WHAT IF WE ARE BOTH CARRIERS?

You can still have children. There is a 25% chance of any child having Thalassaemia major. However, it is now possible to test the baby in early pregnancy to see if it has Thalassaemia major. If the unborn baby has Thalassaemia major then the parents can take the option of terminating the pregnancy if they wish.

WHERE CAN I GET ADVICE?

If you do not know if you are a carrier then your own Doctor or the UK Thalassaemia Society can advise you on how to get tested.

If both you and your partner are carriers then your Doctor should be able to send you to a specialist in Perinatal Medicine or a Consultant in Genetic Disorders who can help. It is best to see the specialist before you start a family. The UK Thalassaemia Society would be able to advise you of your nearest major hospital specialising in this disorder.

For further information please contact:

UK Thalassaemia Society
19 The Broadway
Southgate
London N14 6PH.

Telephone: 020 8882 0011
www.ukts.org

ISBN 1 900254 06 9

United Kingdom Thalassaemia Society

19 The Broadway, Southgate, London N14 6PH.
A Charity Organisation Reg. No. 275107
Telephone: 020 8882 0011 Fax: 020 8882 8618

"WHY YOU NEED TO KNOW ABOUT BETA THALASSAEMIA"

DISTRIBUTION OF β-THALASSAEMIA CARRIERS IN INDIA, PAKISTAN & BANGLADESH.

UNITED KINGDOM THALASSAEMIA SOCIETY

WHY YOU NEED TO KNOW ABOUT THALASSAEMIA

This leaflet aims to inform Asian couples about how to prevent Thalassaemia. It emphasises the need for pre-conception testing to establish, whether the couple are thalassaemia carriers. If both partners are found to be carriers then they should know how to arrange for early testing in pregnancy to see if the baby has Thalassaemia Major. With this knowledge about the future child and knowing about Thalassaemia they would be better placed to make an informed choice about the pregnancy.

WHAT IS THALASSAEMIA?

Thalassaemia is a blood disorder that is inherited from parents. There are two forms: Thalassaemia Carrier (also known as Thalassaemia Minor or Thalassaemia Trait) and Thalassaemia Major. Being a Thalassaemia Carrier causes no ill health but when two people who are carriers of Thalassaemia have a child there is a 25% chance of any baby having Thalassaemia Major.

Thalassaemia Major is a serious disorder where the baby is unable to produce enough red cells in the blood. Without treatment the child eventually dies. With treatment, the child is able to grow and become an adult.

HOW IS IT TREATED?

At present this treatment consists of blood transfusions in hospital every month and using a "continuous" injection at home every night. Rarely, transplantation of the bone-marrow may be helpful.

WHO MAY BE CARRIERS?

Those whose parentage is in the Far East, Indian sub-continent, Near East, Middle East and the Mediterranean. Amongst British Asians, those affected by Thalassaemia come from all the main religious groups spanning all of Pakistan, India and Bangladesh.

Some communities have a higher incidence than others.

1 in 7 to 1 in 10 for Gujeratis
1 in 10 for Sindis
1 in 20 for South Indians
1 in 25 for Pakistanis
1 in 15 to 1 in 30 for Punjabis and Bangladeshis.

WHAT IF THERE IS NO HISTORY OF THALASSAEMIA IN MY FAMILY?

Because of the higher number of deaths in babies and children in the past, many children who died may not have been known to have Thalassaemia. We do know from present research that Thalassaemia existed in those days and it still exists today. The only way to be sure that there is no Thalassaemia in the family is to be tested.

HOW CAN I BE TESTED?

Simple. A small sample of blood is taken from you and sent to a blood laboratory. The result can usually be obtained quickly. This can be done at your GP's surgery or the Family Planning Clinic.

WILL MY DOCTOR OR HOSPITAL NOT KNOW ALREADY?

Not always. In many cases previous blood-test results may be unclear and require more testing. Also you may not have been informed as yet if you were found to be a carrier. It is therefore important to check specifically by asking about Thalassaemia.

WHAT IF I AM A CARRIER AND MY PARTNER IS NOT?

Then there is no need to worry further. You can have children without any further tests as your children cannot have Thalassaemia Major. (There is a 50% chance of them being carriers though).