

New faces around the Thalassemia Clinic and Day Hospital

By Laurice Levine, MA, CCLS, and Elliott Vichinsky, MD



Donna Edwards, LVN

Hello,
My name is Donna Edwards. I work part-time in the Thalassemia Center. I have been a licensed vocational nurse (LVN) for 16 years. I have worked with the Adult Sickle Cell Program here at Children's and in the Pediatric Intensive Care Unit. I have also spent many years working in long-term care as a nurse manager in various capacities, as well as a floor nurse. I enjoy learning new things and have already learned a lot about thalassemia. I look forward to learning more every day. I will be assisting in clinics, helping to coordinate comprehensive care for patients, and maintaining the thalassemia patient database. I am here Monday through Friday and can be reached at 510-428-3885, ext. 2857, or by email at doedwards@mail.cho.org. I look forward to eventually meeting all of the thalassemia patients here at Children's Hospital & Research Center Oakland.

Sincerely,
Donna



Ash Lal, MD

While Ash Lal, MD, is not a new face here at Children's Hospital & Research Center Oakland, he did recently become more involved with Children's thalassemia team. Dr. Lal earned a fellowship in hematology/oncology at Children's in 2005 and has been interested in thalassemia since medical school. He has devoted his research interests to identifying factors that can ameliorate the severity of thalassemia, as well as expanding bone marrow transplant options for patients with thalassemia. Dr. Lal replaced Dr. Eve Golden, who has relocated to Portland, Oregon. We thank Dr. Golden for her hard work and we wish her well as she begins a new chapter in her life. Welcome Dr. Lal!

Fertility Study Now Enrolling Patients

By Titi Singer, MD

Fertility In Females With Thalassemia Major: Determination Of Reproductive Status And Relation To Iron Overload

Infertility and early menopause are among the most difficult issues for adult females with thalassemia major. Fertility is compromised as a result of iron damage to the hypothalamic/pituitary axis and to the ovaries. Newer tests to assess the chances of women getting pregnant are now available, but have not yet been tested in thalassemia females. These include blood tests, a special ultrasound, and ovarian reserve testing (ORT) of the ovaries, which has become established in the fertility setting as a counseling tool and guide for treatment.

This study will assess the reproductive status of transfusion-dependent thalassemia females by utilizing these methods, and will also assess how reproductive status relates to the level of iron overload and effects of iron toxicity.

Who can participate?

Thalassemia females 18 to 40 years old who:

1. Have received regular transfusion therapy for 10 years or longer (8 or more transfusions per year)
2. Are willing to stop hormonal therapy one month prior to lab tests.

What does the study entail?

1. A one-time blood test at Children's Hospital (may need to be coordinated with the timing of the menstrual cycle)
2. A one-time trans-vaginal ultrasound performed at the Center for Reproductive Health at the University of California San Francisco Medical Center (UCSF).
3. A short questionnaire.
(Reimbursement and possible assistance with transportation to UCSF will be provided.) When available, the results of lab tests and ultrasound will be discussed privately with the patient.

Who shall I call?

Sylvia Titi Singer, MD
Children's Hematology/Oncology department
510-428-3169
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Busy Times at Children's

By Matt and Laurice Levine and Eve Alley

The past couple of months have been extremely busy and productive for the Thalassemia Outreach Program at Children's Hospital & Research Center Oakland. Outreach coordinators Laurice Levine, MA, CCLS, and new addition Eve Alley, MA, CCLS, created a full slate of autumn and winter events, and all were extremely successful.

Dr. Vichinsky, Laurice Levine and Liliana Macri traveled to Scottsdale for the annual Italian Catholic Federation Convention (IFC). There was a Saturday banquet, and then on Sunday the ICF presented Dr. Vichinsky with a check for \$54,000. These funds will go towards medical research and care, patient education and outreach, and community outreach. We thank the ICF for their continued generosity, love and support.

On October 11, a crowd of 140 attended the second annual "Evening Under the Stars" at Chabot Space & Science Center in the Oakland hills. The event raised money for the thalassemia and sickle cell anemia programs at Children's. A raffle and silent auction featured outstanding prizes, and attendees participated enthusiastically. In addition, the catered meal was tasty and abundant. The highlight of the food was dessert—a tiered chocolate fountain. It provided the perfect amount of sweetness before the results of the raffle were announced.

We were then treated to a short film on thalassemia, "Live to Give," which was created and produced by Laurice. A spectacular planetarium show on black holes followed that. A terrific time was had by all, and many people walked away with prizes.

On November 9, a group of 30, including 16 thalassemia patients and their siblings, spouses, significant others, children



Liliana Macri, Laurice Levine and Dr. Vichinsky at the ICF Convention 2007.

and friends, trekked down to Monterey for the annual Thalassemia Retreat sponsored by Children's Hospital. Patients came from California, New York, Ohio, Hawaii and Alaska to attend this fun-filled weekend, which was planned and led by Laurice.

On the first night, everyone ate dinner together and greeted those they did not know. Games were played to foster a sense of familiarity, and those who had questions about thalassemia felt encouraged to ask, whether in the group setting or in more private talk sessions.

After breakfast the next morning, Laurice facilitated a three-hour psychosocial session which afforded attendees the opportunity to share stories, ask questions, and gain peer support. Around one o'clock, the group split up for some free time to explore Monterey, but everyone met back at the house in the late afternoon for more food, fun and games.

It was great to see people telling stories and giving advice about thalassemia and its treatment, especially when patients learned new things about their own care and how to go about improving the quality of their lives. Tears, laughter and many hugs were shared, and by Sunday morning, when it was time to leave, the sense of community was powerful.

On December 13, 2007, patients and families gathered for the annual Thalassemia Holiday Party at Children's Hospital & Research Center Oakland. This year's theme, "Under the Boardwalk," proved to be a hit with patients young and old! There was something for everyone, including blue sno cones, cotton candy, face painting, carnival games, a fortune teller and much more! And of course, everyone had a visit with Santa and Mrs. Claus.

We were lucky enough to have several generous donors and over 30 volunteers who helped to make our party a success. It was the perfect start to a very happy holiday season!

The Children's Hospital Oakland Thalassemia Outreach Program is continually growing as more and more patients get involved and come from around the country for comprehensive care. If you are interested in visiting Children's for comprehensive care, becoming involved in outreach as a volunteer, receiving the Perspectives newsletter, or attending these outreach events, please contact the outreach team. They will welcome you with open arms.

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PATIENT PERSPECTIVE

Opening up for the first time

By Jane Huynh

In addition to the regular troubles of everyday living, thalassemia patients go through some painful periods in life. I recently accepted the fact that I had been slightly depressed for a very long time. After years of denial, I finally took steps for treatment and I'm very glad that I did.

As long as I can remember, I've always been a fairly gloomy, withdrawn person. Having my birthday on Halloween never helped much in the matter, either. I accepted it as a part of myself. I am introverted and interested in gothic things. My bookshelf is filled with Anne Rice novels and Phantom of the Opera memorabilia.

Like some other thalassemia patients, I didn't quite hit puberty, so I started taking hormone replacement pills at age 16. Since then, my monthly menstrual cycle was very predictable. I just counted the pills. Along with predictable menstruation periods came very predictable mood swings. Each month, I would go into a bout of slight depression. I would dwell on unhappy thoughts and cry myself to sleep for several nights in a row. Even though I recognized that the situation was caused by the mood swings, I could not control myself. I just waited for the periods to pass. Then life would become normal again for another few weeks.

I lived this way for about eight years. Then my menstrual cycle and mood swings started changing. The mood swings came more often, and were no longer in alignment with my menstrual cycle. They became a daily part of life.

At the time, life had become very different for me. I had graduated from college and was working a very stressful job. Being shy and introverted, I never had many friends, but what friendships I did have were becoming shaky. Living with my parents as an adult was also difficult because I needed more space and independence. All of these issues were probably just too much for me. I had always taken pride in my inner strength and the ability to weather

tough situations, so I faced these issues like I always faced everything else.

To perk myself up, I enrolled in San Francisco City College classes, volunteered at the San Francisco Society for the Prevention of Cruelty to Animals (SPCA), joined an online dating service (yeah...I really did), and just kept myself active.

All these things held my attention when I was involved with them, but the moment I had time to let my mind wander, I'd start thinking unhappy thoughts about myself and my life. Basically, periods of unhappiness had gone from monthly annoyances to daily occurrences.

I started to speak openly with my primary care, women's health and endocrine doctors about possible solutions, such as changing my hormone replacement dose and type. I ended up trying B vitamins and reducing my menstruation from monthly to quarterly. Neither of these efforts seemed to do much to improve my mood.

I just kept spiraling downward to the point where I'd spend my weekends crying in bed. My emotions took control of me and I wasn't able to drag myself to do the things that I enjoyed. I was like this for about a year until I accepted the need to speak to a mental health care professional. My epiphany came when my depression began causing me to physically hurt myself. (Not too much—don't worry!)

Luckily, my health care plan had a mental health component, and I called up the service for a referral. I wasn't quite sure what I needed, and I wasn't even sure what I was experiencing was "depression," but the people I spoke to gave me options and listened to what I was going through. I never knew how good it could feel to share my experience. Although nothing had been solved, I felt great relief just talking with



Jane drinking Exjade at the Thalassemia Retreat.

someone who I knew wasn't going to judge me.

I ended up seeing a psychiatrist who prescribed some low-dose antidepressants for me.

One day, I'd like to see a therapist regularly. It did wonders for me to have someone to talk to. There are just so many

things that I have never felt comfortable talking about with friends or family.

For once, I finally feel really content with life. That isn't to say that I don't feel any sadness anymore, but I can finally move forward again. I typed up my story because I hope it's helpful to someone out there. I never knew how good it could be just to talk and have someone hear me out.

Recently, I went to a thalassemia patient/family retreat in Monterey and noticed how good it felt to speak freely about the awful taste of Exjade and the worry of telling my new boyfriend about thalassemia. We were twenty patients living in a four-bedroom, two-bath house for a weekend, so there was little-to-no privacy. Nonetheless, I felt very comfortable, even around the people I had not met before. The biggest secret of my life (being a thalassemia patient) was common knowledge at the retreat, so there was really no need to hold back. While we played games, cooked dinner, watched television, and hung out, I could just be myself. Knowing there was a common bond and understanding between all of us made me feel very much at home. I've always been an extremely private person, but I am really starting to see the value of opening up and letting loose.

PATIENT PERSPECTIVE

A year of change

By Vincent Lau

The year 2007 was one of tremendous change for me. I was truly on my own and living my life the way I always wanted to— independent and empowered with choices. But making choices proved harder than I'd imagined. Take, for example, chelation. Choosing to chelate is much harder than choosing not to. In the past, I've chosen to let chelation slide once or twice. In the end, I ended up letting it slide for a week! Getting back onto the chelation bandwagon is a lot harder than falling off of it. And believe me, falling off the bandwagon hurt—I've seen my iron levels jump. So a word of advice—if you can stay on the bandwagon, then do so.

In 2007, I moved from Houston, Texas, to San Francisco, Calif., and started to do everything independently. For a thalassemia patient to move halfway across the country and find the right doctors is truly a daunting experience. It's especially daunting if you have no idea where to start or anyone to guide you.

Fortunately, I was able to get great care, and I found a great job and took control of my own life. If I could pick out one event or experience as a highlight from the year, it would be the thalassemia adult patient retreat.

I was introduced to Laurice Levine through a thalassemia patient I met at UCSF Medical Center where I receive my routine care. She told me that Laurice was a great person to talk to who was involved with a terrific network of support for thalassemia patients at Children's Hospital Oakland. With her advice, I contacted Laurice. I really wanted to take advantage of the support network that was available, and to be up-to-date on any information that could help me with my everyday struggle with thalassemia. My first conversation with Laurice was great. She was eager to help and invited me to come to the

thalassemia patient retreat she had planned in November. She felt that it would be an opportunity to meet other thalassemia patients like me and a chance for her to get to know me better.

The retreat was a fantastic experience. The group had rented this nice big house in Monterey, a couple of hours drive from San Francisco. Everyone got settled in, and house duties were assigned. I chose to cook as my contribution, since cooking is one of my all-time favorite hobbies. Laurice had planned some great activities, along with a few sessions where we all gathered to discuss anything and everything related to thalassemia. It was so great to be able to talk openly about thalassemia-related problems—it is rare that others ever understand the hardships we have to go through living with it.

The amount of knowledge I gained was invaluable. Everyone was very open and gladly shared their experiences and ways to cope with thalassemia. The overall feeling of knowing that someone else has either been through a similar situation or is going through the same hardships as you makes you feel less isolated. I should mention that I didn't have anyone to share with or talk to in Houston. I knew only two other thalassemia patients, and I rarely saw them, let alone talked to them. It didn't help that I was much older and that we were all in different stages of our lives.

The retreat for adult patients provided a different experience for me than what I was used to. I met others who were my age,

and some who were older. A few flew in from other states just to attend. The experience was something I had been looking for and wanting for a long time. The retreat was a place where I could talk openly about anything without fear of criticism or lack of understanding. How often do you get a chance to sit down with a big group of people and compare chelation methods and

pumps? It's certainly not a conversation you can have with most people, even your closest friends. Life is already hard enough as it is. Throw thalassemia into the mix, and people often wonder how we all keep going. But how can you not? It's a part of who we are, and living with it sure beats sitting around feeling sorry for yourself. We just have to live the best way possible and fight every day. There's always going to be someone

worse off than you.

After the retreat, I came away with the joyful feeling that I'm not alone. There are others like me, battling the same issues and winning every day. I see that there is still hope that one day there will be a cure for thalassemia. I can't say it any better than this—it takes one to know one. I'm proud to call each and every person I met at the retreat a friend. I'm truly indebted to Laurice for giving me the opportunity to participate in the retreat and be a part of such a wonderful family.

Laurice, I want to thank you for changing my life. To all the friends I met at the retreat, thank you for sharing and filling in that empty void of my life. I can't wait to do it all again at next year's retreat.



Vincent Lau administering Desferal at the Thalassemia Retreat.

PATIENT PERSPECTIVE

My visit to Children's Hospital for comprehensive thalassemia care

By E. Karris

In October 2007, I had the chance to visit Children's Hospital Oakland for a thalassemia comprehensive care visit. With the help of Laurice Levine, the thalassemia outreach coordinator, and Dru Foote, PNP, the thalassemia nurse practitioner, I was able to organize my visit so that it included a bone density scan, a SQUID test (to assess liver iron), and a consultation check-up with Dr. Elliott Vichinsky, one of the finest doctors in the field of thalassemia care. Before going to Oakland, I participated in the EDICT study at Children's Hospital Los Angeles, which enabled me to get an MRI T2* to assess heart iron.

As a patient who lives and receives care in a city where there are few, if any, thalassemia patients, it is sometimes frustrating to see doctors who don't know much about thalassemia. Thankfully, I have a great hematologist locally in Charlotte, North Carolina. Although he doesn't see any other thalassemia patients, he is methodical, a great listener, and intelligent, and therefore able to provide great medical advice. However, I think it is important for all patients to visit a thalassemia specialty center where they can receive comprehensive care annually. The medical specialists at these centers are familiar with different types of issues facing thalassemia patients, including iron overload, cardiac problems, hepatitis and osteoporosis. They understand the comprehensive screening tests needed to measure the overall health of patients and have access to the latest research protocols.

As a patient, going to a specialty center affords the opportunity to educate yourself

so that you can be proactive in your routine care and share newfound knowledge with your primary doctor. This ultimately improves the quality of your care.

I flew into Oakland from Los Angeles on a Monday morning. Upon arriving at Children's, I visited the Day Hospital and saw a friend who was getting transfused. About an hour later, I took the shuttle bus to Children's Hospital Oakland's research institute, where I met with Ellen Butensky, PNP, PhD, one of the research nurses. Since I had never had a SQUID done before, she explained the process to me in detail.

The SQUID process took about 45 minutes. It was a painless procedure, and the staff did everything to ensure I was comfortable. Following the SQUID, Ellen did a DEXA scan, which measures bone density. This was also painless and took only 15 minutes. I then had a break and was able to meet up with Laurice and another patient for lunch.

Every member of the staff in the clinic was accommodating and friendly. Laurice even brought me a bottle of water while I was in the waiting room. First, I met with Titi Singer, MD, and the clinical research nurse, Nancy Sweeters, PNP. Dr. Singer is conducting a pulmonary hypertension (PHT) study to determine the patterns and causes of PHT in thalassemia patients. I was amazed at how much time Dr. Singer spent with me explaining what PHT is, and about the recent findings regarding PHT and thalassemia, and some of the treatment options.

Next, I saw Dr. Vichinsky and Dr. Ash

Lal, along with Dru, who is the most wonderful thalassemia nurse. They went over my medical history with me and reviewed labs and results of other tests that I had done in Charlotte prior to my visit to Oakland. We discussed my transfusion therapy, my chelation therapy, and other concerns. They asked that I have a few more tests done upon returning to Charlotte, since I was flying out that afternoon. They also recommended a change in my transfusion regimen.

Once I returned to Charlotte, I had the final tests performed and sent copies to the doctors in Oakland. I received a final write-up of the comprehensive care visit, and I also received follow-up calls and e-mails from Dr. Lal, Dru and Nancy to go over the recommendations for transfusions and medications.

Emails? Yes, you read correctly: emails! I barely even get to speak with my local doctor and nurse on the phone during business hours, much less correspond with them via email after-hours.

I had a great experience visiting Children's Hospital Oakland. Everyone I met with was extremely helpful and thorough and showed genuine concern for my health. Although I am involved in the Thalassemia Action Group (TAG) and learn a lot about thalassemia through TAG conferences, I became even more educated during my visit to Oakland. I definitely plan on visiting Children's annually for comprehensive care.

Upcoming Events:

May 9-11, 2008
23rd Annual TAG
Conference
Washington, DC

For more information please visit
www.cooleysanemia.org or email
TAG@cooleysanemia.org

May 22-25, 2008
Child Life
Conference
San Diego, Calif.

July 10-15, 2008
Painted Turtle Camp
for Thalassemia patients age 7 to 16
For more information contact
Eve Alley, Thalassemia Outreach
Coordinator at 510-428-3885, ext.
4398



Liliana Macri



In memoriam

In 2007 two dear friends with thalassemia passed away: **Liliana Macri** and **Nicole Inajayan**.



Nicole Inajayan

We Remember

In the rising of the sun and in its going down,
We remember them.
In the blowing of the wind and in the chill of winter,
We remember them.
In the opening of the buds and in the warmth of summer,
We remember them.
In the rustling of leaves and the beauty of autumn,
We remember them.
In the beginning of the year and when it ends,
We remember them.

When we have joys we yearn to share,
We remember them.
So long as we live, they too shall live,
For they are now a part of us
As we remember them.

Poem submitted by Mae Ferraro,
Italian Catholic Federation Branch 4.



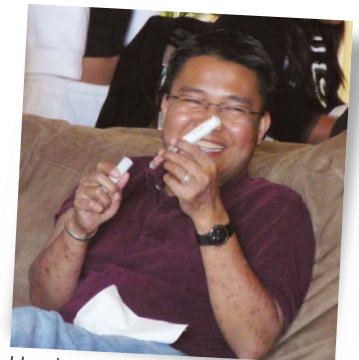
Celebrating Life!

Congratulations to Diane and Robert Aiello on the birth of their first child. Robert Gennaro Aiello was born on December 11, 2007, at 12:13 p.m. He was 8 lbs, 20.5 inches. Diane has thalassemia major and has come to our center for comprehensive care. Everyone is healthy and doing well.



Thalassaemia Retreat 2007 group photo.

Thalassaemia Retreat 2007 Highlights



Huythong administering insulin.

Special Thanks To Our Generous Donors

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

Charles Abella
Judy, Lou and Eve Alley
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Albany Bowl
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Terry Rosser & ICF BR. 161 for their generous donation in memory of Becky Rosser
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Tina Turrini
Twinkle Candy Co.
Waterfront Plaza Hotel
Dan & Ann Weber
Susan Winner
Who’s Your Betty
Dr. Frederick and Carol Wood
Woodfin Suites

An Evening Under the Stars

Special thanks...

- To Novartis Oncology and the Chabot Space & Science Center for sponsoring this event.
- To Ari Feingold and Asqew Catering for their hard work and support.
- To Ellen & Jim Tenney at Chocolate Fountains of Sacramento – for donating their time and tasty delights.
- To Philip Gelp – for his musical talents.
- To Ashley Holley, Susan Winner, Huythong Nguyen and Cheryl Mar for sharing their personal stories.

Special thanks to following individuals who generously volunteered their time to make Evening Under the Stars a success:

Curt Cornell
Alissa Cook
Glenda Dixon
LaVina Finley
Pam Gill
Barbara Gordon
Willynda Gordon
Beverly Hoh
Diane Jung
Chris Knudsen
Suzanne Kowalski

Denise Krufft
Collette Luckie
Joy Mitchell
Matthew Levine
Jennifer Riley
Randy Sabbagh
Claire Saenz
Steven Srisavat
Lisa St. George
Matt White
Stefanie Yurus

Special thanks to our donors, volunteers and vendors at the annual holiday party:

Mae Ferraro
Henry Lapachet
Michael Maltese
Denise Trombete
Rae and Barbara Naan
Yvonne Linero
Rose and Don Arnaudo
Charlene Kramer
Stacy Appel
Susan and Annie Paulukonis and ACLC
Lalee Simora and Holy Names
Mary Malec

Wendy Kwang and Berkeley High volunteers
Larry Davis
Sarah Rogers
Cassie Crowe
Jelly Belly Factory
Asset Mark
Mike Carroll and Sons of Italy
Starlight Starbright Foundation
Ken and Jude Vargas
Party Time Machine Rentals
Southwest Airlines



Volunteers from Berkeley High School serving popcorn.

Holiday Party 2007 Highlights



Michael and Heidi Brown enjoying the festivities.



Little ones enjoying the party.



Hem/Onc's Larry Davis and Susan Paulukonis served beverages with help from the Berkeley High volunteers.

PERSPECTIVES

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

Address change requested

Happy New Year from the Thalassemia Team!



The Thalassemia Team at Children's Hospital Oakland would like to wish all of our patients, families, colleagues and friends good health, happiness and peace in 2008.

Perspectives Newsletter is produced by 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.