

## 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, Laotian, Tagalog and Cambodian.

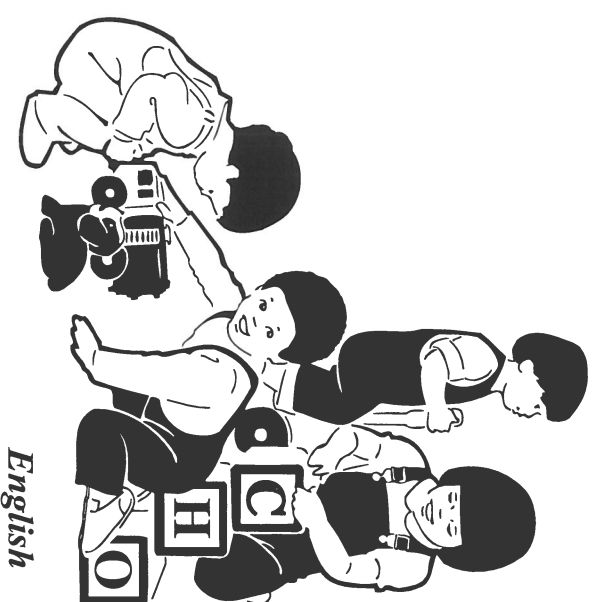
Copyright 2001

Northern California Thalassemia Center  
Thalassemia Outreach Program  
Children's Hospital Oakland  
747 Fifty Second Street, Oakland, CA 94609-1809  
(510) 428-3885 x 4398

All rights reserved.  
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  
Asian Health Services Language Cooperative  
818 Webster Street  
Oakland, CA 94607

# Thalassemia Disease and Trait



*English*

THALASSEMIA  
OUTREACH PROGRAM  
CHILDREN'S HOSPITAL OAKLAND

## What is Thalassemia?

Thalassemia is a genetic blood disorder. People with Thalassemia disease are not able to make enough hemoglobin, which causes severe anemia. Hemoglobin is found in red blood cells and carries oxygen to all parts of the body. When there is not enough hemoglobin in the red blood cells, oxygen cannot get to all parts of the body. Organs then become starved for oxygen and are unable to function properly.

*Because more babies are born each year with Thalassemia, it is becoming a growing healthcare concern.*

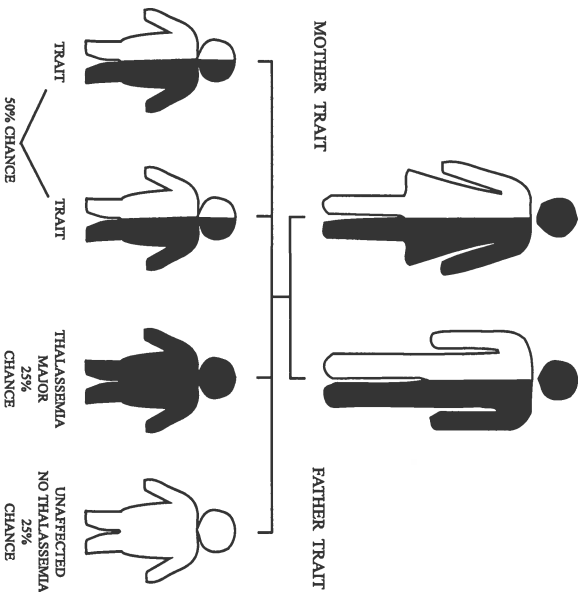
## Who is at Risk?

Thalassemia is most common in the following populations:

- Southeast Asian (Vietnamese, Laotian, Thai, Singaporean, Filipino, Cambodian, Malaysian, Burmese, and Indonesian)
- Chinese
- East Indian
- African
- Middle Eastern
- Greek
- Italian
- Transcaucasian (Georgian, Armenian, and Azerbaijani)

## How Does A Person Get Thalassemia?

Thalassemia is a genetic disease. This means that a person can only get Thalassemia disease or trait by inheriting the genes for Thalassemia from their parents. Genes determine what we look like, such as hair color, and are also responsible for many diseases. Inheritance of Thalassemia happens purely by chance—there is nothing that parents do, or do not do, that will cause their child to inherit Thalassemia. Thalassemia is never 'caught' by another person in the way that a cold or flu is transmitted. People with Thalassemia disease and trait are born with it.



*If both parents carry the trait for Thalassemia, there is a 25% chance with each pregnancy that their child will be born with Beta Thalassemia disease, which is a very serious condition.*

## What is Thalassemia Trait?

Over two million people in the United States carry the genetic trait for Thalassemia. Thalassemia trait is not and never will become Thalassemia disease. There are two main types of Thalassemia trait: Alpha Thalassemia trait and Beta Thalassemia trait. Most types of Thalassemia trait cause the red blood cells to be smaller in size than usual, but there is no scientific evidence that Thalassemia trait causes health problems. Individuals with Thalassemia trait have some level of protection from Malaria. Therefore, although Thalassemia trait is found in all populations, it is most common in people from regions where Malaria occurs.

*California Newborn Screening detects approximately 1,000 cases of Thalassemia trait each year. When planning a family, it is important to know if you and/or your partner carry the trait for Thalassemia.*

## What are the Various Types of Thalassemia Disease?

There are two primary types of Thalassemia disease: Alpha Thalassemia disease and Beta Thalassemia disease.

### Beta Thalassemia Disease

Beta Thalassemia Major (also called Cooley's Anemia) is a serious illness. Symptoms appear in the first two years of life and include paleness of the skin, poor appetite, irritability, and failure to grow. Proper treatment includes routine blood transfusions and other therapies.

# 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