



Information for mums and dads

Your baby carries a gene for
unusual haemoglobin



Your baby's result is written:

Hb AC

Hb AD

Hb AE

Other

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

The test results show that your baby is healthy. There is no need to worry – your child is well.

But the results also show that your baby carries a gene for an unusual haemoglobin.

This is very common. Every year in England, about 9000 healthy babies are born with a gene for unusual haemoglobin.

This leaflet gives you information about being a 'carrier' (having a gene for unusual haemoglobin) and what this means for your baby and for you and your family.



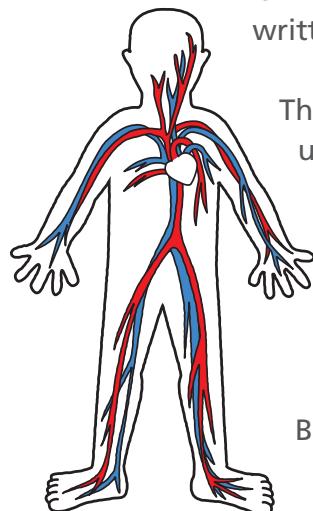
What does it mean to carry a gene for an unusual haemoglobin?

To explain this we must first talk about genes. The genes in your body decide the colour of your eyes, how tall you are – even if you have a beautiful smile!

Your genes also control the type of haemoglobin you have.

Haemoglobin is the substance in your blood which carries oxygen around the body.

Genes work in pairs. For each thing we inherit, we get one gene from our mother and one gene from our father. People who are carriers have inherited one gene that makes usual haemoglobin from one parent. In your baby's test results this is written as 'A'.



They have also inherited one gene that makes unusual haemoglobin from the other parent. The type of haemoglobin your child has is written at the front of this leaflet. The letters 'Hb' stand for haemoglobin. The letter 'A' shows their usual haemoglobin and the other letter shows the unusual type of haemoglobin.

Because your baby has inherited one gene that makes usual haemoglobin, they will never develop a haemoglobin disorder.



What does this result mean for my baby?

Your child is healthy – there is no need to worry.

However, you and your child need to understand about being a carrier. This is important information for your child when they grow up and want to start a family of their own.

If your child has a baby with another person who also carries a gene for an unusual haemoglobin, there is a one in four (25%) chance that their child (your grandchild) could inherit a haemoglobin disorder. This could cause health problems for your grandchild. How serious these problems are will depend on what type of unusual haemoglobin both parents have.

It is important that your child grows up knowing about being a carrier. Then they can talk to their partner about this, and ask their partner to have a test to see if they are also a carrier. There is free counselling to explain the risks and choices involved in having a family.

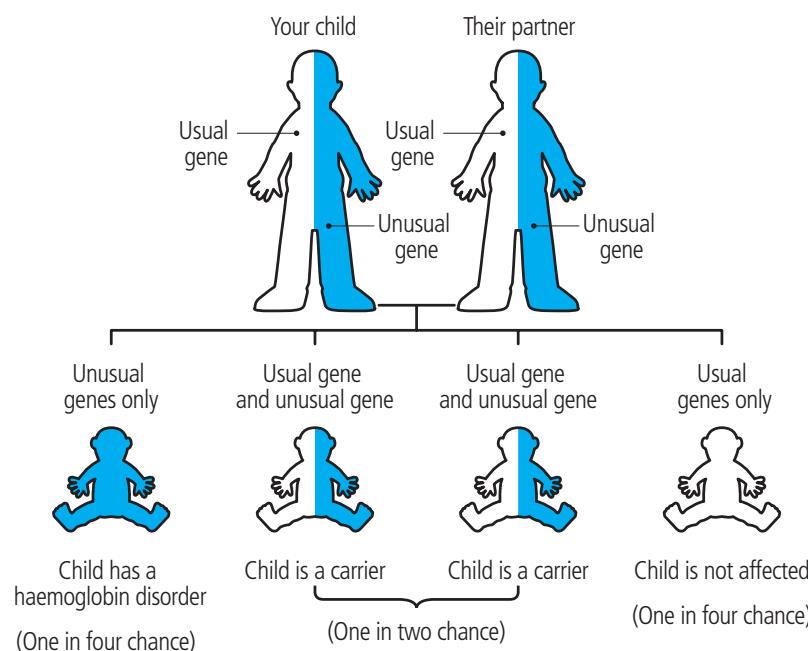
In the section below, we explain how carriers can pass on a disorder to their children.



How can carriers pass on a haemoglobin disorder to their children?

In the diagram below, the parents are both carriers. They are drawn in two colours to show the two genes for haemoglobin that they could pass on to their children.

Your child is the figure on the left - shaded white to show their usual gene for haemoglobin and blue to show their unusual gene for haemoglobin. The figure on the right is their partner – also shaded blue and white to show they are a carrier.



Every time your child has a baby with a partner who is also a carrier, there are three possible outcomes – see below.

- The baby could inherit two genes that make unusual haemoglobin. If this happens, they will have a haemoglobin disorder. There is a one in four (25%) chance of this happening, and it is shown in the diagram as the baby shaded completely blue.
- The baby could inherit one gene that makes usual haemoglobin and one gene that makes unusual haemoglobin. If this happens, they will be a carrier like your child. There is a one in two (50%) chance of this happening and it is shown in the diagram as the two babies shaded blue and white.
- The baby could inherit two usual genes. If this happens they will be completely unaffected – they will not have the disease and will not be a carrier. There is a one in four (25%) chance of this happening and it is shown in the diagram as the baby shaded white.

The chances will be the same in every pregnancy with this partner.

What does this mean for my family?

Your baby inherited their unusual haemoglobin gene from either their mother or father. This means that one of you (or maybe both of you) is also a healthy carrier.

- We recommend that you both find out if you are carriers. This is particularly important if you are thinking of having another baby. If both of you are carriers, there is a chance that you could pass on a haemoglobin disorder to your next baby.
- It may also be a good idea to talk to other members of your family (such as your brothers and sisters, aunts, uncles and cousins) and encourage them to get a test before they start a family, in case they are carriers too.

Showing them this leaflet may help.



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 haemoglobinopathy service or contact one of the support organisations listed at the back of this leaflet.

What should I do now?

- Make sure you write your baby's haemoglobin result in their health record (red book), and make sure your child's GP also puts this on their records.
- As your child grows up, talk to them about being a carrier. It is important that they understand what this means when they come to plan a family of their own.

Common questions

What is a haemoglobin disorder?

Your child is a carrier. They do not have a haemoglobin disorder. The facts below are just for information.

There are many different types of haemoglobin disorders. Some cause very few problems, but for others you will need to have treatment and support for life. The most serious haemoglobin disorders are sickle cell disease and beta thalassaemia major. The type of disorder depends on which genes for unusual haemoglobin you have inherited

What are the different types of haemoglobin?

There are many different types of haemoglobin – such as Hb AC, Hb AD and Hb AO^{Arab}, Hb AE and Hb A Lepore. The unusual haemoglobin which your baby has is shown on the front of this leaflet.

Can my baby develop a haemoglobin disorder?

No. Your baby will never get a haemoglobin disorder. But they will always be a carrier.

Does my baby need any kind of treatment because they are a carrier?

No – your baby is healthy.

Is being a carrier infectious?

No – you cannot catch unusual haemoglobin. You can only be a carrier if you inherit the gene from one of your parents.

Why should I tell my child about being a carrier?

Because your child needs to understand about the risk of passing a haemoglobin disorder to their own children and the choices they can make. See page 6-7 of this leaflet for more information about this.

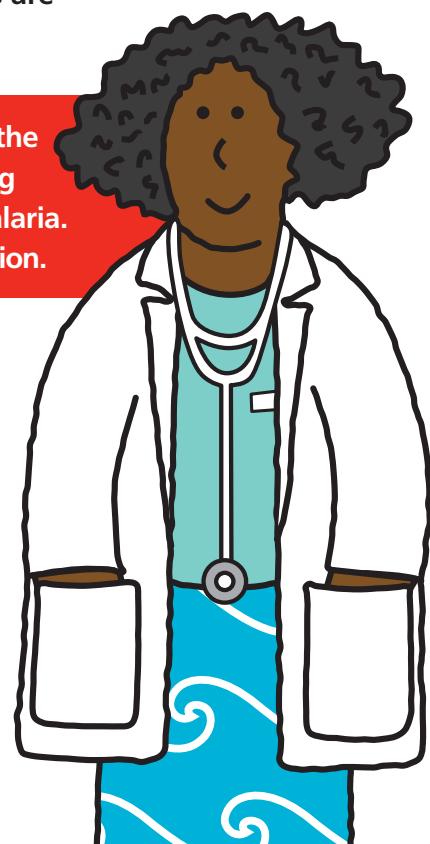
How many people do haemoglobin disorders affect?

Haemoglobin disorders are some of the most common inherited conditions in the world. Around 5% of the world's population carry a gene for an unusual haemoglobin.

I've heard that people who are carriers are protected from malaria. Is that true?

It is important that 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.

Being a carrier does give children some protection against malaria, but only during the first couple of years of their life. Because of this advantage, carrying a gene for an unusual haemoglobin is common among people who come from (or whose ancestors came from) places which have malaria. This includes Africa, Asia and parts of Southern Europe.



Would you like more information?

If you have questions about any of the information in this leaflet, please talk to your health visitor, GP or local haemoglobinopathy service, which is based at:



UK Thalassaemia Society
19 The Broadway
Southgate Circus
London
N14 6PH
Phone: 020 8882 0011
Email: office@ukts.org
Website: www.ukts.org

The Sickle Cell Society
54 Station Road
London
NW10 4UA
Phone: 020 8961 7795
Helpline: 0800 001 5660
Email: info@sicklecellsociety.org
Website: www.sicklecellsociety.org

**Organisation for Sickle Cell Anaemia
Relief and Thalassaemia Support
(OSCAR)**
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Website: www.oscarsandwell.org.uk

**Accessible Publishing of Genetic
Information (APoGI)**
Website: www.chime.ucl.ac.uk/APoGI/



*UK National
Screening Committee*

Would you like more information?

If you would like a copy of this leaflet in another language or on audio tape, please visit:

www.sickleandthal.org



ISBN: 978-0-9565846-0-1

The NHS Sickle Cell and Thalassaemia Screening Programme provides information about screening, being a carrier and living with haemoglobin diseases.

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