Carrying Haemoglobin D

(DNA diagnosis - not haemoglobin D Punjab)

A carrier can use this booklet to...

- help explain carrying haemoglobin D to their partner, blood relatives and others.
- show to any health professional (doctor, nurse or midwife) they see about having a family, or pregnancy, or carrying haemoglobin D.

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Introduction

Haemoglobin D is one of a range of variations in the blood called *haemoglobin gene variants*. Here we call them *haemoglobin variants* for short.

Carriers of haemoglobin D are also sometimes said to to be AD, or to have haemoglobin D trait.

Haemoglobin D is inherited. That is, it is passed on from parents to their children, like height, hair colour or eye colour. It is passed on equally by men and women. It is present at birth, and it remains the same for life.

It is important to distinguish clearly between people who *carry haemoglobin D (not D Punjab)* and people who *carry haemoglobin D Punjab*.

Carriers of haemoglobin D (not D Punjab)...

... inherited haemoglobin D (not D Punjab) from one of their parents. Carrying haemoglobin D does not affect their own health. It is also extremely unlikely to affect the health of their children, even if their partner is also a carrier. Haemoglobin D (not D Punjab) is therefore said to be a harmless haemoglobin variant.

People who carry haemoglobin D Punjab...

... have inherited a haemoglobin variant that could affect the health of their children if their partner is also a carrier.

This document is about carrying haemoglobin D (not D Punjab), one of a group of harmless haemoglobin variants.

What does it mean to carry haemoglobin D (not D Punjab)?

Blood is made up of millions of *red blood cells* floating in a fluid called *plasma*. Red blood cells are full of haemoglobin, which is red. This is why blood is red. The heart pumps blood round the body through the blood vessels. The body needs oxygen to function. Haemoglobin picks up oxygen as blood passes through the lungs, and carries it to the rest of the body as the blood circulates.

The usual type of haemoglobin is adult haemoglobin or haemoglobin A. Carriers of haemoglobin D have an unusual haemoglobin called haemoglobin D as well as haemoglobin A.

Haemoglobin D is *inherited* - it is handed on from parents to their children, it is present at birth, and it remains the same for life.

How is haemoglobin D inherited?

It is inherited through *genes*. Every human characteristic, such as eye colour, or height, or type of haemoglobin is controlled by genes that parents pass on to their children. A child inherits two genes for every characteristic, one from each parent. Most people inherit two genes for the usual type of haemoglobin, *haemoglobin A*. Each gene is responsible for making half of the haemoglobin A in each red blood cell.

A carrier of haemoglobin D has inherited a gene for haemoglobin A from one parent and a gene for haemoglobin D from the other. The haemoglobin D gene makes a type of haemoglobin that is very slightly different from haemoglobin A. Carriers are said to "be AD" because their red blood cells contain both haemoglobin A and haemoglobin D. Their blood functions normally, and carrying haemoglobin D does not cause them any health problems.

How do people find out that they carry haemoglobin D?

By having a special blood test "for haemoglobin disorders". This usually involves two steps.

- The first step is to measure the size of their red blood cells. This shows nothing unusual.
- The second step is to analyse the types of haemoglobin in their blood. This shows that their blood contains haemoglobin D as well as haemoglobin A.

There are seven known types of haemoglobin D. Only one, haemoglobin D Punjab, can cause a serious haemoglobin disorder. A DNA test is needed to show that a person who carries haemoglobin D definitely does not carry haemoglobin D Punjab.

Can carrying haemoglobin D affect your health?

Carriers of haemoglobin D are not ill, and are no more likely to get ill than other people. Carrying haemoglobin D does not make them weak, and they can do any kind of work they choose.

Is there any treatment to get rid of haemoglobin D?

No, a person who is born carrying haemoglobin D will always carry it.

Can carrying haemoglobin D turn into a serious haemoglobin disorder?

It cannot.

Can people catch haemoglobin D from a carrier?

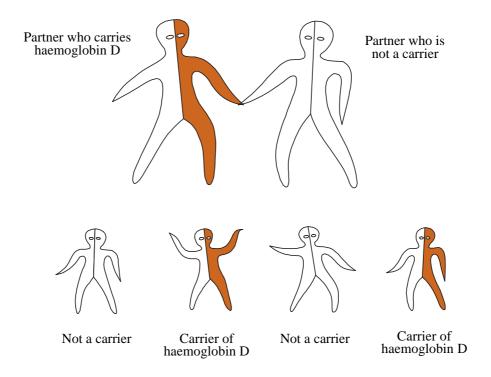
They cannot.

Can a carrier of haemoglobin D be a blood donor?

They can give blood like other people, provided they are not anaemic (do not have a lower haemoglobin level than usual).

Implications for a carrier's children...

If one partner carries haemoglobin D (not D Punjab) and the other does not carry any haemoglobin variant, their children could not have a serious haemoglobin disorder



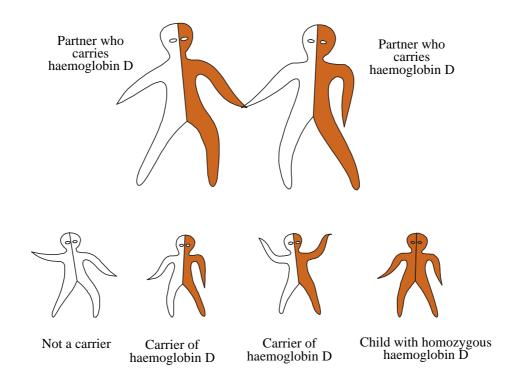
In each pregnancy, there are two possibilities:

- The child may not carry any haemoglobin variant.
- The child may carry haemoglobin D (not D Punjab). This is harmless.

This couple has the same chance of a healthy family as other couples do.

There is also no known risk of a serious haemoglobin disorder if their partner carries any other common haemoglobin variant.

If both partners carry haemoglobin D, their children could have homozygous haemoglobin D (DD)



In each pregnancy, there are three possibilities:

- The child may not carry any haemoglobin variant.
- The child may carry haemoglobin D. This is harmless.
- The child may inherit haemoglobin D from both parents. Such a child would have homozyogous haemoglobin D (DD). This is also known as having only haemoglobin D. It is harmless.

This couple has the same chance of a healthy family as other couples have.

Why is it important for a person to know that they carry haemoglobin D (not D Punjab)?

There are three main reasons.

- Firstly, if they have a blood test for any reason it may show that they carry haemoglobin D. If
 haemoglobin D (not D Ppunjab) is mistaken for a different haemoglobin variant, this can lead to
 confusion, misinformation and uneccessary tests. A person who carries haemoglobin D (not D
 Punjab) and understands that it is harmless can explain it to any health workers they see, and
 these problems can be avoided.
- Secondly, if they are thinking of having children, they should ask their partner to have a blood test "for haemoglobin disorders". If their partner is not a carrier they can be sure that there is no risk to the health of their children. However, if their partner is also a carrier they should see an expert in haemoglobin disorders to confirm that there is no risk to the health of their children.
- Thirdly, their blood relatives, for example their children or brothers or sisters, may also carry haemoglobin D (not D Punjab) and may also have problems with misinformation and uneccessary tests. A carrier should tell their relatives about carrying haemoglobin D (not D Punjab), and advise them to have a blood test "or haemoglobin disorders".

Asking a partner to have a blood test

A carrier who is thinking of having children needs to tell their partner that they carry haemoglobin D, and ask him or her to have a blood test "for haemoglobin disorders".

Is it difficult for a carrier to ask their partner to have a blood test?

It can be easy in some cases and difficult in others. It is easier if both the carrier and their partner know that:

- Carrying a haemoglobin variant is common.
- The test will probably show that the partner does not carry a haemoglobin variant.
- If they do carry a haemoglobin variant it will not affect their health or lifestyle in any way.
- A couple who are both carriers can have a healthy family.
- Expert counselling is available.
- The results of blood tests, and the couples' decisions, are completely confidential.

If a couple are both carriers, can it interfere with their relationship?

It is unusual for a relationship to suffer because one or both of a couple carry a haemoglobin variant.

When is the best time for a carrier to ask their partner to have a blood test?

Ideally as early as possible, because it can take time to arrange a blood test, and for a couple who are both carriers to see an expert. Of course, the best timing depends on the couple's relationship with each other. It may also be influenced by their families' views, and the culture they belong to.

In practice a carrier might suggest a blood test to their partner at one of the following points.

- Before they settle down together.
- After they settle down together but before they start a pregnancy.
- As soon as they have started a pregnancy.

Telling the family about haemoglobin D

A carrier inherited haemoglobin D from one of their parents, so their brothers and sisters and other blood relatives could also be carriers. For example a brother or sister has a 1 in 2 chance of being a carrier.

If a carrier has brothers or sisters, or already has children, they should advise them to ask their GP or practice nurse for a blood test "for haemoglobin disorders".

Carrying haemoglobin D (not Punjab)

(also known as being AD, or having haemoglobin D trait)...

... is not an illness, and will never become an illness. It was passed to you by one of your parents and you could pass it on to your children.

It is a variation of the blood.

It will not affect the health of your children, even if your partner is also a carrier.

- If you are thinking of having children, your partner should have a blood test "for haemoglobin disorders", to confirm that there is nothing to worry about.
- If you have children or brothers and sisters, they could carry haemoglobin D (not Punjab) like you.

To find out more, see your GP or a specialist counsellor.