Results of Newborn Blood-Spot screening

Carrier of a gene for an unusual haemoglobin – sometimes called trait

Hb AC, Hb AD, Hb AE, Hb A LePore.
Newborn Blood-Spot screening tests have shown that your baby is a carrier of a gene that produces an unusual haemoglobin. Your baby does not have a haemoglobin disorder and does not need any medical treatment. The unusual gene will not cause any health problems.

However, it is important that you read this leaflet. It contains information about what this result means for your baby and for your family.

What is my baby's screening result?

When your baby was about a week old, a midwife took some blood from your baby's heel to test for conditions they may have inherited including sickle cell disease and other haemoglobin disorders.

The test shows that your baby has not inherited a haemoglobin disorder.

However, your baby has inherited one gene that makes an unusual haemoglobin. We call this being a 'carrier'. Some people call it having a 'trait'.

Carriers do not have a haemoglobin disorder. But, they may pass on the gene for the unusual haemoglobin to their own children – they can carry the gene to the next generation. It will be important for your child to know about being a carrier when they grow up and want to start a family of their own.

This leaflet explains about unusual haemoglobin, about being a carrier, and about how this might affect your family.

"If you’re discovered to be a carrier it doesn’t affect your general health."

Father who came forward for testing
What action should I take?

We recommend that you:

- keep a copy of your baby's test result (please ask your health visitor if you do not have a copy)
- write the result here and keep this leaflet to show your child when they grow up (my baby’s test result is ____________)
- write the result in your Child Health Record Book (sometimes called the ‘red book’)
- ask your GP or health visitor to write the result in your child’s medical record
- if you do not already know whether you are a carrier, arrange a blood test for yourself and your baby’s father (this is especially important if you plan to have another baby)
- talk to other family members and explain why it is useful for them to know if they are carriers before starting a family.

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

We all have two copies of each gene in our bodies. We inherit one copy of each gene from our mother and one from our father. Genes are the information that our bodies use to shape the way we grow and function.

Some of these genes control haemoglobin — the substance in our blood that carries oxygen around our body. We write the usual haemoglobin as Hb AA (Hb is the short way of writing haemoglobin).

People who have haemoglobin disorders have inherited two unusual genes — one from their mother, and one from their father. We write their haemoglobin in different ways depending on which genes they have inherited — for example Hb SC, Hb SS.

People who are carriers — like your baby — have inherited one gene that makes the usual haemoglobin A, and one gene that makes an unusual haemoglobin. So, we write their haemoglobin as Hb A plus another letter, for example Hb AC or Hb AE.

Because your baby makes some usual haemoglobin A, they will never have a haemoglobin disorder. They will always be a healthy carrier.

But, if they have a baby with someone else who also carries unusual haemoglobin, there is a chance that their child could inherit a haemoglobin disorder.
"In future it's something to sit down and just go through... Just in case there's a health risk to future grandchildren. I'm glad, you know, I'm happy that we know now."

The father of a baby identified as a carrier

How will being a carrier affect my child?

Your child's health
Your child is healthy and needs no special care.

Planning a family in the future
It is important that you tell your child about being a carrier. This will be valuable information when they grow up and want to start a family. Your child will be able to explain about being a carrier and suggest a blood test for their partner. If the partner is also a carrier, there is a chance that their baby could inherit a haemoglobin disorder. The diagram on page 4 shows the different chances of this happening.

How might the carrier result affect our family?

Your baby's test result means that:

- you or the baby's father is a carrier of a gene that makes an unusual haemoglobin (it could be the father or mother);
- both of you could be carriers;
- one of you could have a haemoglobin disorder; or
- one of you could be a carrier and the other have a haemoglobin disorder.

If you do not already know whether you are a carrier and you are planning to have another baby, we strongly recommend that both you and the baby's father have a blood test to find out if you are carriers. This is because there is a chance that your next baby could inherit a haemoglobin disorder. The diagram on page 4 shows the different chances of this happening.

Your baby's test result also means that:

- other children in the family might be carriers (or might have a haemoglobin disorder);
- other people in the wider family might be carriers (or might have a haemoglobin disorder).

We recommend that you talk about your baby's screening result with other members of your family, and encourage them to think about having a blood test to find out if they are carriers. This is important if they are planning to have a family.

If you want to arrange blood tests, please talk to your family doctor (GP) or your local haemoglobinopathy service (see the back page of this leaflet for details of your nearest service).
What are haemoglobin disorders?

There are many different types of unusual haemoglobin. Some cause few or no problems whilst others cause serious conditions that need lifelong treatment and support. The most serious conditions are sickle cell diseases (such as sickle cell anaemia, Hb SC, Hb S-beta thalassaemia) and beta thalassaemia major. The type of condition depends on which genes for haemoglobin a person has inherited.

You can find out more about conditions caused by unusual haemoglobin from your health professional or from the organisations listed at the back of this leaflet.

We are providing this for information only. Your baby does not have a haemoglobin disorder.

How are haemoglobin disorders passed on?

Babies can only inherit a haemoglobin disorder if both parents pass on a gene for an unusual haemoglobin.

When a mother and a father both carry a gene for unusual haemoglobin, every time they have a baby, there is:

- a 25% (one in four) chance that their baby will have usual haemoglobin
- a 50% (two in four) chance that their baby will be a carrier
- a 25% (one in four) chance that their baby will have a haemoglobin disorder.

This is shown in the diagram below.

It is important to remember that many haemoglobin disorders cause few or no health problems.

The diagram below shows the chances (for each pregnancy) of two carrier parents having a child with a haemoglobin disorder.
"[The fact that our baby is a carrier] is just something that will just sort of sit in the background, up until either we decide to extend the family or we’re waiting for grandchildren. And I think that’s the only times that it will come up."

The mother of a baby identified as a carrier

Other questions that parents of carriers often ask

Can my baby develop a haemoglobin disorder?
No – your baby will never have a haemoglobin disorder. But they will always be a carrier.

Is being a carrier infectious?
No – you cannot catch a haemoglobin disorder. You can only be a carrier if you inherit the gene from one of your parents.

Why is it important to tell my child about being a carrier?
It is important information for the future. Your child needs to know about being a carrier if they are planning to start a family because, as we have already explained, their child could inherit a haemoglobin disorder.

You can talk about it in different ways as your child grows up. Try to introduce the subject in a calm way and use opportunities that come up naturally – for example learning about blood at school. Do reassure your child that they are healthy and do not need any treatment.

Does being a carrier protect my child from malaria?
Carrying a gene for an unusual haemoglobin may help to protect people against malaria in childhood. This explains why the gene became common and why you are more likely to carry an unusual gene if your ancestors came from places where malaria has been widespread. These places include countries around the Mediterranean (for example Cyprus, Turkey, Italy, Greece), Africa, the Caribbean Islands, the Middle East, parts of India, Pakistan, south and south-east Asia. But anyone can carry a gene for an unusual haemoglobin, and people who are carriers should still take precautions and medicines against malaria when they are travelling in countries where malaria is common.

Facts about haemoglobin disorders

- Haemoglobin disorders are some of the most common inherited conditions in the world.
- Around 7% of the world's population carry an unusual haemoglobin gene.
Questions?
If you have questions about any of the information in this leaflet, please talk to your health visitor or GP. They may know other organisations that can give you information. We have listed some of these on the next page.

More information
The NHS Sickle Cell and Thalassaemia Screening Programme is developing more detailed information about carrying different types of unusual haemoglobin genes, the haemoglobin disorders and the chances of babies inheriting a haemoglobin disorder. Visit www.sickleandthal.org.uk.

Read more real-life experiences of screening for unusual haemoglobins like the ones shown in this leaflet. Visit www.dipex.org/sicklecellandthalassaemia.

Find out more detailed information about being a carrier and haemoglobin disorders at www.chime.ucl.ac.uk/APoGI (click on 'APoGI' for haemoglobin gene variants).
Your local haemoglobinopathy service is based at:

Other organisations

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

United Kingdom Thalassaemia Society (UKTS)
19 The Broadway,
Southgate Circus,
London N14 6PH
Phone: 020 8882 0011
Fax: 020 882 8618
Email: office@ukts.org
Website: www.ukts.org

Sickle and Thalassaemia
Association of Counsellors (STAC)
South West London Sickle Cell and Thalassaemia Centre,
Balham Health Centre,
120 Bedford Hill, Balham,
London SW12 9HP
Phone: 020 8700 0615
Email: info@stac.org
Website: www.stacuk.org

We aim to treat all records relating to screening for sickle cell, thalassaemia and other haemoglobin disorders in line with the Data Protection Act 1998.

This leaflet was produced by the NHS Sickle Cell and Thalassaemia Screening Programme in September 2007. We will provide versions of this leaflet in other languages and on audio tape, in large print and in Braille during 2007-2008. For more details, please see the programme website at www.sickleandthal.org.uk

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