WHAT IF BOTH PARTNERS ARE CARRIERS?

You can still have children. You have a 25% chance at **each** future pregnancy that the child has Thalassaemia Major.

HOW AND WHEN DO THEY TEST PREGNANCIES?

A couple is offered an opportunity to test the pregnancy when both partners are found to be carriers and have been counselled as to what Thalassaemia is and what their risks are. They must understand and give their consent to test the pregnancy.

The pregnancy must be tested as early as possible. This is between 10-12 weeks from the last menstrual period. A simple test called a Chorionic Villus Sampling (CVS) test is then performed.

The CVS test involves taking of a small sample of the placenta and then a genetic test is done on it. The test is straight forward but rarely can this cause complications.

WHAT HAPPENS IF THE PREGNANCY IS AFFECTED?

If the genetic test reveals that the pregnancy is affected, the couple will then be counselled and offered support to make an informed choice. The couple will have the full right of confidentiality and all the aspects of Thalassaemia Major will be explained to them. They then have to make an informed choice to continue or terminate the pregnancy.

This is a very difficult and trying period. Although full support and counselling is available, we still advise that all couples should be tested before planning a family as you need a lot of time and privacy to deal with your emotions , the facts about Thalassaemia and your future.

PUT YOUR MIND AT REST HAVE THAT TEST!

ESSENTIAL FACTS ABOUT THALASSAEMIA

1. Thalassaemia is a serious genetic blood disorder. You cannot catch it or develop it. It is inherited as Carrier form or as Thalassaemia Major. One form can t change into the other.

2.The Carrier has inherited just one Thalassaemia gene from either parent. A Thalassaemia Major baby inherits two Thalassaemia genes -one from each parent. Both parents must be carriers in order to have a Thalassaemia Major child.

3. Carriers are perfectly healthy. Only the Haemoglobin Electrophoresis blood test can reveal a carrier.

4. Up to 1 in 7 Asians are Carriers of the Thalassaemia Gene.

5. If both Partners are Carriers, there is then a 25% chance at each pregnancy that the child will inherit both their Thalassaemia genes and have Thalassaemia MAJOR.

6. A child with Thalassaemia Major is unable to make enough red blood cells and develops a severe life threatening anaemia. If this child is not transfused with blood he/she could die in childhood. 80% of Thalassaemia Major births in the UK occur in Asian families.

7. Besides blood transfusions every month, this child requires daily iron removing treatment that involves 8-12 hours of a pump- driven continuous injection . This is done at home.

8. There is no effective cure for Thalassaemia Major . The blood transfusions and the treatment are life long.

9. Thalassaemia Major can be prevented. A simple blood test done by your GP will reveal if you are a Carrier.

10. Where both partners are carriers, you can still have children. There is 25% chance at each pregnancy that the child has Thalassaemia Major. You can have the pregnancy tested and find out if the baby is affected. You then have an informed choice of continuing with the pregnancy.

UNITED KINGDOM THALASSAEMIA SOCIETY

UK THALASSAEMIA SOCIETY
FOR FURTHER INFORMATION
RING US ON 020 8882 0011
OR
VISIT OUR WEB SITE:
www.ukts.org

UNITED KINGDOM THALASSAEMIA SOCIETY

THALASSAEMIA

YOUR LIFE.YOUR CHOICE.

YOUR TEST !

WHY YOU NEED TO KNOW ABOUT THALASSAEMIA

This leaflet aims to inform Asian communities in Britain about how to prevent Thalassaemia.

Thalassaemia is a common genetic blood disorder found amongst the Asian communities that can have a devastating impact upon you and your future family.

This leaflet emphasises the need for preconception testing (testing before planning a family) to determine if you are a healthy carrier of Thalassaemia.

If both you and your future/current partner are found to be Carriers then you should know before planning a family what Thalassaemia is and how to arrange for early testing in a pregnancy to see if the baby has Thalassaemia Major.

With this knowledge about Thalassaemia and its risks upon your future children you will be better placed to make an informed choice about an affected pregnancy if and when the need arises.

WHAT IS THALASSAEMIA?

Thalassaemia is a genetic blood disorder that is inherited from Parents.

There are two forms: Thalassaemia **CARRIER** (also known as Thalassaemia Minor or Trait) and Thalassaemia **MAJOR.**

Being a Thalassaemia ***CARRIER*** causes no ill health but when two people who are Thalassaemia carriers have a child, there is a 25% chance at each pregnancy that they will have a baby with Thalassaemia **MAJOR**.

Thalassaemia **MAJOR** is a serious blood disorder where the baby is unable to produce enough red cells in the blood. Without treatment this child eventually dies. With treatment, the child is able to grow and become an adult but faces many health complications. There is no safe and effective cure for Thalassaemia.

HOW IS THALASSAEMIA MAJOR TREATED?

At present the treatment consists of blood transfusions in hospital every month and using a “continuous” injection for 8-12 hours each night at home.

Despite treatment the Thalassaemia Major sufferer may face many health complications like diabetes, growth and sexual development problems and heart problems.

The treatment is life long and there is no safe and effective cure for Thalassaemia. Rarely, bone marrow transplant may be helpful.

WHO MAY BE CARRIERS?

In the UK the 2.1 million Asian community is at risk. It is estimated that up to 1 in 7 Asians may be carriers.

If you or your family originate from Pakistan, India, Bangladesh or Sri Lanka, you may be at risk of being a carrier of Thalassaemia.

WHY MAY IT BE HIDDEN IN YOUR FAMILY HISTORY?

Because a Thalassaemia carrier is a healthy individual, he or she has no outward signs or symptoms and will not be be aware of their condition. They can only be discovered by a simple but specific blood test. Any parents or ancestors who were carriers may never have been identified in the past.

Because of the higher number of deaths in babies and children in the past, many children who died from Thalassaemia Major may not have been known to have Thalassaemia Major . We do know from present research that Thalassaemia Major existed in those days and it still exists today.

Genetics is a new Science. It is quite recent that we are able to predict and prevent Thalassaemia Major by testing for Carriers and doing genetic tests on affected pregnancies.

HOW CAN I BE TESTED ?

Simple. A small sample of your blood is taken and sent to the laboratory. The result is usually obtained very quickly. Ask your GP or family planning clinic to arrange for the Thalassaemia blood test. Please get the blood test done as soon as possible and before you plan a family.

WILL THE GP OR HOSPITAL NOT KNOW ALREADY?

Not always. Past blood tests may have been done for other reasons to investigate infections or other illness. It is important that the GP is asked for a Thalassaemia blood test specifically.

Put your mind at rest, when you go into your GP next, ask for the Thalassaemia Blood test. The test is known as “Haemoglobin Electrophoresis”. You will then be certain.

WHAT IF I AM FOUND TO BE A CARRIER?

If your tests reveal that you are a carrier, the GP or health professional will discuss the results with you. Please ring us for further information and advice.

You will not develop Thalassaemia Major nor will anyone “catch” your Thalassaemia.

However, the important point for you is that specifically before planning a family you must get your partner tested at the earliest opportunity.

If your partner is not a Carrier you have nothing to worry about. At each pregnancy you have a 50% chance that the child is a Carrier like you and a 50% chance that they are normal and have no Thalassaemia Genes. You have no chance of having a child with Thalassaemia Major.

PUT YOUR MIND AT REST HAVE THAT TEST!