

PERSPECTIVES

Summer/Fall 2007 – p.4

EVENTS CALENDAR

For more information on events, or if you would like to volunteer, please visit our Web site at www.thalassemia.com or contact Laurice Levine, thalassemia outreach coordinator, at 510-428-3885, ext. 5427, or LLevine@mail.cho.org.

July 14-15 – Lotus festival, Los Angeles, Calif.

Aug. 5 – Patient lunch and ice cream at Fenton's Creamery, Oakland

Aug. 13 – Sons of Italy dinner

Sept. 1-2 – ICF Convention, Scottsdale, Ariz.

Oct. 5 – Head Start Annual Family Day and Resource Fair, Sacramento, Calif.

Oct. 11 – The 2nd Annual Evening Under the Stars at the Chabot Space and Science Center, Oakland

AN EVENING

under the stars

Oct. 13 – YMCA Cheadle Healthfair, Stockton, Calif.

Nov. 9-11 – Thalassemia Retreat, Monterey, Calif.

Dec. 13 – Thalassemia Annual Holiday Party, Children's Outpatient Center Atrium, Oakland

Thank you to our recent supporters!

ICF Healdsburg/
Santa Rosa
District

ICF Branch 351

ICF Branch 91

The Cerrito Theater

Son's of Sicily

Mary Sperrazzo

Frangoulis Family

Charles Abela

Ken Vargas

Lydia Salib

Louis and Mary
Salib

Thank you to our amazing volunteers!

Jeanyoung Lee

Sueyoung Lee

Michelle Ma

Annie Paulukonis

Jennifer Riley

Dhiraj Singh

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MedicAlert Foundation
2323 Colorado Avenue
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PERSPECTIVES

Northern California Thalassemia Center
Children's Hospital & Research Center Oakland
747 52nd Street, Oakland, CA 94609

Address change requested



Perspectives Newsletter is produced by the thalassemia outreach coordinator, Laurice Levine, MA, CCLS, and the Communications department at Children's Hospital & Research Center Oakland. For questions regarding the newsletter or for more information on thalassemia, call 510-428-3885, ext. 5427, or visit www.thalassemia.com.

The Second Annual Thalassemia Support Foundation Conference

By Sueyoung and Jeanyoung Lee

Patients, parents, doctors and friends from all over the country attended the Second Annual Thalassemia Support Foundation (TSF) Conference, held in Los Angeles on April 21, 2007. Whether attendees were from Alaska or Arizona, the conference proved to be a wonderful and engaging support opportunity for all of those who are directly or indirectly affected by thalassemia. The TSF collaborated with Children's Hospital Los Angeles (CHLA) and Children's Hospital & Research Center Oakland to plan this event.

The conference commenced with a continental breakfast where attendees anticipated the day with great excitement. Instant bonds were formed as people openly asked questions of one another, questions such as: "Do you have thalassemia?" and "Who in your family has thalassemia?"

Tearing oneself away from the conversation was harder than resisting a last bite of breakfast! Nevertheless, once breakfast was over, the pleasant chatter gave way to the quiet contemplation of an attentive group. In-depth PowerPoint presentations by John Wood, MD, CHLA, and Elliott Vichinsky, MD, Children's Hospital Oakland, provided valuable medical information to all, particularly making note of the recent advancements in thalassemia care and treatment. Their thorough and comprehensive presentations prompted a wide array of questions and clarifications from members of their audience.

An open panel followed, during which attendees had the opportunity to candidly share their experiences. It was during this panel that some patients were able to identify with one another, and



share their thoughts, frustrations, concerns and happiness about thalassemia. Parents and friends of the patients also received words of advice and answers to their questions. The discussion brought the audience together into a wonderful, close-knit support group.

A children's program ran throughout the day for kids ages 3 to 12. The children's program was carefully designed for children with thalassemia, their siblings, and children whose parents have thalassemia, so the kids could learn about thalassemia at their developmental level. Educational activities, games and art projects were planned by Child Life Specialists Lisa Gray, CCLS, from UCSF Children's Hospital, and Carola Mendez, CCLS, from CHLA, who kept the program running smoothly all day.

A sincere thank you goes to Carola and Lisa for their dedication and hard work.

Also on the agenda were focus groups: A group for patients, a group for parents and a group for spouses/significant others. This time lent itself well to the discussion of specific challenges that each group faces. Special thanks to group leaders Paul DiLorenzo and Laurice Levine; Pat Saia and Charlie Hunt; and Melissa DiLorenzo and Matt Levine.



Attendees participate in medical play, which uses props, such as dolls, so children can mimic performing the procedure that awaits them. On the left, Thuy Carpenter performs a blood draw on a doll.

The TSF Conference was undoubtedly an amazing opportunity to meet and hear the experiences of thalassemia patients and their supportive parents, friends, and doctors. It was a memorable day for everyone who attended and definitely a conference to anticipate in coming years!

We would like to extend our gratitude to the TSF and Bryce Imbler at CHLA for putting on this conference, and for their continued dedication to the thalassemia community.

Jeanyoung Lee and Sueyoung Lee just completed their third and first years respectively at the University of California, Berkeley, majoring in molecular cell biology. They recently became interested in thalassemia and the lack of public awareness about it. The importance of thalassemia awareness, as well as future ramifications for individuals and society as a whole, became evident to them and motivated them to become a part of the thalassemia team at Children's. They have participated in informing the public about the disease and its implications at various health fairs and attended the TSF Conference in April. "Our involvement meant even more with our attendance at the thalassemia conference, meeting the heroes and their families who battle the disease daily with utmost courage and positivity."

An Interview with Paul DiLorenzo, President of the Thalassemia Support Foundation

By Jeanyoung and Sueyoung Lee

An interview with Paul DiLorenzo at the Second Annual Thalassemia Support Foundation Conference revealed a fiercely dedicated leader who takes life in stride and envisions a thalassemia community marked by strength, support and encouragement.

What is the most difficult aspect of living with this disease?

It is extremely difficult to keep up with the medical maintenance that thalassemia requires. Having to see your primary doctor, a hematologist, an endocrinologist, an audiologist, an optometrist, and, of course, your thalassemia specialist—it becomes a huge burden over time. But there are great joys in my life that keep me going. For example, this August, I will have been married for four years. I am just completing my fifth year of PhD studies in computer science and have been involved with the Thalassemia Support Foundation since its inception in January 2005. Keeping all of these activities balanced is difficult, but very rewarding.

When did you realize that you had thalassemia?

I was in the fifth grade when I found out that other people didn't have to have regular blood transfusions and take desferal every night through injection. I was spending the night over at a friend's house and noticed he didn't have to do desferal like I did. That brings back memories of my family's nightly routine of me running around the house and them trying to catch me so I could do Desferal.

I think the true realization about my thalassemia really hit home when we were trying to determine if I could get a bone marrow transplant. They tested my mom, my dad and my brother, and there was no match. That realization that I would have thalassemia for the rest of my life, that lost hope—that's when it hit home and really seeped in.

What is the most pressing challenge for the thalassemia community?

I believe there are two major fronts for the thalassemia community: medical research and support. Medical research is



important to push the boundaries of what is possible for the lives of thalassemia patients. We have seen many exciting advances, such as an oral chelator and noninvasive techniques to determine the iron in the heart and liver. This will make it easier for doctors to know what is wrong and easier for patients to comply.

The other front, support, is just as important, but usually not given the same amount of attention and resources as medical research. Support has many components to it. For example, noncompliance. Why are patients not doing their desferal? The medical community provides a vehicle, but we're missing the driver. The patient has to drive the compliance. Another important component is psychosocial issues. There are some patients who think no matter what they do, there is no hope. The Thalassemia Support Foundation recognizes these problems and is trying to provide resources to help fix them.

Do you have plans to collaborate with any blood banks?

Yes. Many people think that donating blood is a one-time event. But blood has a shelf life, so people need to donate consistently. Some of the biggest consumers of whole blood are thalassemia patients. I receive three units of blood every three weeks. I think they have calculated for my life thus far that I have used 200 gallons of blood. So to educate the community about the consistent need for blood rather than one-time instances is important, as well as collaborations with blood banks.

When people find out that you have thalassemia, do you get a negative response?

Ninety-nine percent of the time I do

not receive a negative response. But I do have an interesting story regarding one time when I did receive a negative response. I was getting my hair cut during the time when I was working with a blood bank. The hairdresser told me that she didn't believe in blood transfusions. She told me that I could take pills that would elevate my hemoglobin levels, or if I was going into surgery, put away some of the blood before the surgery. I tried explaining to her why her suggestions would not work in my case, but she misunderstood me. This experience didn't stop me [from] telling others about thalassemia or continuing the mission of the TSF. Confidence is the best way to battle ignorance.

What is your ultimate vision for this organization?

In the next five to 10 years, I would like to open up local chapters that would be self-sufficient in helping support people with thalassemia in their local area. I think this is the only way we can truly reach all the thalassemia patients in this country. It has to be a grassroots effort. We need groups of people to get together to open up their own chapters, to create their own community and find out ways they can help thalassemia patients in their area.

The goal is to make sure that everyone has a connection with another person in the thalassemia community. These connections do not have to be only patient-to-patient. They can span parent-to-parent, patient-to-parent, spouse-to-patient, etc. These lines are the very essence of a support network. Currently, I believe these lines are sparse and extremely localized. We need to make these lines of support denser and more widespread on a national, maybe even a global, level. I believe a lot of these current support problems can be solved with this dense network.

We have only started on this work. But with help from the thalassemia community, the medical community and the public at large, I believe we can make great strides in helping support thalassemia patients.

7th Annual Blood Drive in Honor of International Thalassemia Day

The 7th Annual Blood Drive in honor of International Thalassemia Day was held on May 4, 2007, in the Children's Hospital Outpatient Center basement. This year, the National Marrow Donor Program was present to collect bone marrow samples for the registry. Forty-eight units of whole blood were collected, and 41 people were added to the bone marrow registry.

The Engineering department had the largest presence at the blood drive and were winners of the dessert party.

Our sincere thanks go to the following:

- The Thalassemia Action Group (TAG) ~ Sponsor of this year's blood drive; special thanks to **Huythong Nguyen** of TAG for volunteering the day of the drive
- Starbucks Coffee Company/**Erica Mapes** ~ For donating the french press sets and \$5 gift cards for each donor
- The American Red Cross staff
- The National Marrow Donor Program and **Cynthia Carlson**.

OUR MOST SINCERE GRATITUDE GOES TO ALL OF THE BLOOD DONORS!

Thank you for giving the gift of life.

Farewell, Toutu

Dear Friends,

After five years as the Thalassemia Outreach Coordinator, it is hard to say good-bye. I am very grateful to have had the opportunity to work in the Thalassemia Program. The ex-perience I have gained has been amazing! The friendships I have developed throughout the years, I will not forget. The things that I have learned, I will continue to build on. Thanks to all of you for making my experience and time at Children's Oakland memorable. Thank you so much for your friendship, trust, love and support. And most importantly, thank you for sharing your lives, which have inspired me. I hope in the near future I will have other opportunities to help and serve you again in different capacity. Thank you all so very much for everything. I wish you all the very best of luck!

Love,
Toutu Vongphrachanh

The thalassemia staff, patients and families would like to thank Toutu for her years of dedication and support.

We will miss you, Toutu!



Toutu dressed up at one of her many wonderfully planned events.

Welcome, Eve Alley

By Laurice Levine

We've struck gold again! In June, Eve Alley joined the thalassemia team, working alongside Laurice Levine.

Eve grew up in Berkeley, attended high school at the College Preparatory School (CPS), and then went on to the University of California, Davis, to study psychology and human development. She later earned her master's degree in Child Life at Oakland's Mills College.

After becoming a certified Child Life specialist, Eve relocated to Kapiolani Hospital in Honolulu, Hawaii, for her first Child Life position. She then moved back to the Bay Area and has worked at UCSF Children's Hospital for the last six years.

It was at UCSF that Eve worked with children who had thalassemia, sickle cell and other hematological disorders. Eve also worked with children undergoing bone marrow transplants, and she started the "Little Wishes" Program, where children are granted a small wish if they are admitted to the hospital for more than a week.

When Eve is not hard at work, she enjoys spending time with friends and family—especially her husband, Tom, and her son, Leo. Eve is incredibly talented, creative and hardworking. We are fortunate to have her join the thalassemia outreach program.



TRAVEL TIPS

By Laurice Levine

Traveling and exploring the world is one of life's most fulfilling experiences. Thalassemia does not impair your ability to travel and have fun. It is important for people to keep in mind the following tips in order to stay healthy and safe "on the road."

1. Sign up for MedicAlert (see article on back page for details).
2. Bring a medical letter written by your provider explaining your condition, treatment and a list of your medications and medical supplies that you use. Carry a copy of the letter in your carry-on bag and a copy in your checked luggage. Keep a copy at

home as well. Include the contact information for your medical provider and the hospital where you get treated.

3. Pack the needed quantities of medications and some extra to avoid running out. Bring your medication in your carry-on bag.
4. Desferal and supplies can be pre-mixed for up to seven days. This will save you room in your luggage. Bring extra Desferal and supplies if you are traveling longer than a week. Check with your airline about carrying liquids on board; this will determine if your Desferal can be carried on or if it needs to be checked in your luggage.
5. Bring a travel-size sharps container from the home-care company that provides your Desferal supplies.

6. Talk to your provider about bringing a prescription of antibiotics in case of infection.
 7. Take extra precaution to wash hands to prevent the spread of infection. It is a good idea to have some antibacterial hand sanitizer available, especially for long flights.
 8. Most airlines do not serve food. Pack some healthy snacks for the trip. Drink plenty of water on the plane. It is recommended to drink eight ounces every hour to prevent dehydration.
 9. Check the extent and limitations of your medical insurance policies before leaving the state or country.
 10. Consider obtaining travel insurance.
- II. Have fun!