

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

Northern California Thalassemia Center
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Address change requested



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.

Upcoming Events

Feb. 13, 2010: ICF Branch 52 Valentine's Day fundraiser benefiting thalassemia, Healdsburg, CA

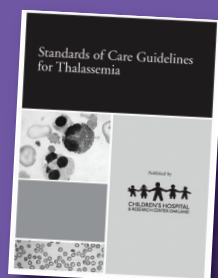
Feb. 27, 2010: Thalassemia Outreach Patient Lunch, Seattle, WA

Mar. 6, 2010: ICF Branch 184 Meeting, Los Gatos, CA

If you would like to volunteer with the Thalassemia Outreach Program, please contact Thalassemia Outreach Coordinators Eve Alley (510-428-2885, ext. 4398, or EAlley@mail.cho.org) or Laurice Levine (510-428-3885, ext. 5427, or LLevine@mail.cho.org).

The Standards of Care for Thalassemia, 2nd Edition

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



Thank you!

We would like to thank our sponsors, donors, volunteers, and vendors for their generosity, dedication, and support to our program over the past year. We are grateful for their many contributions which have made our events a success.

Italian Catholic Federation
Genworth Financial Wealth Management, Inc.
Thalassemia Support Foundation
Cooley's Anemia Foundation
Thalassemia Action Group
Starlight Children's Foundation
Colombo Club Auxiliary
Children's Hospital Oakland Volunteer department
Andy and Sid Pappani
Deanna and Al De Nurra
Jim and Janice Jones
Marlene Farber
Charlene Kramer
Rose Jarrett
Matt Levine

Darlene Fitzgerald
Bob Basuino
Jane Dianda
Terry Rosser
Elsie Giuntoli
Mary Sperrazzo
Vy Keang and Chad Sitzman
Felipe Garcia and the U.C. Berkeley Lambda Theta Phi Latin Fraternity
Romeena Ghaziani and friends
Joanne Hoegsberg and friends, Metabolex, Inc.
Angela Coleman, Comcast
Asqew Grill
Panda Express and Ling Wu
Oakland Chinatown Lions Club and Frances Chow

Happy New Year!

Dr. Elliott Vichinsky and the entire thalassemia staff wish all our patients, families, friends, donors and colleagues a happy, healthy, and peaceful New Year.

On December 5, 2009, 150 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 a Hollywood scene, thanks to the hard work of our volunteers, complete with a movie backdrop, theater-style treats, and a magician. Asqew Grill catered this year's fine cuisine and Panda Express employees volunteered at the party and donated appetizers. Of course, the biggest highlight was a visit from Santa and his #1 elf.

Clockwise from top left: Santa, this is what I want for Christmas; ICF members celebrate with Santa; Rameet and her sister have a good time with Santa and his elf; Eve Alley and son Leo with Panda; Oakland Lion's Club volunteers.



The 2009 Children's Hospital Holiday Party

by Tanou Chanhchaleun

The 2009 Children's Hospital of Oakland Holiday Party was another success. Thanks to Eve Alley, Laurice Levine, and many other hard-working volunteers, Children's patients were able to have this one day to forget about the conditions they live with. Patients, families, and friends all gathered together to eat, drink, and sit on Santa's lap as he and his wonderful workers handed out presents to warm the kids' hearts. That's just the kind of place CHO is. You couldn't find a sweeter, more sincere outreach staff anywhere.

Children's has always offered great outreach activities to thal patients. More and more people have come together for these events over time.

I have been participating in Children's outreach activities for many years. Over time, I have met many amazing adults and kids who have inspired me.

It was always difficult for me as a child growing up with a condition that required constant hospital treatment. As a thal patient, having to deal with the pain and emotional roller coaster was

always a challenge. Participating in outreach activities has helped me balance my emotions by coming into contact with positive, outgoing people.

Even though taking part in these activities won't help cure my condition, it helps to remind me of the people who still care about us, no matter who we are. Amazing, positive people like Laurice, Eve, and many others have always given me a reason to come out and participate in events such as the holiday party.

2009 Thalassemia Retreat

The annual thalassemia retreat was held in Lake Tahoe, Calif. from October 9 to 11. Approximately twenty adults with thalassemia—some of them attending for the first time (including people from as far away as Alaska and Washington)—and their spouses, significant others, children, and friends attended the retreat and enjoyed a weekend of bonding with friends, both old and new; sharing culinary talents; playing games; and sharing personal stories while giving and gaining support.

Clockwise from top left: Retreat 2009 Lake Tahoe; Happy 30th Birthday, Abby!; Steven checks Michelle's blood sugar; Eva and Lori show off their designer cupcakes.



PATIENT PERSPECTIVE

Nature Versus Nurture: How about both?

By Abby Torkelson

This year's thalassemia retreat was in beautiful Lake Tahoe. After a lengthy hair-raising, character-building road trip, we pulled into a serene wooden lodge and settled in for a week-end of memory making. The absolute grandeur of our location was not fully realized until the morning light peeked over the majestic mountaintops and the sun's rays filtered through the towering trees, which stood guard over us like sentries.

Yet all of this beauty could not compare to the magnificent sanctuary provided to us by those who have watched over and guided us for as long as we have known them. Laurice Levine and Huythong Nguyen have become our guardians, sheltering us from storms with their strength, and using their wisdom to teach us how to survive the winds and trials. I sincerely believe the reason that I have lived to consider myself an "older" thal is because of the vigilance of the people at Children's Hospital Oakland and the insights of Laurice and Huy.

Laurice and Huy moderated our psychosocial workshop on Saturday, teaching how to get the most out of life by viewing it as a jar. We filled the jar with rocks, pebbles, sand, and coffee; each represented different events, projects, or items that fill up your time or stress you out.

Huy shared with us some important information to have when interacting with health-care providers that he has learned over the years. We also had plenty of time for catching up and bonding with new friends.

One of the most memorable moments of my life happened at the retreat this year. Everyone threw me a surprise 30th birthday party! It was my very first surprise party, and I never imagined hitting the third-decade mark. It was very special to be able to experience it with my "thalassemia family."

What did I learn from this year's thalassemia retreat? It is that nature made us similar in health, but nurture made us friends for life.

PATIENT PERSPECTIVE

Looking from the outside in

By Lori Zipp-Smith

I have been asked to write about my first experience with the thalassemia patient retreat, which was held in Lake Tahoe this year.

Until recently, I did not even know this outreach program existed. I have been living with thalassemia in Seattle, Wash., for the past 48 years, with only the support of my family and close friends. Little did I know that out there in the world were others who are living and experiencing the same things I have been, trying to survive with thalassemia.

Coming together with other thal patients was like joining a club—not any club, but The Club. After a day of playing games and sharing personal stories, everything started to make sense to me. It all fell into place, and this was a place I needed to be. Through the weekend, we played games together, we cooked together, we cleaned together, we shopped together, and most of all, we talked together. By Sunday, I began to realize that I looked upon these people, whom I had just met for the first time, as friends.

Two of my most memorable moments were the car rides up and back from Lake Tahoe. My car mates and I bonded while singing to the radio, laughing, and just having a good ol' time, even if we did get lost and were the last ones to arrive.

This experience will live on with me forever, and I can't thank everyone enough for making me feel so included in our special club. I learned a lot, I made new friends, and I can't wait for next year. A special thanks goes out to Laurice for all her dedication and hard work to make sure we all had a great time. To all my new friends, have a safe and healthy winter, and I will see you all next year at the retreat.

The New York Academy of Sciences Ninth Symposium on Cooley's Anemia/Thalassemia Action Group Patient and Family Conference

The New York Academy of Sciences (NYAS) Ninth Symposium on Cooley's Anemia/Thalassemia Action Group Patient/Family Conference took place Oct. 21 to 24 in New York City. The symposium and the conferences were both well attended by medical professionals and people with thalassemia and their families from around the world. It was incredible to be surrounded by so many experts and advocates in the field of thalassemia. Special thanks to NYAS, the Cooley's Anemia Foundation, and the Thalassemia Action Group for their tireless dedication and hard work in making this event a success.

Families gather together to listen, laugh and provide support; Dr. Pakbaz participates in the poster session; colleagues Olivia Vega and Gabe Wong from Children's Hospital Oakland facilitated a meaningful psychosocial session; the International Crew



The Children's Hospital thalassemia outreach program is continually growing as more and more patients get involved and come from around the country for comprehensive care. Please contact the outreach team if you are interested in any of the following:

- ¥ Visiting Children's for comprehensive care
- ¥ Appointment, to participate in a medical study or to get your liver iron assessed by the SQUID
- ¥ Becoming involved as an outreach volunteer
- ¥ Receiving the Perspectives newsletter
- ¥ Attending outreach events
- ¥ Planning a fundraiser
- ¥ Making a donation of much-needed funds

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In Memory of Jean Marie Knudsen

by Dru Foote

When I think of Jean Marie, I am reminded of her passion for people and politics. Jean Marie truly cared for people with thalassemia. She did everything she could to make their lives easier by resolving problems with schools, insurance, and finances. She was also an empathetic listener who tried to help people identify their own problems and solve them. Like the parable says, you can give a man a fish and feed him once, or teach the man to fish and he will never be hungry. Jean Marie's philosophy was to try as much as possible to teach people how to handle their issues rather than solve them herself. Jean Marie had a wisdom about people and life that I truly miss.

Her passion for politics was infectious. She loved to debate issues; but she did not limit herself to discussions—she got

involved. In 1972, she worked for the McGovern campaign. She carried on a regular debate in the editorial pages of various newspapers, advocating liberal causes. Jean Marie was our political conscience and worked hard to make sure we were aware of the issues of the day.

Jean Marie was a devoted mother to her daughter, Chloe, who is a senior at UCLA majoring in music and biology. She glowed with pride when discussing Chloe's many musical and academic achievements. Chloe is a wonderful gift that Jean Marie has given the world.



I am thankful for the gift of Jean Marie to the thalassemia program at Children's Hospital Oakland, and I am thankful that she was my friend.

To share some fun Jean Marie facts:

She was born in Norway and came to the United States aboard the Queen Mary at the age of four. Ever since, she was a lover of all things Norwegian.

After college, she worked aboard a Norwegian freighter and had the opportunity to travel the Pacific, including a stop in Bora Bora.

In the early 1990s, Jean Marie spent three weeks in Cuba, which sparked her desire to become a documentary filmmaker.

Italian Catholic Federation (ICF) Update

We would like to extend our most sincere gratitude for the Italian Catholic Federation's generous donation of \$62,000, presented to Dr. Vichinsky, Laurice Levine, and Eve Alley at the Annual Italian Catholic Federation Convention in San Jose, Calif.

As always, it was an honor to attend the convention—we enjoyed catching up with old friends, meeting new ones, and honoring the dedicated members of the ICF who work tirelessly on behalf of the thalassemia program. This year, we presented an award to recognize the outgoing ICF president, Mike Rossi, and thanked him for his years of service and dedication to thalassemia. We also presented an award to ICF Branch 4 in San Jose, which was received by Branch President Darlene Fitzgerald, Ann Fitzgerald, and Central Council Member Bob Basuino, in memory of Mae Ferraro, who dedicated her life to helping the community, especially people with thalassemia.

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 refer to www.ICF.org.

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

ICF Branch 285, Livermore, CA
 ICF Branch 432, Brentwood, CA
 ICF Branch 163, San Mateo, CA
 ICF Branch 108 and L.A. District, Los Angeles, CA
 ICF Branch 367, Las Vegas, NV



ICF Br. 4 members Darlene and Ann Fitzgerald receive an award in memory of Mae Ferraro; the donation check presented by ICF Grand President Mike Rossi and ICF Cooley's Anemia Chairwoman, Jane Dianda; San Gennaro Festival 2009; ICF Br. 367 members Hilda and Manny Valley celebrate the holidays.

Welcome, Catherine Gariépy

Catherine Gariépy has just graduated with a Masters of Science in Kinesiology from the University of Massachusetts-Amherst, where her research was on walking asymmetries in children with scoliosis. She worked with the Shriners' Hospital for Children on that project. Catherine has always been interested in children's health.

Catherine came to Children's Hospital Oakland because of a strong interest in pediatric health, the quality of care offered, the great employees, and the hospital's commitment to helping out the

community. She will be applying to medical school in a few years, so the experience she is gaining from working here is priceless. Meeting all the patients who come for a SQUID teaches her a thing or two about life.

When Catherine is not working at Children's, you can see her ride her bike to and from work every day. She loves to cook, row, do Pilates, and read good books. She says, "If I haven't met you yet, I'm looking forward to your next appointment at the SQUID!"



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The Third Thalassemia Support Foundation Conference

by Laurice Levine, MA, CCLS

The third Thalassemia Support Foundation (TSF) Conference, held in Los Angeles on Sept. 12, 2009, was attended by approximately 50 patients, parents, doctors, and friends. The TSF conference proved to be a wonderful and engaging event and facilitated a support network for all of those who are directly or indirectly affected by thalassemia. TSF collaborated with Children's Hospital & Research Center Oakland and Children's Hospital Los Angeles (CHLA) to plan this event.

The conference began with a continental breakfast where attendees effervesced with excitement in anticipation of the day. Instant bonds were formed as people took the opportunity to casually and openly ask questions to one another such as, "Do you have thal?" and, "Who in your family has thalassemia?"

The morning session began with a panel discussion on insurance led by Susan Carson, RN, MSN, CPNP, from CHLA. Susan also presented on the pain study that is being conducted at both children's hospitals. Charlie Hunt, TSF board member, went on to discuss volunteering opportunities with TSF, and Carolina Rodriguez, medical writer, talked about launching "Thalapedia."

Following a fantastic buffet lunch, at which people were able to mingle and talk with each other, the afternoon session began with an in-depth PowerPoint presentation by Dr. Elliott Vichinsky (Children's Oakland) on the new Standards of Care booklet published in 2009. Dr. Vichinsky provided valuable medical information to all, particularly making note of the recent advances in thalassemia care and treatment. His thorough and comprehensive presenta-

tion prompted a wide array of questions from members of the audience.

Shortly afterward was the open panel on psychosocial issues, moderated by Johnny Chou, MSW, from CHLA. This was a defining moment of the conference, in which attendees had the opportunity to candidly share their experiences with one another.

Patients were able to identify with one another and express their thoughts, frustrations, concerns, and happiness regarding their similar treks with thalassemia. Parents and friends of the patients also received words of advice and answers to their questions from those who have had longer experiences and ties with thalassemia patients. On the whole, the discussion brought the audience together, creating a close-knit support group that made a lasting impression on all.

In the afternoon, there were three breakout sessions—one for patients, one for parents, and one for spouses. These proved to be vital, because the level of understanding that is shared among those who are going through similar experiences is both informative and cathartic.

A children's program ran throughout the day for kids ages three and up. The children's program was carefully designed for children (with thalassemia or related to someone with thalassemia) to learn about the disorder and health in general at their developmental level.

Educational activities, games, and art projects were planned by thalassemia outreach coordinators Laurice Levine, MA, CCLS, and Eve Alley, MA, CCLS, and Child Life Specialist Rose Luna from CHLA.

The day came to an end with a reception, which included more delicious food and drinks, and a few words from TSF president Paul DiLorenzo.

"This conference is a central part of our mission to provide hope to the thalassemia community," Paul said. "It is our goal to continue to expand the conference and the number of people we help."

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 Board and the staff at CHLA for collaborating with us and putting on this conference and for their continued dedication to the thalassemia community.



President of TSF Paul DiLorenzo and TSF secretary Melissa DiLorenzo.



Makaela Dato decorating cupcakes at the Children's program.

Exjade ScriptAssist

Exjade ScriptAssist is a new program offered by Novartis Pharmaceuticals that may reduce your Exjade prescription copayments. The ScriptAssist program will run through May 31, 2010. If you are currently on Exjade, contact your specialty pharmacy to determine your eligibility for enrollment, or for more general information, contact EPASS at 1-888-90-EPASS (1-888-903-7277).