University Hospitals of Leicester
NHS Trust

Understanding alpha thalassaemia

Haemoglobinopathies Service

Information for Patients

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Introduction

This information leaflet is for people who have had a blood test that has suggested they may be a carrier of alpha thalassaemia.

This may have been suggested because of the appearance of your red blood cells at the time of your blood test as well as your ethnic origin. You have not been diagnosed as being an Alpha thalassaemia carrier. This can only be diagnosed by specific genetic testing. This genetic test is not usually needed as alpha thalassaemia carriers are usually healthy and have no symptoms.

What is thalassaemia?

Thalassaemia is an inherited blood disorder. This means it is passed to a child from 1 or both parents through their genes. Genes are the building blocks of the body. They control most physical traits such as eye colour, hair type and nose shape.

When you have thalassaemia, your body makes less haemoglobin than normal. Haemoglobin is a substance in the red blood cells. It carries oxygen to all parts of the body.

Thalassaemia can cause mild or severe anaemia. Anaemia happens when your body does not make enough red blood cells or haemoglobin. How severe the anaemia is depends on the number of genes affected.

There are 2 main types of thalassaemia: alpha and beta. Each type is affected by different genes. This leaflet is about alpha thalassaemia.

What causes alpha thalassaemia?

Normal haemoglobin is made up of 4 alpha globin genes and 2 beta globin genes. Alpha thalassaemia happens when some or all of the alpha globin genes are missing or damaged. There are 2 types of alpha thalassaemia:

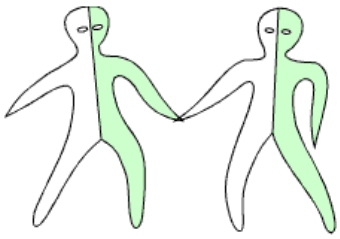
Alpha Plus Thalassaemia

If you are a carrier of alpha thalassaemia and your parents, grandparents or ancestors are from:

- Africa
- the Caribbean
- India
- Pakistan
- Bangladesh

Then you are more likely to be a carrier of the alpha plus type of alpha thalassaemia. This is harmless.

If both parents are carriers of alpha plus thalassaemia, this would **not** cause a serious inherited anaemia in their children. It is a harmless condition and does not usually cause any significant symptoms.

<table>
<tr><td>Parent who carries alpha plus thalassaemia</td><td colspan="2">  </td><td>Parent who carries alpha plus thalassaemia</td></tr>
<tr><td>  </td><td>  </td><td>  </td><td>  </td></tr>
<tr><td>Not a carrier</td><td>Carrier of alpha plus thalassaemia</td><td>Carrier of alpha plus thalassaemia</td><td>Child with alpha plus thalassaemia</td></tr>
</table>

In each pregnancy, there **is a:**

- 1 in 4 chance the child will not carry any alpha plus thalassaemia gene.
- 2 in 4 chance the child will carry alpha plus thalassaemia gene, sometimes known as alpha plus thalassaemia trait. This is harmless.
- 1 in 4 chance the child will inherit alpha plus thalassaemia. This is considered harmless.

If your family ethnic origins are unknown or are not recorded on the blood form this can affect how your results are reported. You may be reported as being a possible alpha zero thalassaemia carrier or as unable to exclude alpha zero thalassaemia.

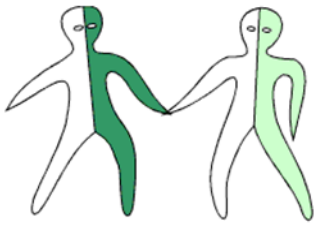
Alpha Zero Thalassaemia

If you are a carrier of alpha thalassaemia and your parents, grandparents or ancestors are from:

China, Hong Kong, Taiwan, Thailand, Cambodia, Laos, Vietnam, Burma, Malaysia, Singapore, Indonesia, Philippines, Cyprus, Greece, Sardinia, Turkey, Southern Italy you have a higher risk of being a carrier of the alpha zero type of alpha thalassaemia.

Some people whose ancestors are from the Middle East may also be carriers of alpha zero thalassaemia.

If 1 parent carries **alpha zero thalassaemia** and the other carries **alpha plus thalassaemia**:

Parent who carries alpha zero thalassaemia			Parent who carries alpha plus thalassaemia
			
Not a carrier	Carrier of alpha zero thalassaemia	Carrier of alpha plus thalassaemia	Child with "haemoglobin H disease"

In each pregnancy, there is a:

- 1 in 4 chance the child will not carry any haemoglobin disorder.
- 1 in 4 chance the child will carry alpha plus thalassaemia. This is harmless.
- 1 in 4 chance the child will carry alpha zero thalassaemia. This is harmless.
- 1 in 4 chance the child will inherit alpha plus thalassaemia gene from 1 parent and alpha zero thalassaemia gene from the other. This child will have an inherited anaemia called **haemoglobin H disease**.

Haemoglobin H disease is a form of anaemia. Most people with haemoglobin H disease lead a normal life. They go to school, work and have children just like other people. They sometimes need medical treatment and would usually be seen at a haematology clinic every year for a check-up.

If both parents carry **alpha zero thalassaemia.** They could have a child with no alpha genes. This is a very severe condition called **alpha zero thalassaemia major.**

Parent who carries alpha zero thalassaemia			Parent who carries alpha zero thalassaemia
			
Not a carrier	Carrier of alpha zero thalassaemia	Carrier of alpha zero thalassaemia	Child with alpha zero thalassaemia major

In each pregnancy, there is a:

- 1 in 4 chance the child will not carry any haemoglobin disorder.
- 2 in 4 chance the child will carry alpha zero thalassaemia. This is harmless.
- 1 in 4 chance the child will inherit alpha zero thalassaemia from both parents. This baby would have **alpha zero thalassaemia major**. This is also called **alpha thalassaemia hydrops fetalis** or **Haemoglobin Bart's hydrops fetalis**.

Alpha zero thalassaemia major causes a severe anaemia that affects the baby in the womb. The pregnancy may appear to progress normally up to around 5 months or sometimes longer. It can cause serious health problems for the pregnant mother. Alpha zero thalassaemia major almost always leads to the baby not surviving during the pregnancy or after birth.

In Leicestershire, during the first appointment with a midwife (pregnancy booking), women are offered a haemoglobin screening blood test which will identify if they are suspected of being **alpha zero thalassaemia carriers.** If they are then the father of the baby will be offered a blood test. If both parents are suspected of being carriers they would be invited to clinic to talk about their results and more tests that may be available.

Useful contacts

Leicestershire Sickle Cell and Thalassaemia Service

Ground floor, Osborne Building

Leicester Royal Infirmary LE1 5WW

Telephone: 0116 258 6081

UK Thalassaemia Society

19 The Broadway

Southgate Circus

London N14 6PH

Telephone: 020 8882 0011

Email: office@ukts.org

Website link: www.ukts.org/

This leaflet can also be found online via the following QR Code

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔

على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

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