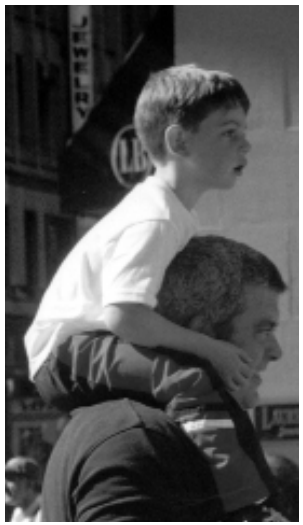
The Cooley's Anemia Foundation

Incorporated in 1954, the Cooley's Anemia Foundation is a national non-profit organization dedicated to serving families living with various forms of thalassemia, particularly the major form of this blood disorder, Cooley's anemia.

Our Mission is:

- Advancing the treatment and cure for this genetic blood disease.
- Enhancing the quality of life of patients.
- Educating the medical profession, thalassemia trait carriers and the public about thalassemia.



The
Cooley's Anemia
Foundation

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What Should I Know About Thalassemia?

Cooley's Anemia
FOUNDATION
Leading the Fight Against Thalassemia

What is Thalassemia?

Thalassemia is the name given to a group of genetic blood disorders. People born with a severe form of thalassemia, such as Cooley's anemia, must undergo a difficult treatment program in order to live. This program includes blood transfusions every two to three weeks and daily administration of a drug to fight the iron toxicity caused by these transfusions.

While relatively few people suffer from severe forms of thalassemia, some 2,000,000 Americans carry the trait for the disorder. If two carriers have children, there is a one-in-four chance with each pregnancy that their child will inherit a severe form of thalassemia.

How Do I Know If I Have the Trait?

Thalassemia is most often found among people of Mediterranean, Middle Eastern, South Asian, Chinese, Southeast Asian, Northern African and Caribbean descent.

However, even people whose ancestry is not strongly associated with these locations may still carry the thalassemia trait. For that reason, the Cooley's Anemia Foundation strongly recommends that all individuals be tested to determine if they are trait carriers.

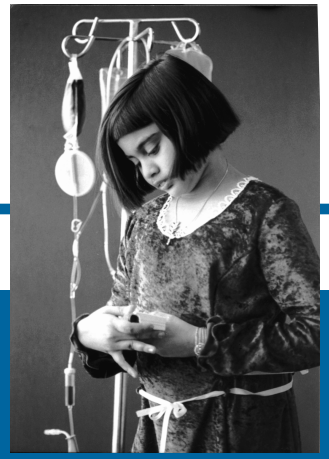
Trait testing is a Simple Process

1. Ask your doctor if you have a Complete Blood Count (CBC) on file. If you do not, ask to get one.

2. Ask your doctor to look at the MCV (Mean Corpuscular Volume) of your CBC. If the MCV reading is less than 75, and if you are NOT iron deficient, you may be a trait carrier.

You should then ask your doctor to perform additional tests - a hemoglobin electrophoresis and quantification of hemoglobin A2 and hemoglobin F - to verify whether you carry the thalassemia trait.

For more information, contact the Cooley's Anemia Foundation at (800) 522-7222 or info@cooleysanemia.org



Facts About Thalassemia

- An estimated 2,000,000 Amerians carry the genetic trait for thalassemia.
- Thalassemia is common among people of Mediterranean, Middle Eastern, South Asian, Chinese, Southeast Asian, Northern African and Caribbean backgrounds.
- Parents who both carry the same kind of genetic trait have a one-in-four chance with each pregnancy of having a child with a serious form of the disorder.
- Thalassemia in its most serious form is a genetic disorder that results in the failure to produce sufficient hemoglobin, the oxygen-carrying component of red blood cells.
- In order to stay alive, patients must undergo blood transfusions every two to three weeks, starting in infancy.
- Frequent blood transfusions cause iron in the transfused blood cells to build up and become toxic to tissues and organs, particularly the liver and heart.
- To help remove excess iron, patients must undergo a process called chelation, which binds iron and removes it from the body. For many patients, this means inserting a needle into the body and pumping a drug into the body for up to 12 hours every day.
- While there is no universal cure for thalassemia, advances in gene therapy and bone marrow transplantation hold the promise that such a cure will be found.