Alpha Thalassemia Disease

There are two main types of Alpha Thalassemia disease. Alpha Thalassemia Major is a very serious disease in which severe anemia begins even before birth and survival past the first few hours of life is rare. Pregnant women carrying affected fetuses are themselves at risk for serious pregnancy and delivery complications. Another type of Alpha Thalassemia is Hemoglobin H disease. There are varying degrees of Hemoglobin H disease that your Health Care Provider can explain to you.

Is There Testing Available for Thalassemia Trait and Disease?

Yes, testing for Thalassemia trait involves having a single blood sample drawn. The following screening tests identify most types of Thalassemia:

- Hemoglobin electrophoresis with quantitative hemoglobin A2 and hemoglobin F.
- Complete Blood Count (CBC).
- Iron studies (free erythrocyte protoporphyrin, lead, ferritin, and/or other iron studies).

You can make an appointment with your Health Care Provider to be tested for Thalassemia Trait.

Important Facts:

- If you learn that you have Thalassemia trait, you may have questions about the implications for you, your future children, and other family members. Your Health Care Provider will be able to answer these questions for you.
- Early diagnosis and proper treatment are very important. Consult with your Health Care Provider if you think you are a trait carrier or if your child is displaying symptoms of Thalassemia disease.
- California State Newborn Screening can detect the most severe forms of Beta Thalassemia and most forms of Alpha Thalassemia. Newborn Screening may not detect forms of Thalassemia trait.

If you would like more information about Thalassemia talk to your Health Care Provider.

This brochure is available in English, Chinese, Vietnamese, Lao, Tagalog and Cambodian.

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Northern California Thalassemia Center
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(510) 428-385 x 4398
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Funding provided by
Project #2 H46 MC 00012-10
from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Dept. of Health and Human Services.

Designed and Translated By
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THALASSEMA
OUTREACH PROGRAM
CHILDREN'S HOSPITAL OAKLAND
Thalassemia is a genetic disease. Transfusion therapy, iron chelation therapy, and organ transplantation are the three major types of therapy.

Other therapies include bone marrow transplantation and liver transplantation. The transfusion therapy involves the administration of blood products to replace lost blood. This therapy is usually used in the early stages of thalassemia major, where the spleen is still able to function normally. In later stages, however, transfusion therapy may not be effective because the spleen becomes enlarged and unable to filter out the iron from the transfused blood.

Iron chelation therapy is used to remove excess iron from the body. This is important because excess iron can damage the heart, liver, and other organs. Chelators, such as deferoxamine, are given intravenously or orally. The chelator binds to the iron in the body and is then excreted in the urine or stool.

Organ transplantation involves the removal and replacement of a diseased organ with a healthy one. This is a last resort for patients who have severe complications from thalassemia major and have failed to respond to other treatments.

Thalassemia is most common in people of Mediterranean heritage and African descent. It is also more common in regions where malaria is endemic. The disease is inherited in an autosomal recessive pattern, meaning that both parents must carry the gene for thalassemia in order for the child to be affected.
Thalassemia Trait: What you should know

If you have thalassemia trait, YOU DO NOT HAVE THE DISEASE. However, there is a possibility that your children could have thalassemia disease.

People who carry thalassemia trait need to know that...

- Thalassemia trait is NOT THE DISEASE. It is not an illness and will never turn into an illness.

- A trait carrier of thalassemia will always be a trait carrier. It is a genetic trait passed down from parents to children. Being a trait carrier is not contagious.

- Over two million people in the United States carry the genetic trait for thalassemia.

- There are two types of thalassemia trait: Alpha thalassemia trait and Beta thalassemia trait.

- A carrier of thalassemia trait is a healthy person. Being a carrier of thalassemia does not cause known health problems which require medical treatment. Thalassemia trait will not impair your work, diet or exercise.

- Thalassemia carriers have smaller red blood cells that may cause a mild anemia. The anemia is so mild that it does not require medical treatment

- Trait carriers should not take iron supplements unless a special blood test (serum iron or serum ferritin) shows that you are iron deficient.

- Carriers can give blood providing they are not anemic (do not have a lower hemoglobin than usual).

- If you and your partner both have thalassemia trait, for each pregnancy, there is a:
  - 25% chance that the child will have thalassemia disease
  - 25% chance that the child will have normal hemoglobin
  - 50% chance that the child will have thalassemia trait

If you have not been tested or unsure of your trait status IT IS BEST TO GET TESTED! Trait testing is easy and virtually painless, and may be ordered by your health care provider.

For more information about thalassemia trait and disease, or to find out more about the Thalassemia Outreach Program, please call 510-428-3885 ext.4398 or ext.5427

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