

Carrying haemoglobin Lepore, a form of beta thalassaemia

(also known as having haemoglobin Lepore trait)

- A carrier of haemoglobin Lepore is a healthy person.
- Carrying haemoglobin Lepore does not weaken them physically or mentally.
- They do not need any medical treatment because they carry haemoglobin Lepore.

What does it mean to carry haemoglobin Lepore?

Haemoglobin Lepore is one of many possible variations in the blood called *haemoglobin gene variants*, or *haemoglobin variants*.

Haemoglobin is what makes blood red. It is packed into red blood cells. Carriers of thalassaemia have smaller red blood cells, but more of them, than other people.

A carrier will always be a carrier, and no-one can catch it from them. They inherited haemoglobin Lepore from one of their parents, and could pass it on to their children.

Anyone can carry haemoglobin Lepore but it is uncommon. It is found occasionally among people who originate from Southern Europe, the Mediterranean area, the Middle East, India, West Africa, or the Caribbean area. It is rare among North Europeans.

Can carrying haemoglobin Lepore cause any health problems?

Carrying haemoglobin Lepore is not an illness, and will never turn into an illness. In fact, carriers are less likely than other people to catch malaria or suffer from heart attacks. Carriers can eat what they want, and do any kind of work they choose.

Some carriers are slightly anaemic (have a lower haemoglobin level than usual). This anaemia has no effect on health or length of life. However, it can become more severe during pregnancy, and sometimes a pregnant carrier needs a blood transfusion. A carrier who is anaemic should have a diet with enough iron and vitamins to make sure that the anaemia does not get worse.

Occasionally a doctor thinks a carrier must be short of iron because they have small red blood cells. If the doctor prescribes iron medicine, in the long run this could do more harm than good. A carrier should take iron medicine only if a special blood test (serum iron or serum ferritin) shows that they are short of iron.

Carriers can give blood provided that they are not anaemic (do not have a lower haemoglobin level than usual).

Could a carrier of haemoglobin Lepore have children with a serious haemoglobin disorder?

Only if their partner carries a haemoglobin variant.

With medical help, such a couple can have healthy children.

What should a carrier do if they are thinking of having children?

They should tell their partner that they carry haemoglobin Lepore, and ask him or her to have a blood test “for haemoglobin disorders”. This test should be done before they start a pregnancy, or as soon as possible once a pregnancy has started. Their GP can arrange it.

If their partner is not a carrier, there is nothing to worry about.

What should they do if their partner is also a carrier?

They should ask their GP for an immediate appointment with a specialist counsellor. This is particularly important if they have already started a pregnancy. They can also contact the counselling service directly.

Is there anything else that a carrier should do?

If a carrier has brothers or sisters, or already has children, they need to know that they may also carry haemoglobin Lepore. They should ask their GP or practice nurse for a blood test “for haemoglobin disorders”.

Counselling services for haemoglobin gene variants are provided in this area by: