



PERSPECTIVES

NEWSLETTER OF THE NORTHERN CALIFORNIA THALASSEMIA CENTER – WINTER 2007

Happy New Year from the Thalassemia Team!

We would like to extend our sincere thank yous to:

...**our patients and their families**—Thank you for your trust, and for allowing us to provide care for you; thank you for participating in studies so we can improve the quality of life for patients and provide hope for future generations;

...**our colleagues**—Thank you for working as a team to provide the best comprehensive care to all of our patients;

...**our supporters and donors**—It is because of your generosity that we can provide the best care, conduct research and obtain state-of-the-art technology that improves the care and enhances the quality of life of our patients.

We wish all of you a happy, healthy and prosperous New Year!



Photos [l-r, clockwise]: Entertainment by the Wild Catahoulas; Vy and the kids celebrating; The Saephan family; Holiday party volunteers: UC Berkeley's Pre-Med Honor Society.



Thank you to our sponsors for the holiday party:

Assetmark

Italian Catholic Federation

Starlight/Starbright Children's Foundation

And our volunteers:

Acalanes Varsity Basketball Team

UC Berkeley Pre-Medical Honor Society/Alex Noburi

Boy Scouts: Sandy and Randy

Welcome to the Thalassemia Program, Dr. Eve Golden!

By Larry Davis and Laurice Levine

We are privileged to introduce Eve Golden, MD, as our new clinical hemoglobinopathy thalassemia physician. Dr. Golden did her undergraduate work at Cornell University and went on to receive a Masters of Science at the Harvard School of Public Health. After further studies at the University of California at Berkeley's Department of Public Health, she completed her formal education with an MD degree from the University of Pennsylvania.

Dr. Golden did her residency in pediatrics here at Children's Hospital

Oakland. She then completed a fellowship in adolescent medicine at the University of California, San Francisco, and later joined the pediatric hematology fellowship program here at Children's.

Dr. Golden never shies away from difficult medical issues: She has done most of her research in the field of AIDS and HIV infection.

Prior to joining our department, she was a pediatric hospitalist at Children's, which has made for an easy transition.



Eve Golden, MD

Outreach Highlights from Fall 2006

AN EVENING *under the stars*

Over 80 people attended the dinner, raffle and silent auction at the Chabot Space and Science Center in Oakland on Sept. 28 for the “Evening Under the Stars,” a fundraiser for thalassemia. *Live to Give*, a short film on thalassemia, made its debut in the Ask Jeeves Planetarium, followed by a stellar show called *Black Holes: The Other Side of Infinity*.

For more information on Chabot Space and Science Center, please visit their website at www.chabotspace.org. We would like to thank **Chabot Space and Science Center** for sponsoring this event. We appreciate the center’s generosity and support, and are also grateful for their hard working staff, especially **Sarah Rogers** and **Kimberlee Garfinkle**, for their dedication, hard work and giving freely of their time.

- Special thanks to **Cheryl Mar**, **Huythong Nguyen** and **Susan Winner** for sharing their personal stories in *Live to Give*. Thank you to all the people with thalassemia who were highlighted in this film.
- Special thanks to **Peter Brown** and **pba media** for his production of *Live to Give* and his donation of many hours of time.
- To **Elliott Vichinsky, MD**, and **Debbie Jett, RN**, for their participation in *Live to Give*.
- To **Diana Rowan**, harpist, for her tranquil music and her donation of time.
- To **Jessica Lasky**, for catering.

Special thanks to following individuals who generously volunteered their time to make this event a success:

Matt Currie ~ Pam Gill * Willynda Gordon ~ Beverly Hoh * Diane Jung ~ Katherine Karolick
 Suzanne Kowalski ~ Denise Kruft * Matthew Levine ~ Sarah Reilly * Jennifer Riley ~ Darcia Slape
 Steven Srisavat ~ Lisa St. George * Toutu Vongphrachanh ~ Matt White * Stefanie Yurus

“Live to Give,” Thalassemia Walk-A-Thon & Community Health Fair was held on October 28 in the Berkeley Marina. We would like to thank **Novartis Pharmaceuticals** for sponsoring the event, and **Leslie Fields** at Novartis for her support and hard work in making this dream become a reality. We appreciate all of our friends, family and community members who walked to raise money for thalassemia. We appreciate their contributions and their sponsors’ support. Thank you to all who donated giveaways and food for the walkers, the healthfair vendors, and especially to our volunteers:

- **Debbie Jett** (our beloved Day Hospital nurse and her Boy Scout troop)
- **Eryn Reeder** and students from Cal State East Bay
- TAG members **Huythong Nguyen**, **Cheryl Mar** and **Hay Cheng**
- and **Suzanne Kowalski**.



Hardworking volunteers: Our lifesavers!



Proud walkers in support of thalassemia.

LIVE TO GIVE Thalassemia Walk-A-Thon & Community Health Fair



Health fair vendors helping the community.



TAG Members Cheryl Mar and Hay Cheng teach the community about thalassemia.

STILL AVAILABLE FOR PURCHASE:

- **Thalassemia DVD Live to Give:** \$10/copy
- **Live to Give Thalassemia Walk-a-thon T-Shirts:** \$10/shirt or two for \$18 (M, L, XL available)

All proceeds will go towards patient programs. Please contact Laurice Levine at 510-428-3885, ext. 5427 or LLevine@mail.cho.org

Thalassemia Retreat 2006

Family Ties

By Abby Torkelson

“What do you like most about having thalassemia?” This very stimulating question was asked of us at November’s thalassemia retreat. As one of two thalassemia major patients living in Alaska, thousands of miles away from any other thalassemia patients—a state that the U.S. postal service treats as a different country, where people still think we live in igloos and have to dog mush to a first-aid station to be transfused bear’s blood—I feel rather alone. Staying alive is a challenge, and to die is to become a statistic. At least, it felt that way for most of my life.

One day, I met Oakland Children’s very own Thalassemia Outreach Coordinator, Laurice Levine, and my life changed. Sunlight broke through the clouds and warmed me to the core; it shed its light on the narrow path I walked alone. Suddenly, I found myself belonging to a family with invisible ties that were waiting to be uncovered.

The thalassemia retreat, organized by Laurice, was truly a retreat, a haven, and a place of safety from frustrations and fears. Although I met many people for the first time at this retreat, the weekend mirrored a family reunion. Conversations could instantly drop to a deeper level; bonds were made and strengthened as though each side had been waiting to connect to just the right piece.

From carpooling together, to playing games and talking, to making meals and doing chores, the experience was amazing. The memory of waking up that first morning and



wandering around to see what others were doing still brings a smile to my face. There was a cluster of people in the kitchen making breakfast, and a table with food where more people were gathered. Another group of participants were checking their blood sugars, while others were already eating. I belonged to the group that couldn’t dig in to the food until the little white tablets of the oral chelator Exjade had dissolved all the way into making gritty, milky white water, and the water had been drunk—the only thing allowed in my stomach for 30 minutes before I could put anything else down there to keep it company. But almost all the little groups had to swallow pills to begin the day.

Besides the wonderful opportunities to ask my new friends questions such as, “How often do you get blood?” and “Does Exjade make you constipated?” we also had a group session where Huythong Nguyen and Laurice lead us, as only they could, in therapeutic discussions. Only those who have stabbed themselves thousands of times with needles, swallowed enough horse pills to kill a horse, and watched their life trickle

away in medical waiting rooms have the moral authority and credentials to say, “I know it is hard, but you really need to be compliant.”

Still, the most interesting question posed was, “What do you like most about having thalassemia?”

What do I like most about thalassemia? It is all the amazing people I have met and the fact that I am invisibly linked to them like family. I am not implying that this “family” is perfect, but it seems very much like a family to me. Many families have inside jokes and family lingo—such as “getting poked,” “Exjade,” “L1,” “squid,” and “HMOs.” I think this is why even though I have only known Laurice since this summer, when she did outreach activities with my sister and me while we participated in the EDICT study, it feels as though I have known her my whole life.

What do I like about thal? I like that the uncertainties in life have made so many of us stronger. It pushes us to live life to the fullest. It pulls us together as family. It gives us the opportunity to encourage others.

Thalassemia Retreat 2006

Thalassemia Retreat 2006

By Liliana Macri

Hi, I'm Liliana, a 38-year-old woman with beta-thalassemia major, and I have been getting blood since I was 6-months old. I have been coming to Children's Hospital Oakland since Dec. 2005. Since then, I have met a lot of wonderful people, including doctors, nurses and fellow thalassemia patients. This leads me to tell you about this year's thalassemia retreat in November 2006.

WOW! Let me tell you that it was

one of the best experiences that I have had in a long time. I really loved the fact that the patients were able to bring loved ones—a boyfriend or girlfriend, a sister, husband, and even some of the kids.

Sitting in the group circle and listening to everyone talk about themselves was my favorite part: how patients and loved ones expressed their thoughts, tears, laughter and fears. Seeing everyone share the parts of the disease that our outside friends and family cannot understand; such as when you're really feeling down on the day someone happens to ask, "What's wrong?," and you just simply smile and say nothing, because they are not

aware of all the challenges that having thalassemia involves.

The retreat held a lot of impact for all of those who attended. We came from near home and out of state for this wonderful retreat. Thank you to each and every one of you who attended! You have made memories for me that I am proud of, and I am already looking forward to next year's retreat.

Oh, and to Laurice Levine, who organized the event: What can I say? You truly are the captain of the ship! You do go the extra mile, and we will never let you sink, girl—we are all still above water and always will be with you around. Like Tupac Shakur said, "Hold your head up!"



Mona, Lydia, Michelle, Eva and Cheryl enjoy the beach.



Best buddies, Andrew and Blake.



Liliana, Lydia, Laurice, Abby and Huy take an afternoon stroll.

Thank you to our recent donors

We would like to extend our gratitude for all of the donors who supported the “Evening Under the Stars,” “Live to Give” Thalassaemia Walk-a-thon, the thalassaemia retreat and the annual holiday party. We are honored by their passionate dedication to our program and to people with thalassaemia and their families:

Assetmark

Rose and Don Arnaudo

Bellissima Day Spa

Jeanna Brushwood

Karen & Mike Carroll

Carneros Inn

Claremont Spa & Resort

Colombo Club Women’s
Auxiliary

Cooley’s Anemia Foundation

Tony & Beverly Compagno

Curves, Berkeley

Larry Davis

Doña Tomás Restaurant

Fenestra Winery

Mae Ferraro

Kathleen Grey

Letty Hernandez, Gold’s Gym

Hertz Equipment Rental

Italian American Women’s Guild

Italian Catholic Federation

The Junket Restaurant

Kucinich Family

Sean Laungrheh – Leapfrog

Jay Lee - Penzoil Speed Oil
Change

Matt & Laurice Levine

Lovejoy’s Tea Room

Michael Manushaw, Manushaw
Cellars

Linda Moreno, Spun Sugar

Pasta Pomodoro

Marion Pernoux

Pleasanton Playhouse

Postino’s Restaurant

Regal Entertainment

Ritz-Carleton, San Francisco

Rosenblum Cellars

Terry Rosser – Project Linus

Lydia Salib

Inga Saulis, True Body Wraps

See’s Candies

SF 49’ers

San Jose Sharks

Starlight/Starbright Children’s Foundation

Philip Schurman

Carrie Scott, Sonic

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Emeryville

Thalassaemia Support Foundation

Thalassaemia Action Group

Tina Turrini

Twinkle Candy Co.

UC Berkeley Pre-Medical Honor
Society – Alex Noburi

Dan & Ann Weber

Deborah Woo

Young Men’s institute

Karim Zamani

Proceeds from our fundraisers go towards the following:

- Care for patients who do not have medical insurance
- Transportation to our center for patients traveling a distance to receive care
- Medical research
- Maintenance of equipment such as the SQUID to assess liver iron
- Obtaining new equipment such as the MRI T2 to assess heart iron
- Psychosocial programs such as patient retreats, Desferal events and the annual holiday party
- Community outreach and education.

We are always in need of your support.

If you would like to make a donation please make a check payable to “Children’s Hospital Foundation” with THALASSEMIA in the subject heading and send to:

Laurice Levine, MA, CCLS
Children’s Hospital & Research Center Oakland
Hematology/Oncology Dept.
747 52nd St., Oakland, CA 94609-1809
510-428-3885, ext. 5427

Upcoming Event:

April 21, 2007

Thalassemia Support Foundation Conference 2007 Beverly Garland Hotel, Los Angeles

The 2nd Annual Thalassemia Support Foundation Conference will be held on April 21, 2007, at the beautiful Beverly Garland Hotel in Los Angeles, located only a mile away from Universal Studios. The conference is for thalassemia patients, parents and loved ones, as well as members of the medical community. The focus of the conference is to learn about recent advancements in thalassemia care and to provide a unique opportunity to meet others who are affected by thalassemia.

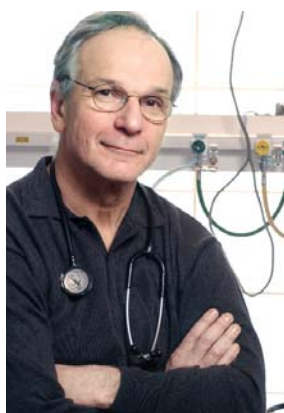
Guest speakers will include Dr. Elliott Vichinsky (Children's Hospital & Research Center Oakland) and Dr. John Wood (Children's Hospital Los Angeles). Additionally, there will be a psychosocial panel with Bryce Imbler, Laurice Levine and others.

More speakers and panelists are being scheduled, so please visit our website regularly at www.helpthals.org to receive updates on speakers, the event schedule and registration information.

Submitted by Paul DiLorenzo



Beverly Garland Hotel



Elliott Vichinsky, MD



John Wood, MD

P E R S P E C T I V E S

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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. 4398, or visit www.thalassemia.com.