About The AHEPA And The Cooley's Anemia Foundation

The American Hellenic Educational Progressive Association (AHEPA) is by far the largest and oldest Greek-American organization. Founded in 1922, the mission of the AHEPA Family is to promote Hellenism, Education, Philanthropy, Civic Responsibility and Family and Individual Excellence.

For the past twenty years, The AHEPA Cooley's Anemia Foundation has worked diligently to eradicate this deadly disease that has the potential to affect millions of Greek-Americans. But, we need your help! Only through your tax deductable contributions are we are able to continue to host screenings, develop and distribute educational materials and support progressive medical research of our country's leading hematologists and geneticists.

We Need To Find A Cure Now! Your Support Is Critical!

To make your tax-deductible contribution to The AHEPA Cooley's Anemia Foundation, tear out this page and complete the form below. Include your check or credit card information and mail to:

AHEPA Cooley's Anemia Foundation
1909 Q Street, NW Suite 500
Washington, DC 20009

☐ ***Yes!*** I support The AHEPA Cooley's Anemia Foundation so it can continue to host screenings, develop and distribute educational materials and support progressive medical research.

Enclosed is my check in the amount of $_____

TO PAY BY CREDIT CARD, PLEASE COMPLETE THE INFORMATION BELOW:

Name of cardholder:_____

Credit card type: ❍ VISA ❍ MasterCard ❍ American Express ❍ Diner's Club

Card number:_____ Exp. date:_____

Signature:_____

E-mail:_____ Phone: (_____) _____

☐ ***Yes!*** I want more information on AHEPA and The Cooley's Anemia Foundation.

Name:_____

Address:_____

City:_____ State:_____ Zip:_____

You received no goods, services or other benefits with this contribution. This contribution is deductible pursuant to Section 170 (c) (4) of the Internal Revenue Code for charitable purposes.

1909 Q Street, NW Suite 500
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What You Need To Know About Cooley's Anemia

The Thalassemia Trait

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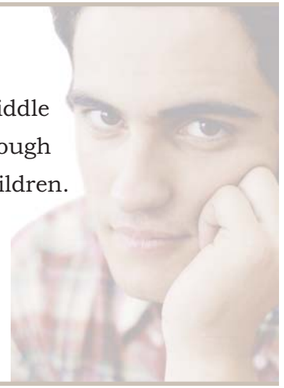
The Thalassemia Trait

Cooley's Anemia, also known as Thalassemia, is a fatal genetic blood disorder that has plagued the Hellenic people for over 2000 years. The Cooley's Anemia Foundation of the American Hellenic Educational Progressive Association (AHEPA) is a non-profit, humanitarian organization created to educate and screen potential carriers, and to financially support much needed medical research leading to a cure.

What You Need To Know About Cooley's Anemia



- In its major form, Cooley's Anemia is fatal.
- Over two million people in the United States, mostly of Mediterranean, Middle Eastern or Asian descent, carry the minor form of Cooley's Anemia. Although unaware, they are at risk of passing along the major form if they have children.
- A simple blood test can determine whether you are a carrier.
- Currently, education is our best weapon to fight this deadly disease.

There Are Two Types Of Cooley's Anemia (Thalassemia):

- The first type is Thalassemia trait or Thalassemia minor. People with Thalassemia minor are perfectly healthy, but can pass the more serious type on to their children. They are sometimes referred to as "healthy carriers of Thalassemia".
- The second and very serious type is Thalassemia major. Beginning in early childhood, those with Thalassemia major fail to produce sufficient hemoglobin in their blood, requiring frequent blood transfusions and other very aggressive and unpleasant medical treatment just to stay alive.

Children with Thalassemia major are normal at birth, but become anemic between the ages of three months and eighteen months. Symptoms vary, but usually include paleness, insomnia, loss of appetite and vomiting. If children with Thalassemia major are not treated, they typically suffer difficult lives and die between one and eight years of age.

Frequently Asked Questions

Am I at risk for carrying Thalassemia trait?

Possibly. If you are of Mediterranean, Middle Eastern or Asian descent, you are at much greater risk of carrying Thalassemia trait than Northern Europeans.

How can I find out if I have Thalassemia trait?

Talk to your family physician. A simple blood test will detect whether you carry Thalassemia trait.

Why should I know or care whether I carry Thalassemia trait?

If both you and your partner have Thalassemia trait, then in each pregnancy there is a one in four chance you will have a child with Thalassemia major.

How expensive is the blood test and will my medical insurance pay for it?

The blood test is relatively inexpensive, and may be covered by medical insurance. Contact your insurance company representative for a determination of benefits.

What should I do if I learn I carry the Thalassemia trait?

Talk to your family physician. You have no immediate health concerns to address and no reason to alter your activities. However, you need to consider prenatal planning once you and your partner decide to start a family.

If I carry the Thalassemia trait, will it affect my health or my activities?

Absolutely not. Without the blood test, Thalassemia trait remains undetected because it does not affect one's health or activities. However, it is vital that you learn whether you carry Thalassemia trait before starting a family.

Can Thalassemia trait turn into Thalassemia major?

No. Thalassemia is inherited. The type of Thalassemia one has at birth is the same type one has throughout life.

Can Thalassemia major be treated?

The main treatment for Thalassemia major is regular blood transfusions, and medication. Most children who have these transfusions can live normal, full lives.

> "The only available curative therapy at this time is a bone marrow transplant."
>
> Dr. Thomas Howard,
> Director of Pediatric Hemotology and Oncology,
> University of Alabama-Birmingham

Can Thalassemia major be prevented?

If either you or your partner has normal blood, there is no chance that your children will have Thalassemia major, although they may inherit Thalassemia trait. However, if both you and your partner have Thalassemia trait, then in each pregnancy there is a one in four chance you will have a child with Thalassemia major. Currently, prenatal diagnosis is the only method to reduce the incidence of Thalassemia major.

How do I learn more about Thalassemia?

Contact The AHEPA Cooley's Anemia Foundation or your family physician to learn more about Thalassemia.

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