



## Thalassemia Patient Retreat 2008

The annual thalassemia retreat was held on Nov. 14 to 16 in Russian River, Calif. Twenty-five thalassemia patients and their spouses, significant others, children and friends attended the retreat and enjoyed a weekend of bonding with friends, old and new; sharing culinary talents; playing games; and sharing personal stories while giving and gaining support. There were many tears, much laughter, and many hugs; and when Sunday morning came, and it was time to leave, the sense of community and positive feelings were incredible.



## Welcome back, Claire!

Claire Richardson Saenz is excited to return to Children's Hospital & Research Center Oakland after a four-month absence. You may remember her from her former role as a study coordinator for thalassemia research in the Hematology department's CTSI Clinical Research Center. Claire is now one of Hematology's thalassemia outreach coordinators, working alongside Eve Alley and Laurice Levine.

Claire spent August to December 2008 in Asia, where she traveled and served

as a public health outreach worker and staffer in a home for children living on the street in Pune, Maharashtra, India. Claire also spent



*Claire is elated to be the 3,246th person to donate blood at Kantha Bopha Children's Hospital in Siem Reap, Cambodia. 12/11/08*

time traveling extensively through India, Thailand and Cambodia. Before coming to Children's Hospital Oakland, Claire worked in several public health positions, coordi-

nating programs and doing community-based health outreach and education.

She has master's degrees in Medical Anthropology and Public Health from the University of Hawaii, where her research focused on the anthropology of

infectious disease and how to put disease prevention/health promotion programs in place to serve multiethnic, immigrant and underserved populations.

Standards of Care Guidelines  
for Thalassemia



### The Standards of Care for Thalassemia, 2nd Edition

The Standards of Care for Thalassemia, 2nd Edition is now available online at [www.thalassemia.com](http://www.thalassemia.com). If you would like a hard copy, please email [LLevine@mail.cho.org](mailto:LLevine@mail.cho.org) or [EAlley@mail.cho.org](mailto:EAlley@mail.cho.org), or call 510-428-3385, ext 4398.

# Patient's Perspective: Uncommon Threads

by Abby Torkelson

Whether you are meeting a new thalassemia patient for the first time, or picking up where you left off with one from last year, there is an instant deep connection that ties us to each other.

Some may see thalassemia as an affliction; but I am beginning to see it as a special mark that inspires us to strive to be extraordinary, rather than to settle for mediocrity. In the tapestry of life, we have the honor of being woven with the same uncommon thread. We are unique and yet the same; our struggles and fears may be individual, but are also similar. You could say that it is in our genes.

This year's thalassemia retreat was held up in the beautiful wine country, but there was no whine found among the patients. We spent our weekend together in the Russian River area, where Laurice Levine had arranged for us to stay at a beautiful secluded estate.

Our schedule included settling in, exploring, cooking, cleaning, playing games and catching up with one another as much as possible. On Saturday, we had our psychosocial session, moderated by Laurice. If I had to pick a title for it, I think I would call it "No Taboos."

Imagine sitting in a group of 18 to 20 people, some of whom you have known for years and others whom you have only

met for the first or second time. You can ask one question that every participant has to answer. The atmosphere is honest and truthful. What would your question be?

The questions included:

- "If you knew it was your last meal, what would you eat?"
- "For what would you want to be most remembered?"
- "Where would you go if it was the last trip you would ever take?"

Some of the comments that surfaced in answer to thought-provoking questions posed by patients during the session included:

- "I never expected to live past 30."
- "They told my parents I would die in my teens."
- "I just want to live into my 50s to see my child grow up."
- "I'm living on borrowed time; I try to make the most of every moment."
- "We need to live life to the fullest."
- "It's about the quality, not the quantity, of time."

Although death is not a popular subject in our society, it is a real part of a thalassemia patient's life. I once heard someone say, "Thalassemia years are like dog years." This is not to say that thalassemia patients live like dogs but that our lifes-

pan is different, and each must decide to face it or try to flee from it.

We spent several hours posing questions and pondering answers, but interestingly, the theme remained constant. Although no one's question included the words "death" or "dying," somehow all the answers centered on that topic.

To an outsider, the session might have seemed weird or depressing, but for us, it was very meaningful and needed. Only other thalassemia patients understand the struggle of getting up each day. No one else can imagine the fears or frustrations of having thalassemia. No one can empathize with the loss of a friend who had thalassemia more than another patient who has lived your greatest struggles, experienced your deepest fears and felt your biggest dreams.

For me, having thalassemia means that I have to make every moment count. It means that no time or person should be taken for granted and that I should try to live with no regrets.

I believe there are only a few things that will truly matter to me when I'm on my deathbed: those whom I love, those who love me and where I'm going to spend eternity.

## MILESTONES



Congratulations to Vy, Chad and Andrew! Vy Keang gave birth to baby Melanie on Dec. 10, 2008



Congratulations to Karim Zamani for graduating with his CPT-I License (Phlebotomy) on Dec. 18, 2008.

## Holiday Party 2008: Highlights

On Dec. 14, 2008, 175 patients and families with thalassemia, friends of the program, and staff, gathered together for the annual Thalassemia Holiday Party at Children's Hospital & Research Center Oakland. The Outpatient Center atrium was transformed into Little Italy to celebrate this year's theme, "Viva Italia."

Italian food was catered by Pasta Pomodoro and Panda Express donated delicious Chinese appetizers. Highlights included the Italian Ice cart, holiday craft projects and entertainment by the Amazing Tap Dancing Santas. All the patients and siblings had a memorable time visiting Santa and Mrs. Claus who were generous enough to bring gifts for all of them.

We would like to thank our donors and volunteers for their generosity, dedication and support. We are grateful to them for making the holiday party a smashing success!



**Michael** enjoys a craft project.



Tap dancing Santas celebrate Hanukkah.



Members of the Italian Catholic Federation enjoy the celebration. Viva Italia!



**Rameet** gets her face painted.

### A very special Thank You to all of our donors, volunteers and vendors, including:

- Italian Catholic Federation - Members, Branches, Districts, Central Council
- Thalassemia Support Foundation
- Genworth Financial
- Sons of Italy
- Sons of Sicily
- Colombo Club Auxiliary
- Young Men's Institute San Jose Council No.2
- UNICO Marin and San Jose Chapters
- Children's Hospital Oakland Volunteer Department
- Santa and Mrs. Claus
- Cristina Gonzalez and Girl Scout Troop 33993
- Southwest Airlines
- Cal State University East Bay Women's Basketball Team
- Leah McGowan-Hare
- Starlight Children's Foundation
- Ann Briones and Girl Scout Troop 32100
- Elsie Giuntoli
- Marlene Farber
- Charlene Kramer
- Bob and Elaine Osorio
- Jane Dianda
- Irene Sarubbi
- Terry Rosser
- Mae Ferraro
- Rose and Don Arnaudo
- Mary Sperrazzo
- D.J. Nugent
- Rose Tallarida
- Priscilla Lindberg
- Rory O'Connor
- Pasta Pomodoro
- Panda Express
- Rainbow Ice
- The Amazing Tap Dancing Santas

# Italian Catholic Federation (ICF) Update:



(above) ICF LA District and Branch 108 – San Gennaro Festival 2008

(middle) Vegas Branch President Joe Donato and Danny Centurioni

(right) Installation of officers, Las Vegas



We would like to extend our most sincere gratitude for the Italian Catholic Federation's generous donation of \$57,000, presented to Dr. Vichinsky, Laurice and Matt Levine at the 78th Annual Italian Catholic Federation Convention, in Garden Grove, Calif.

As always, it was an honor to attend the convention. We enjoy catching up with old friends and meeting new ones, celebrating at the banquet and honoring the dedicated

members of the ICF who work to create a better world by touching thousands of lives. ICF donations have contributed significantly to the quality of life of people with thalassemia, here at Children's Hospital Oakland, and around the world.

ICF contributions support medical research, community education and psychosocial programs for patients and families. If you are interested in learning more about the ICF please visit [www.ICF.org](http://www.ICF.org).

**Thank you to the many ICF branches for their hospitality during our recent visits!**

- ICF Larkspur
- ICF Las Vegas
- ICF Branch 108
- ICF LA District

## Stay healthy by knowing drug-nutrient interactions

by Eva Choy

It's important to remember that the foods you eat can interact with some of the medications you take. Some nutrients found in food can make medications work slower or even prevent them from working at all.

To get the most potent power out of your medication, you must learn about possible drug-nutrient interactions for any medication you take, and then take the necessary dietary precautions. Below are some common drug-nutrient interactions to be aware of.

### Anti-coagulants: Coumadin® and aspirin

Drug purpose: To prevent blood clots from forming in the body.

Monitor intake of: Vitamin K (higher concentrations of Vitamin K are found in the outer leaves and peels of vegetables) and herbs that affect blood clotting, including ginger, ginkgo biloba, garlic and ginseng.

Significant sources include:

spinach	collard greens	kale	cabbage
broccoli	mustard greens	lettuce	Brussels sprouts
asparagus	cauliflower	lentils	mung beans
soybeans	canola oil	egg yolks	green tea leaves
green apple peels	bran	garbanzo beans	

\* Source: Pronsky, ZM. *Food-Medication Interactions*. 13th ed. reprinted with permission.

### Anti-hypertensives: ACE inhibitors, beta-blockers, diuretics such as Lasix®

Drug purpose: To control high blood pressure, fluid over load, and heart disease.

Monitor intake of: dietary fat and sodium.

### Thyroid medications: Levoxyl® and Synthroid®

Drug purpose: To stimulate thyroid hormone production.

Monitor intake of: Soy products, walnuts, dietary fiber and calcium

Take calcium at least 4 hours after taking drug.

# My Experience at the Painted Turtle Camp

by Meghan Foe

Dear Readers,  
If you are reading this right now, you are probably interested in my trip to the Painted Turtle summer camp. The Painted Turtle is a camp



Arrival time photo

founded by a group of people who wanted to help children who are chronically ill. Among them was the Oscar-winning actor Paul Newman. If you don't know who he is, you probably know him as the guy on the salad dressing bottles.

The Painted Turtle gives kids with illnesses a chance to have fun, escape hospitals, and just be a kid—all in one week. At camp I rode a horse down a scenic trail, glided across a lake in a canoe, felt the thrill of the wind rushing past my face as I zipped down a zip line, and expressed myself in art and woodshop.

I did things I had never done, and would never have dreamt of getting to do if I hadn't been at the Painted

Turtle. Thanks to generous donors, the Painted Turtle is filled to the brim with tons of awesome things: like a Shamu-shaped swimming pool, a grand dining hall and even a movie star

horse you can pet and ride.

Now what would all these activities be worth if you weren't comfortable? The camp provides beds that I know are comfortable; and the food is excellent. Every day you will have three healthy meals—different every day—with dessert after lunch and dinner.

Each cabin has a nurse to take care of you and give you your medicine, and counselors to befriend you and make sure you're comfortable.

To keep your stay exciting, the camp holds events such as the Pinewood Derby, in which you race

a car of your own on a track; Stage Night, where you show off your talents to the camp; and the Silly Olympics, where you can cream your counselors with food, slime and muck made with things I don't want to know about.

What I do know is that at the Painted Turtle, I spent one week of my vacation, and it was a week well spent.

Sincerely,

Meghan Foe



Chalk art in front of cabin.

**Painted Turtle Camp 2009**  
July 23–28, 2009  
For more information on this amazing camp visit  
[www.thepaintedturtle.org](http://www.thepaintedturtle.org).

## OUTREACH UPDATE

**Feb. 3 to 4:** Annual Thalassemia Clinical Research Network Meeting, Oakland, Calif.

**Feb. 14:** ICF Healdsburg Valentines Dinner benefitting Thalassemia, Healdsburg, Calif.

**Feb. 15:** Lunch and Ice Cream at Fenton's Creamery for adult patients, Piedmont, Calif

**Feb 20:** ICF Branch 285 Annual Thalassemia Fundraiser, Livermore, Calif.

**Feb. 23:** ICF Branch Meeting, Brentwood, Calif.

**April 4:** ICF Branch Meeting, Thousand Oaks, Calif.

**April 8:** ICF Branch 163 Meeting, San Mateo, Calif.

**April 18:** TAG Mini-Conference, Children's Hospital Oakland

**May 8:** 8th Annual Blood Drive in Honor of International Thalassemia Day, Children's Hospital Oakland

**July 23 to 28:** Painted Turtle Camp, Lake Hughes, Calif.

**September 12:** Thalassemia Support Foundation Conference, Garden Grove, Calif.

**October 21 to 24:** New York Academy of Sciences' Cooley's Anemia Symposium, New York.

If you would like to volunteer in the thalassemia outreach program please call thalassemia outreach coordinators Eve Alley at 510-428-2885, ext. 4398 or email her at [EAlley@mail.cho.org](mailto:EAlley@mail.cho.org); or call Claire Richardson Saenz at 510-428-3885, ext 5427 or email her at [CSaenz@mail.cho.org](mailto:CSaenz@mail.cho.org).

# Medical Research Studies

## The Fertility Study

The Fertility Study, conducted by Titi Singer, MD, and funded by the Cooley's Anemia Foundation, is still open for enrollment. To qualify for this study, women with thalassemia must be transfusion-dependent, 18 or older, and available to come to the Bay Area for study visits. If you are interested in participating in, or learning more about the fertility study, please call Dr. Singer at 510-428-3169.

## Assessment of Pain Survey

The principal investigator of the Thalassemia Clinical Research Network's (TCRN) "Assessment of Pain Survey," Dru Foote, PNP, is scheduled to begin enrolling patients in March 2009 at Children's Hospital & Research Center Oakland. This study's primary aim is to assess the prevalence of pain in patients with transfusion- and non-transfusion-dependant thalassemia. The study will be open to patients older than 12 years of age, who are seen at TCRN funded sites.

## BE A PART OF THE THALASSEMIA OUTREACH PROGRAM

The Children's Hospital Oakland thalassemia outreach program is continually growing, as more and more patients get involved and come from around the country to Oakland 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 a member of the outreach team; they will welcome you with open arms.

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**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](http://www.thalassemia.com).