

# Community Focus: Thalassemia Support Foundation

*By Paul DiLorenzo*

My name is Paul DiLorenzo and I have thalassemia major. I am 25 years old and live in Southern California with my wife Melissa. We are both going for our PhDs (computer science for me, psychology for her) at the University of California, Riverside. In the last year, we have helped co-found, along with five other fine individuals, a new non-profit organization, the Thalassemia Support Foundation. We created this organization to help fill the void of local support for patients with Thalassemia in California. The Thalassemia Support Foundation's goal is to create a support network for every single thalassemia patient. But I am getting ahead of myself. To understand how I got into this situation, you must understand the back-story.

I got involved helping Thalassemia patients through the California Chapter of the Cooley's Anemia Foundation, in 1998. My father, Carmen DiLorenzo, was a board member and encouraged me to join the board as well. It was the perfect time for me because I just started college and I felt that I should start giving back to the Thalassemia community. In my two years as a board member, I was the newsletter editor and helped out with the chapters' events. I truly enjoyed helping out the local community of Southern California.

During this time I was always interested in creating a support group for patients in California. Unknown to me, Laurice Compagno, a board member of the Thalassemia Action Group (TAG), was interested in me being on the board. So in 2000, I was nominated and accepted to be on the TAG board.

For those who don't know, TAG is a patient run, patient support group. It is national in scope and is a separate entity under the Cooley's Anemia Foundation organization. TAG's main mission is to put on a large conference, once a year, in different parts of the country. This conference is two days long, and has doctors from all over the world come and speak about Thalassemia. In addition, and I think this is the most important part, there is time for patients to talk with other patients and share their hardships, accomplishments, struggles, and good times. Also exchange ideas about what they do for blood transfusions, Desferal, etc.

I was part of TAG from 2000 to 2003. I was just beginning my third year with TAG when I began to realize that TAG wasn't exactly what I wanted to do. I was passionate about their mission of helping patients here and now and believe that it is terribly important to share knowledge, experience, and wisdom with other Thalassemia patients before it is too late. But, I preferred I was doing with the California Chapter by creating a community in my own backyard.

So I returned to the California Chapter with the hopes of using the experience I gained working with TAG to help the local community of Thalassemia patients. During this time my father was President. He believed that it was vitally important to create a sense of community among the patients. He enjoyed putting on fun and informative events. For example, we had one of our annual conferences at Sea World. We had an informative session with doctors speaking and allowed patients and parents to talk to each other.

He also knew that local families had a lot to worry about financially. So, whenever we could we would provide financial assistance so that families could come out to the conference and have time to talk with the doctors. Or, provide help to families so that they can take their children to the SQUID machine in Oakland. We tried every way possible to support the families in California. After many long and heartfelt discussions, a group of us came to the conclusion that to do this most effectively, we would have to create a new non-profit organization. So, in January of 2005, Charlie and Rosalind Hunt, Pat Saia, Carmen and Vince DiLorenzo, and Melissa and I had our first meeting as the Thalassemia Support Foundation.

So that is how I got to where I am today. Currently I am the president of this outstanding organization, and for the last nine months, we have been working hard to figure out what is our vision, our mission, and our purpose for this organization. In addition, we put on an ice cream social at Children's Hospital Los Angeles to get to know the patients and how we can best support them. And finally, we have created a website, <http://www.helpthals.org>. that has information and news about our organization and thalassemia.

This organization is new and emerging and has the potential for great success. To ensure this, we are always looking for patients, parents, spouses, friends, family members, health providers, or anyone that wants to help our organization and make a difference in this community. I truly hope that you will give us an opportunity to serve you and the Thalassemia community to the best of our abilities.

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### **Thalassemia Support Foundation**

**Vision:** For every patient to have a support network.

**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.

### **Purpose of Organization Support**

1. To help Thalassemia patients and parents understand the disease and the actions around improving the quality of life and finding a cure
2. To ensure patients and parents have access to doctors and information that will allow them to be advocates for their needs.
3. Provide Standards of Care Booklet to parents and patients
4. Provide funds for patients to receive initial examination by expert doctors at one of the Thalassemia Centers
5. Build and maintain a database of Thalassemia patients and parents
6. Organize annual conference in at risk communities to provide updated information on Thalassemia
7. Organize, facilitate, and participate in community based events throughout the year
8. To provide a support system among the thalassemia community (patients, parents, friends, etc.), so that people can get into contact with other people.
9. Have fun

### **Medical Relationship**

1. Build and maintain a close relationships with primary Thalassemia Centers and staffs
2. Encourage doctors who specialize in thalassemia to consult and advise the medical community so that every patient receives the highest quality of care
3. Facilitate events for doctors to share information about the treatment of Thalassemia
4. Support Thalassemia events at Thalassemia Centers

**Research Support**

1. Support Research for improving treatment, diagnosis and cure of Thalassemia

**Activist**

1. Advocate / Lobby for Thalassemia causes to affect changes in state laws and support
2. Have a clear channel of communications to patients, medical community, and general public about the affects of the disease
3. Connect with the State of California for information on Newborn Screening and assist with information flow to patients for their knowledge and care