

TSF NEWSLETTER

Thalassemia Support Foundation

From a Parent's Perspective By: Vincie DiLorenzo

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"Thalassemia doesn't just impact the patient; it impacts everyone that knows them."

Paul was diagnosed with thalassemia major when he was four months old. At that time, he looked pale, but otherwise appeared to be healthy. Blood tests would prove otherwise.

My husband and I were unaware that we were carriers of this genetic disease; that there was a one in four chance in every pregnancy that a child would be born with thalassemia major. It was even more shocking to us because Paul has an older brother who doesn't even carry the thalassemia trait.

We had no idea what this was or how our lives were about to change. We went to see a specialist on blood disorders. I brought a tape recorder so I could record the visit, afraid I would miss something important. I still have that tape, twenty-five years later.

The specialist told us that Paul's red blood cells were abnormal in shape and size and that he could not reproduce his own blood cells. Because Paul could not repro-

duce his blood cells, he would need blood transfusions to keep his hemoglobin at a normal level. All this seemed unreal, but at the same time, we wanted his home life to be as normal as possible.

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.

And with the transfusions came a high iron count. When Paul was two, I had to

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24th Annual KLOS Blood Drive

On August 4, 2005, TSF president, Paul DiLorenzo, spoke on two prominent KLOS radio talk-shows in order to help kick off their 24th Annual KLOS Blood Drive. The blood drive, which has collected nearly 77,000 pints of blood since its inception,

took place over a three-day period in Los Angeles, San Bernardino, and Riverside counties.

In order to help promote this undertaking, Paul appeared on "Mark & Brian" and

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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.



We Are...

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President's Message

Hello and welcome to the first issue of the Thalassemia Support Foundation (TSF) newsletter! Since this is our first issue, I would like to use this space to talk about our organization.

TSF was founded in January of 2005 by a group of people (patients, parents, and loved ones) who have over 30 years of non-profit experience in previous organizations. Our organization was founded on the belief that there is more to helping a patient than through research, drugs, blood tests. We believe that none of this will be helpful if the patient doesn't have hope. Hope that they can live a fun, productive, and happy life. Hope that being normal is not a fantasy but can truly be a reality. Once they have this hope instilled in them, any obstacle can easily be conquered with support and a helping hand along the way.

It is our belief that the support of family, friends, and a committed non-profit organization is vital to the quality of life for all Thalassemia patients. And we are committed to providing this one-on-one, local support for the Thalassemia community in California. We want to help people in their own backyard and put hope back in their hearts.

If you believe what I believe, **we need your help!** Please go to our website <http://www.helpthals.org> and join our mailing list, so we can keep you updated on our organization and how you can help. If you would like to be a volunteer, please click 'Yes! I am interested in volunteering' when joining the mailing list, or e-mail me at pdilorenzo@helpthals.org with your ideas of how you can help.

Thank you for taking the time to learn about our organization. With your help, we can ensure a bright future for Thalassemia patients everywhere.

24th Annual KLOS Blood Drive (cont.)

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“Cynthia Fox.” During both of these appearances, he stressed the importance of giving blood and had the wonderful opportunity to thank the many donors out there that have helped save his life. At the end of the three-day period, the KLOS Blood drive, in partnership with the Blood Bank of San Bernardino and Riverside Counties and the American Red Cross, collected over 6,573 units of blood – setting a new record. Paul was grateful for the opportunity to take part in

this record-breaking event, and would like to thank Tammy Rotellini, of the Blood Bank of San Bernardino and Riverside Counties, the San Antonio Community Hospital, everyone at KLOS, including Mark Thompson, Brian Phelps, and Cynthia Fox, and all of the amazing volunteers. He would also like to give special thanks to all of the selfless donors that came out and rolled up their sleeves to help save lives.





Ice Cream Social



We had our first *Ice Cream Social* on May 6th, 2005 at the Children's Hospital Los Angeles (CHLA) and it was a resounding success. We were able to meet and talk to the parents, patients, staff, and medical community that make up CHLA. We, of course, handed out ice cream and sodas to all who came. We also had a craft table for the children to make Mother's Day bookmarks among other things. We hope that this was only the first of many events at CHLA. Special thanks to Bryce Imbler who helped make this event a success.

Our Guardian Angles

We would like to extend our gratitude to the following people who have been a constant source of generosity for the Thalassemia Support Foundation:



Churon Winery
33233 Rancho California Rd
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As Well as...
Alisa DiLorenzo,
Maria DiLorenzo,
Wayne Wacker, &
Dan Trudo

The Italian American Club of Temecula
The Churon Winery
DiLorenzo Bros., Inc.
Rosetti Construction
NewVest Investment Company
NewPath Investment
Fire Safety First
&
Children's Hospital Los Angeles



From a Parent's Perspective (cont.)

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learn to insert a needle in Paul's stomach every night so the drug Desferal could excrete the excess iron out of his system through his urine. Just imagine a two year old running around to get away from the treatment and the full family effort it took every night to make sure that he was getting his medication. We can laugh now but it wasn't so funny then.

In patients who have thalassemia the excess iron, from transfusions, binds itself to vital organs if it is not removed through treatments such as Desferal. Over time this excess iron can shorten his life span by causing complications to his organs.

His ferritin level, a measure of the iron in Paul's body, remains fairly low, but liver biopsies are showing that his liver is becoming overloaded with iron, so he is on a more aggressive Desferal treatment.

Years ago a child rarely lived to adulthood. Now they are living productive lives well into their 40's.

At twenty-five years old, Paul is doing quite well. He is married and he and his wife, Melissa, are pursuing their doctorate degrees. Paul now has an implanted portacath that allows him to receive his blood transfusions and Desferal treatment thru the port, instead of through his overused veins. He has taken

over the responsibility of scheduling his transfusions and making appointments with home health care nurses for the Desferal treatments. Paul has developed a wonderful relationship with all his doctors and nurses at the hospital.

The hospital trips, doctor appointments, and calls to nurses are a daily reminder that he has to continually monitor his condition. Even a slight fever can mean a trip to the doctor's office to check for infection. We are very fortunate that over the years Paul has taken an active role in his treatment. He is not afraid to question the doctors or make suggestions.

It has not been easy having a child with thalassemia, there are constant worries about his health and worries about his future. Yet over time we have learned to deal with these issues as they come. We have become part of organizations such as the Thalassemia Support Foundation because it's not just Paul who needs to know and be supported by other thalassemia patients; we parents need that support as well. We have done our best to provide Paul with a "normal" life in spite of the circumstances. As part of a close knit family, Paul will always have our love and support.

Thalassemia doesn't just impact the patient; it impacts everyone that knows them.



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Event Announcement

The **Thalassemia Support Foundation** (TSF), along with the **Children's Hospital Los Angeles** (CHLA), is proud to present the **1st Annual Thalassemia Educational Conference**. The event will take place on **Saturday, April 1st** from 8:30 to 2:00 pm in the **Page Conference room** at CHLA.

This event is for patients, parents, loved ones, and members of the medical community to learn about the new oral chelator, Exjade (see right), along with other important topics in the Thalassemia community. Guest speakers include Dr. Thomas Coates, Dr. Punam Malik, and Susan Carson, R.N. Morning refreshments and lunch will be served to all attendees. For an invitation or more information, please contact Bryce Imbler from CHLA at 323-669-5469 or visit our website at <http://www.helpthals.org>

Exjade® Approved

For many years Thalassemia patients only had Desferal available to them for iron chelation (a process of removing excess iron from their body). With Desferal, they had to get a subcutaneous infusion between eight to twelve hours a day, five to seven days a week. Because of this burdensome way of administering Desferal, many patients were noncompliant.

Fortunately, on November 3, 2005, Novartis announced the approval of Exjade, the first once-daily, oral, iron chelator by the U.S. Food and Drug Administration (FDA). Exjade was approved for Thalassemia patients with chronic iron overload over the age of 2. Because of this wonderful development, Thalassemia patients have more hope in their futures regarding their chelation treatment. We are grateful for Novartis' hard work. For more information, visit Novartis' website at www.novartis.com.