassaemia major. It is usually serious and needs regular treatment.
If your partner is a carrier of haemoglobin E (Hb AE)	There is a 25% (1 in 4) chance your child could inherit haemoglobin E/haemoglobin Lepore.	This is a type of thalassaemia intermedia. It is usually moderate or mild.
If your partner is a carrier of haemoglobin OArab (Hb A OArab)	There is a 25% (1 in 4) chance your child could inherit haemoglobin OArab/ haemoglobin Lepore.	This is a type of thalassaemia intermedia. It is usually moderate or mild.
If your partner is a carrier of haemoglobin S(Hb AS) (sickle cell carrier)	There is a 25% (1 in 4) chance your child could inherit haemoglobin S/haemoglobin Lepore.	This is a type of sickle cell disease. It can be moderate or mild and needs regular treatment.

What does my result mean for other people in my family?

The fact that you are a haemoglobin Lepore carrier means other members of your family could be carriers too.

It is a good idea to talk to your blood relatives (such as your parents, brothers, sisters, uncles, aunts and cousins) and encourage them to get a test before they start a family, or have any more children. Showing them this leaflet may help.

Information about the most serious haemoglobin disorders

Please remember that you are a 'carrier'. You do not have any of the haemoglobin disorders described below. The following is for information only.

The most severe haemoglobin disorders are thalassaemia major and sickle cell disease. People who have these conditions will need specialist care throughout their lives. Other types of haemoglobin disorders that may need treatment are shown in the table on page 5.

People with thalassaemia major:

- are very anaemic (their blood has difficulty carrying oxygen);
- need blood transfusions every three to five weeks; and
- need medicines throughout their lives to stop the iron overload which is a result of the blood transfusions.

People with thalassaemia intermedia:

This condition is very variable and not usually as serious as thalassaemia major, but sometimes does need regular treatment. Your health professional will be able to give you more advice about this.

People with sickle cell disease:

- can have attacks of very severe pain;
- can get serious, life-threatening infections;
- are usually anaemic (which means that their blood has difficulty carrying oxygen); and
- need medicines and injections when they are children and throughout the rest of their lives to prevent infections.

There are also other, less common haemoglobin disorders. Many of these are not serious.

Common questions

Why didn't I know about this? I have had blood tests before.
Routine blood tests do not show if you are a carrier. To find this out you need a special blood test for unusual haemoglobin.

What's the difference between being a carrier and having a disorder?
Carriers are generally well and are only identified with careful testing. People with a disorder are often ill and need treatment.

As a carrier could I develop a haemoglobin disorder?
No, you cannot develop a haemoglobin disorder because you have one gene which makes the usual haemoglobin, Hb A. But you will always be a carrier.

Is being a carrier infectious?
No, you can only be a carrier if you inherit the gene from one of your biological parents.

Does being a carrier affect my ability to have children?
No, it does not affect your ability to have children.

Am I protected from malaria?
No you are not protected from malaria. It is important that you take all the normal precautions if you are travelling to a country where there is a risk of malaria. This includes taking anti-malaria medication.

What should I do now?

- Let your family doctor (GP) know that you are a haemoglobin Lepore carrier.

- If you are expecting a baby or planning to have a baby, now or in the future, we strongly recommend that your partner gets tested to see if they are a carrier.

- You can get free information and advice to help you understand the implications of being a haemoglobin Lepore carrier. Ask your doctor or health professional to refer you to your nearest sickle cell and thalassaemia centre.

- If you already have children, you may want to have them tested as well.

- It is a good idea to talk to other members of your family and encourage them to have a test before they start a family, or have any more children. It is equally important for men and women to be tested.

- The test for unusual haemoglobin is a simple blood test and takes just a few minutes. People can ask for the test at any time in their life.

More Information?

If you have questions about any of the information in this leaflet, please talk to your midwife.

Healthtalkonline describes people's experiences of being a carrier, having children, and living with haemoglobin disorders. Website: www.healthtalkonline.org

For further information and support contact:

UK Thalassaemia Society
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Email: office@ukts.org
Website: www.ukts.org

The Sickle Cell Society
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Website: www.sicklecellsociety.org

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