

Mission Statement

The Thalassemia Support Foundation was founded by patients, parents and friends affected by Thalassemia. The foundation provides hope, comfort and encouragement to those battling this disorder. At the heart of the organization is a strong desire to

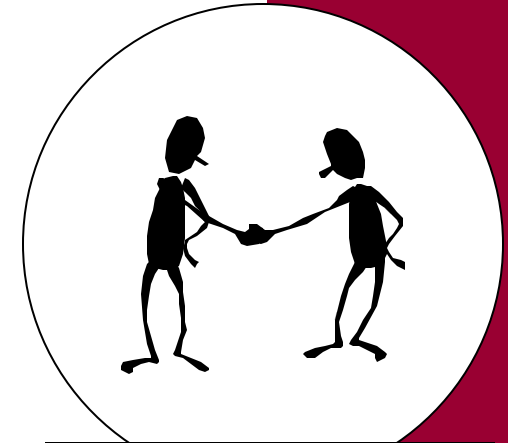


help improve the quality of life for all patients with Thalassemia. We volunteer our time to

organize conferences, raise funds to educate the community, ensure patients and parents know the latest in care, and donate to the work of researchers. The foundation maintains a strong relationship with the medical community that provides diagnoses, treatment and care.

Thalassemia Support Foundation

P.O. Box 26398
Santa Ana, CA 92799-6398
Phone: 800-846-8076
Website: www.helpthals.org



Thalassemia Support
Foundation

You are not alone!

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About Thalassemia???

What is Thalassemia?

Thalassemia is a term that refers to a group of genetic disorders characterized by insufficient production of hemoglobin. There are two proteins involved in the production of hemoglobin, alpha and beta. If there is a deficiency in either of these proteins the red blood cells do not form properly and cannot carry adequate amounts of oxygen to all parts of the body. This then results in organs that are starved for oxygen and unable to function properly.

How would I get Thalassemia?

Thalassemia is a genetic disorder caused by the inheritance of a recessive gene from both



parents. You cannot "catch it" from someone. In pregnancies where both parents carry the recessive gene there

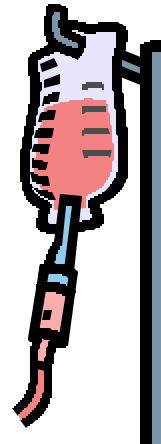
is a 1 in 4 chance that the child will have the severe form of thalassemia, a 2 in 4 chance that the child will carry the gene for thalassemia and a 1 in 4 chance that the child will neither have the disease or be a carrier.

How do you treat Thalassemia?

Patients have to get blood transfusions, usually every two to three weeks. These blood transfusions are done at a hospital and can take anywhere from six to eight hours or more.

After some time, the blood cells break down and leave iron in the patient's body.

This iron will bind to the major organs of the body, such as the liver or heart. If left alone, the iron will overload these organs until they will not be able to do their job creating other health problems for the patient.



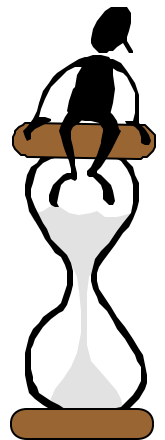
Thankfully there is a drug called Desferal. Desferal binds to the iron in the patient's body and removes it. This process is called chelation. This drug is usually administered subcutaneously, in places like the stomach or legs, every night up to twelve hours a day. This treatment will start early, usually when a child is between one and two years old.

An excerpt from
"A Parent's Perspective"
By: Vincie DiLorenzo

The blood transfusions started when Paul was twelve months old. They have continued every three to four weeks for the last twenty four years and will continue for the rest of his life.

A nurse once told me "you do what you have to do". And we did.

There were the constant blood tests. Watching the nurses trying to find a vein in my small child always broke my heart. There were all the late nights at the hospital, waiting for the type and cross, waiting for the blood, waiting for the blood to finish transfusing so we could go home. Always waiting.



Read the full article at
www.helpthals.org