

Facts About Thalassemia

- An estimated 2,000,000 Americans carry the genetic trait for thalassemia.
- Thalassemia is common among people of Mediterranean, Middle Eastern, South Asian, Southeast Asian, Chinese, 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 thalassemia.
- Thalassemia in its most serious form is a genetic blood disease 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 daily process called "chelation." In some patients, this can be achieved through an oral medication; in others, this requires inserting a needle into the stomach or leg and pumping a drug into the body for up to 12 hours.
- CAF continues to encourage researchers to develop new chelators in order to give physicians options to better tailor treatment for each individual patient and to improve patient compliance.
- There is no universal cure for thalassemia, although some individuals have been cured through bone marrow transplantation. Current and upcoming human trials in gene therapy for thalassemia offer the hope of an eventual cure for the greater thalassemia community.



Cooley's Anemia
FOUNDATION

Leading the Fight Against Thalassemia

330 Seventh Avenue, #200, New York, NY 10001

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A History of Caring

For over fifty years, the Cooley's Anemia Foundation has been a strong and supportive partner between families confronting the challenges of living with thalassemia and the medical community.



- Parents whose young child has just been diagnosed with thalassemia call CAF and receive sensitive, knowledgeable advice on the care of their child.
- A doctor, using technology championed by CAF, sees early warning signs of heart trouble in a patient and starts treatment to prevent its development.
- A young girl who has never met another child with thalassemia is flown to the annual Patient/Parent Conference where she meets other young patients who share her experiences, hopes and dreams.
- A scientist receives funding from CAF that allows him to conduct the important medical research that brings us one step closer to a cure.



With a comprehensive range of programs and services, CAF provides vital, hands-on support that helps thalassemia patients live positive, productive lives.



The Cooley's Anemia Foundation

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

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 drug treatments which may require pumping a drug into the body for hours every night.



While relatively few people suffer from severe forms of thalassemia, some 2,000,000 Americans carry the trait for the disease. 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, Southeast Asian, Chinese, 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, CAF 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 Mean Corpuscular Volume (MCV) of your CBC. If the MCV reading is less than 80, 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.

CAF PROGRAMS

Patient Services

Patient Services staff help patients and families contend with many issues, from navigating through difficult insurance matters to providing information on new therapies to connecting patients with expert medical professionals. Aided by a certified on-site social worker, the patient services program offers invaluable psychosocial support in confronting the challenges of a lifelong illness. CAF is in constant contact with the major thalassemia treatment centers, maintaining a two-way flow of information with experienced thalassemia professionals. And our Patient Outreach Director seeks to identify and make contact with thalassemia patients currently unknown to CAF in order to make sure they are receiving important information regarding their care.



Patient-Family Conference

CAF annually holds a special conference for U.S. patients and family members at which experts from the thalassemia community share vital news and information that impacts patient health.

Public & Professional Education

CAF works to educate the public and medical profession about thalassemia through television and radio public service announcements, medical symposia, videos, print materials and a comprehensive website (www.thalassemia.org). Educational multilingual materials, many of which are free, are available on request.

CAF also works with area blood banks to expand and diversify the nation's blood supply, both for our own patients and all those who need blood.

Medical Research

CAF's Medical Advisory Board is comprised of leading hematologists, clinicians and researchers who keep the Foundation advised of the latest medical advances and review applications for research fellowships.

CAF's Medical Research Fellowships are awarded annually for research projects aimed at advancing treatment and a cure for thalassemia. Fellowships are awarded at a \$32,500 level, generally for two years.

In response to advances in treatment translating into longer lives for patients, CAF created a Translational Research Grant program. These grants focus on issues that have more relevance to individuals in the adult thalassemic community. CAF also has initiated a grant for gene therapy and stem cell transplantation.

Research funded by CAF has contributed to medical knowledge about diseases such as sickle cell, diabetes and cancer and has substantially advanced knowledge in the gene therapy field.



How You Can Help

Contributions to CAF support a wide range of programs that improve the quality of life of thalassemia patients.

The Foundation also offers a range of Planned Giving options for interested donors.

Contributions may be made by mail or by phone: (212-279-8090), or at the CAF's website, www.thalassemia.org (e-mail: info@thalassemia.org).