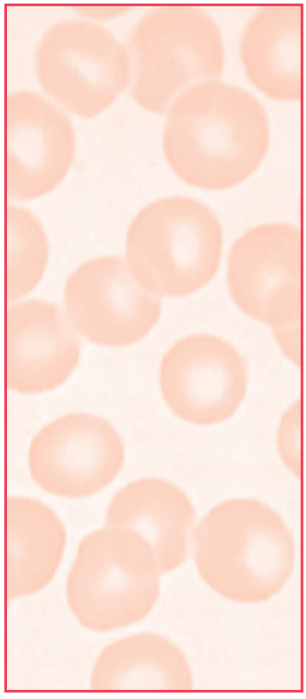
Information for people who carry

Alpha Thalassaemia



A UK Thalassaemia Society Publication

This booklet is for people who have had a blood test that suggests they carry alpha thalassaemia

People who carry alpha thalassaemia are said to have *alpha thalassaemia trait*. This is often written α thalassaemia trait.

Please keep this booklet handy with your medical card and show it to your doctor or midwife if they discuss thalassaemia with you

Published By:
UK Thalassaemia Society
19 The Broadway, Southgate Circus
London N14 6PH
Tel: 020 8882 0011 Fax: 020 8882 8618
E-mail: office@ukts.org Web: www.ukts.org
A Registered Charity No: 275107

ISBN 1 900254 00 X

1996®

Information For People Who Carry Alpha Thalassaemia

Many people originating from the Mediterranean area, the Middle East, Africa or Asia carry thalassaemia. It is common in these regions because it helps to protect carriers against malaria. It is rare in Northern Europeans.

Thalassaemia is a characteristic of the blood. It is inherited, that is, it is passed on from parents to children, like hair colour, eye colour or skin colour. It is passed on equally by men and women. It is *not* catching, and will *not* turn into an illness.

There are two forms of thalassaemia: alpha thalassaemia (α thalassaemia) and beta thalassaemia (β thalassaemia).

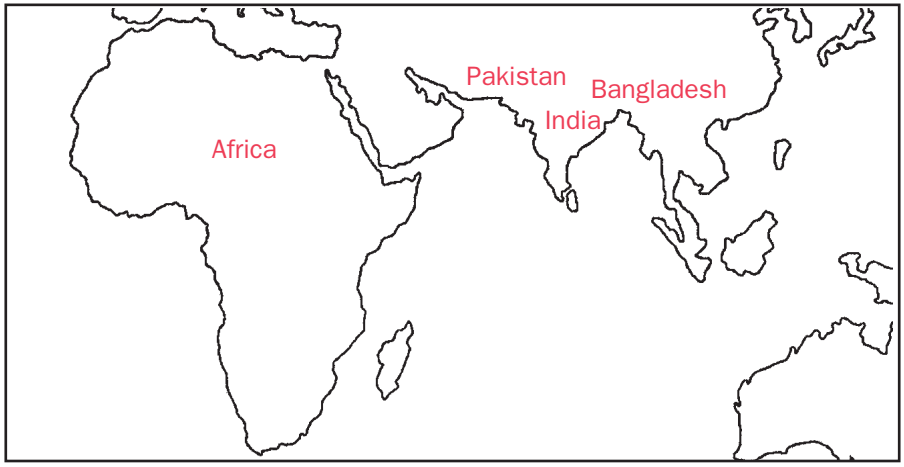
Carrying alpha thalassaemia does not cause any illness. Most people who carry alpha thalassaemia do not know they have it. They only discover it when they have a special blood test. However, it can cause confusion and in some cases it could affect the health of your children. “Alpha Thalassaemia Trait” is the same as being a carrier of Alpha Thalassaemia.

There are two types of alpha thalassaemia: alpha plus thalassaemia, which is harmless, and alpha zero thalassaemia which may have more serious implications. This booklet applies to both types.

Harmless Alpha Thalassaemia: *Alpha Plus Thalassaemia*

If you, or one or both of your parents or grandparents, or in fact any of your ancestors originally came from: **Africa** (this includes African Caribbeans, unless they have some Chinese ancestry), **India**, **Pakistan**, **Bangladesh** ***your alpha thalassaemia is likely to be harmless for you and your children.***

You probably have a form of alpha thalassaemia called **alpha plus thalassaemia**. This is the mildest form of thalassaemia. It will never affect your health. You may pass it on to some of your children, but it will not affect their health.



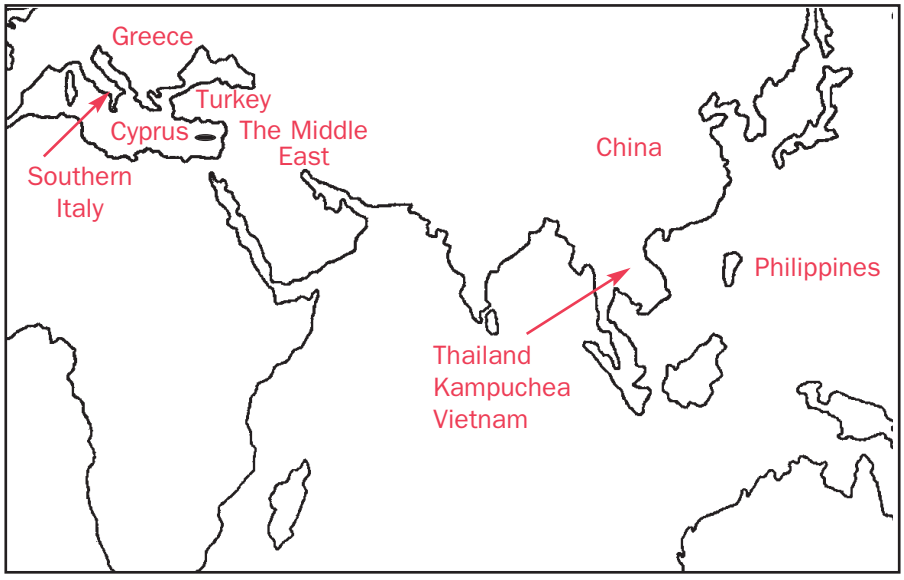
About 1 in 3 people originating from Africa or the Indian sub–continent carry alpha plus thalassaemia. In fact, it is normal for many people whose ancestors came from these areas to carry mild alpha thalassaemia. So you should not worrry about it.

It is useful for you to know that you carry alpha plus thalassaemia, because otherwise, when you have a blood test, doctors may think that you carry a more serious form of thalassaemia. This could worry you unnecessarily. Your alpha thalassaemia could also be mistaken for iron deficiency. In your case, iron deficiency can be diagnosed only by measuring your serum iron or ferritin level.

The Important Form of Alpha Thalassaemia: *Alpha Zero Thalassaemia*

If you carry alpha thalassaemia and you or your parents or grandparents, or in fact any of your ancestors originally came from:

South East Asia, China (this includes people of Chinese origin from Hong Kong, Singapore, Malaysia, Indonesia), Thailand, Vietnam, Kampuchea, The Philippines. **The Mediterranean area** Cyprus, Greece, Turkey, Southern Italy, **The Middle East** or if you do not know where your ancestors came from, or you are a North European **you could carry alpha zero (α^0) thalassaemia, or you could carry alpha plus ($\alpha+$) thalassaemia.**



Alpha zero thalassaemia is uncommon. It does not cause any illness. However, it could be a problem for some of the children of people who carry it.

If ***both*** parents carry alpha zero thalassaemia, some of their babies could have a very severe anaemia. But if they know they both carry alpha zero thalassaemia they can avoid this risk.

So if you carry alpha thalassaemia and you come from China or another part of South East Asia, the Mediterranean area or the Middle East, it may be important for you to find out which type of alpha thalassaemia you carry.

If you do not yet have a partner, remember that your alpha thalassaemia will not do you any harm. You need not do anything more now. Once you have a partner, take him or her for a blood test ***before you have children***. If your partner does not have any type of thalassaemia, there is no risk for your children, and you have nothing to worry about. But if your partner's blood test result shows any unusual finding which might be associated with thalassaemia, you should see an expert in haemoglobin disorders for advice.

If you are not sure what type of alpha thalassaemia you carry, and you need to find out, go to see your doctor, and ***take this booklet with you***.

Your doctor can arrange further information, and tests for you when necessary, through your local consultant haematologist, or the expert centres listed opposite.

Is there anything else I should do now?

You inherited your alpha thalassaemia from your father or your mother, so your brother and sisters, and other blood relatives, could also be carriers. If you, or your ancestors come from South East Asia, the Mediterranean or the Middle East, show your relatives this booklet, and advise them to ask for a blood test for alpha thalassaemia before they have children.

Further information and testing can be arranged through the following centres:

University College Hospital NHS Trust Regional Haemoglobinopathy Genetics Centre (Perinatal Centre) 86-96 Chenies News, London WC1E 6HY. Tel: 020 7388 9246, 0845 155 5000 ext. 5230 Fax: 020 7380 9864.

The SE Thames Regional Centre for Blood Disorders, Department of Haematological Medicine, King's College Hospital, Denmark Hill, London SE5 9RS. Tel: 020 7346 3242.

The National Haemoglobinopathy Reference Laboratory, Oxford Haemophilia Centre, Churchill Hospital, Oxford OX3 7LJ. Tel: 01865 225 329.

The UK Thalassaemia Society
19 The Broadway, Southgate Circus,London N14 6PH
Tel: 020 8882 0011 Fax: 020 8882 8618

£0.20

ISBN 1 900254 00 X

Written for the London Haemoglobinopathy Discussion Group