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.

April 21, 2007
Thalassemia Support Foundation, conference,
Beverly Hills

April 28-29, 2007
ICF Branch and District meeting, Healdsburg

May 4, 2007
8 a.m to 2 p.m.
7th Annual Blood and Bone Marrow Drive
in honor of International Thalassemia Day
Children's Hospital Oakland Outpatient Center basement
744 52nd Street, Oakland

May 5, 2007
Blood Centers of the Pacific Donor Recognition Brunch,
San Francisco

May 6, 2007
Come see "*The Iron Giant*" and support
the thalassemia program at
Children's Hospital Oakland.
Cerrito Speakeasy Theater
10070 San Pablo Avenue, El Cerrito, 94530
www.cerritospeakeasy.com
Admission is $8; Show starts at 2 p.m.

May 11, 2007
Inservice for the Perinatal Program at Asian Health Services

May 12, 2007
Children's Health and Safety Fair, Tracy

May 23, 2007
Cal State East Bay Healthfair, Hayward

May 24, 2007
Clinical Meeting on Pulmonary Hypertension
For more information, please contact Nancy Sweeters
at 510-428-4151.

June 3, 2007
CommUnity Resource Fair, San Jose, CA

June 6-10, 2007
Child Life Conference, Orlando, FL

June 10, 2007
Oakland Chinatown Lions Club Health Fair, Oakland, CA

September 1-2, 2007
ICF Annual Convention, Scottsdale, AZ

October 11, 2007
AN EVENING *under the stars*

The 2nd Annual Evening Under the Stars
at Chabot Space and Science Center
Time TBA.

Back by popular demand!

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

Address change requested

Children's Hospital & Research Center Oakland
Thalassemia Outreach

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.

CHILDREN'S HOSPITAL & RESEARCH CENTER OAKLAND

PERSPECTIVES

NEWSLETTER OF THE NORTHERN CALIFORNIA THALASSEMIA CENTER – SPRING 2007

PATIENT PERSPECTIVE

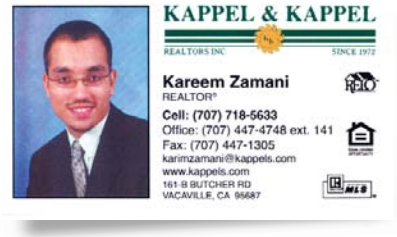
A Month of My Life

by Karim Zamani

Karim Zamani

Hi, my name is Karim, and I've been coming to Children's Hospital & Research Center Oakland for almost 10 years now—since I was 12 years old. I have beta thalassemia major, and I get blood transfusions every three weeks. Because of routine blood transfusions, thalassemia patients like me have too much iron in our bodies, and that's why we take Desferal. Desferal is a medicine that removes iron from the body.

The past few years have been tough for me because I haven't been compliant with my Desferal. I felt in top shape, physically fit, and I didn't want to take Desferal because I didn't feel like I needed it.



When you become sick with a cough or sore throat, you immediately want to cure it because it bothers you. Right? But I didn't feel any symptoms when I was becoming iron overloaded—until recently, when my heart started skipping beats. I told my doctors, and they said that it was critical that I do something about lowering my ferritin because it had (mysteriously) gone up to a very dangerous level of 7,600. I couldn't believe it, but I understood it was time for a major change to prevent my heart and my other organs from failing. How was I going to explain this to my parents, since I didn't want them to worry?

I did tell them, after my doctors suggested I come in to the hospital 48 hours a week to get intravenous Desferal. I did this for about four months, until my doctors informed me that 48 hours a week was not lowering my ferritin enough. Disappointed, I didn't know what was to come next. The doctors suggested being admitted to the hospital for one month to do Desferal intravenously for 24 hours a day.

I was shocked, but I agreed to their decision because I knew how important it was to take action right away. I really needed to get rid of all the excess iron that had been affecting my organs for so many years. I had one week of free time before I was admitted on February 1. I had a pretty flexible schedule for work because I am in real estate, so it was easy to get some time off. I said goodbye to friends and family and came to the hospital. I decided to get a PICC (peripherally inserted central catheter) so I wouldn't have to be stuck with needles all the time. I think that this was a great decision. The PICC procedure was very easy and painless, and it made it simple for my nurses to draw blood and administer Desferal through it.

The experience of being in the hospital for so long was terrible! Time went by slowly, and I gave up counting days. I would look at the clock and it would be 3 p.m. Two hours later, it was still 3 p.m.! I am ordinarily very active, but staying in the hospital for a month took away a lot of my energy, because I wasn't playing soccer or basketball, or running and jumping like I did at home. Even worse, now my appetite was gone, and hospital food was not my favorite. That's when my mom came to my rescue from our Vacaville home. For the last two weeks of my hospitalization, Mom stayed with me and got me back on my feet. I would take walks with her and she would cook food for me at Family House, which is where parents and families can stay while their kids are being hospitalized for long periods of time. Finally, toward the end, I was seeing better results. My ferritin had dropped to 3,400!

I was so happy when it was time to go home. I had missed my friends, family and work so much. But I'm also really happy I made the decision to stay in the hospital for a month, because I saw great results. Now I'm continuing my Desferal at home, and I totally appreciate it so much more.

This all taught me a lesson, and from now on, I will take care of my body. I want to thank God for this opportunity, care and health. I would also like to thank all my doctors, especially Dr. Vichinsky, Dr. Lal, Dr. Singer and Dr. Golden. I'd also like to thank Elmo and all my nurses and charge nurses; Ozetta and all my PCAs; Suzanne and Rachelle from Child Life; and all of the playroom volunteers. Special thanks also to Scott, Beth, Toshi and her assistant; Ellen Fung, Dru Foote, and Jean-Marie Knudsen; Pinocchio, G-sus, Ron, and Azim; Mom and Dad; and especially to Laurice and Matt for making my stay at Children's easy. Thank you! May peace be upon you all!

Diabetes and Thalassemia

by Laurice Levine, MA, CCLS, and Zahra Pakbaz, MD

Many individuals with thalassemia have diabetes or are at risk for getting diabetes. Diabetes is a chronic condition in which the pancreas no longer produces insulin, or the body is unable to use the insulin the pancreas makes. Insulin is a hormone that controls blood sugar. The consequences of insulin deficiency are that sugar—in the form of glucose—cannot enter and fuel the cells of the body and the cells become starved for energy.

Signs and symptoms of diabetes include extreme thirst, frequent urination, changes in appetite and weight, blurry vision, confusion and dizziness. If blood sugar is not controlled well, cardiovascular problems such as high blood pressure and hardening of the blood vessels may result. Kidney dysfunction, blindness, damage to the nervous system (neuropathy), and infection are also possible complications.

Good control of blood sugar can prevent these complications and enable a person to live an active and healthy life. As with any medical condition, treatment options for diabetes should be discussed with your medical provider.

Like thalassemia, diabetes can be high maintenance and require a lot of monitoring and adherence to a medical regiment. The following is a description of the three primary types of diabetes and the relationship between diabetes and thalassemia.

Pre-diabetes is a condition that occurs when a person's blood sugar is higher than normal, but not high enough to warrant a diagnosis of diabetes. This condition can be detected by a test called the Oral Glucose Tolerance Test (OGTT). There are 54 million Americans who have pre-diabetes, in addition to the 20.8 million people with diabetes.

Type I diabetes results when the pancreas does not produce insulin. This type of diabetes usually starts in childhood. It is estimated that 5 to 10 percent of Americans have type I diabetes. People with type I diabetes are insulin-dependent and have to inject themselves with insulin on a regular basis for life.

Type II diabetes, which is the most common form of diabetes, occurs when the pancreas does not produce enough insulin or the cells ignore the insulin that the pancreas is producing. Type II diabetes can be controlled by diet modifications, exercise, and anti-diabetic pills, although eventually insulin might be needed for optimum blood sugar control. There is an increasing incidence of type II diabetes appearing in childhood due to obesity.

Individuals with thalassemia are at high risk for diabetes if their iron overload is not controlled. Like every other organ in the body, the pancreas can be damaged by excess body iron. Additionally, liver damage from excess iron can also play a role in diabetes. Those who have a family history of diabetes might be at even higher risk of developing diabetes.

To prevent diabetes in individuals with thalassemia, a good adherence to chelation therapy—i.e., Desferal, Exjade, L1—is required. Starting at age 10, children with thalassemia should be screened for diabetes annually. If an OGTT is abnormal, intensive iron-chelation therapy may reverse the pre-diabetes state or prevent full-blown diabetes. If this is not done in a timely manner and the patient becomes diabetic, it is almost always irreversible.

Remember—good chelation therapy can help prevent diabetes in people with thalassemia!

American Diabetes Association
ATTN: National Call Center
1701 North Beauregard Street
Alexandria, VA 22311
1-800-DIABETES
www.diabetes.org

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Blood Centers of the Pacific — Radio interview and presentation on blood donation

ICF Br. 161, Larkspur

ICF Branch 343, Castro Valley

ICF Branch 11, Oakland

ICF Branch 351, Menlo Park

ICF Branch 27, Petaluma

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Debra and Taylor Purvis — Thank you for the donation of stuffed animals in honor of your beloved mother and grandmother, ICF's Marie Rose

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Mr. & Mrs. Nguyen

Sons of Sicily

HIGHLIGHTS

Happy 21st birthday, **Steven Srisavat**! And congratulations on your job, too!

India-U.S. Symposium

by Ashutosh Lal, MD

Children's Hospital's research institute collaborated with the Banaras Hindu University in India to hold the first Indo-U.S. Symposium on Genetic Disorders: Focus on Hemoglobinopathies, in Varanasi, India, from October 29 to 31, 2006. The Indo-U.S. Science and Technology Forum sponsored the symposium through a grant to **Bert Lubin, MD**, Children's senior vice president, research, and **Ashutosh Lal, MD**, a Children's physician and researcher. There were 104 participants from the United States, United Kingdom, Canada and India.

India has one of the world's largest populations of patients with genetic blood diseases. Nearly 10,000 children with severe thalassemia, and an equally large number of children with sickle-cell anemia or complex genetic disorders of hemoglobin, are born every year. Despite rapidly improving health care in the large urban centers in India, the availability of multi-specialty care for the several hundred thousand patients with serious inherited hemoglobin disorders remains fragmentary and inconsistent.

The scientific program addressed clinical and research highlights in thalassemia and sickle cell disease. Speaker topics included "*Clinical Issues in Thalassemia*" and "*Iron Overload, Chelation, and Economics of Thalassemia in India,*" which concentrated on the problem posed by having an enormous number of thalassemic individuals in India and an inadequate healthcare infrastructure. This session featured Children's **Titi Singer, MD**, and **Dru Foote, PNP**, as speakers.

Ms. S. Tuli, president of the Thalassemia International Federation (TIF), presented the perspective of the families and patients living with thalassemia in India. **Frans Kuypers, PhD**, and Dr. Lal, both from Children's, then discussed sickle cell disease, with input from Indian researchers on the epidemiology of this disorder in India. Several speakers presented advances in the genetics of thalassemia and stem cell therapy, including a talk by Children's **Carolyn Hoppe, MD**. Dr. Lubin described experiences with sibling umbilical cord blood banking and its potential as an important therapeutic option for treatment of thalassemia in India.

Two sessions aided in transforming this international symposium into a unique experience. The first was an interactive session between individuals with thalassemia and their families, and the clinicians from India and abroad. The thalassemia community asked numerous questions and raised multiple concerns about the current treatment practices in India. The stark medical inadequacies and the need for resources were brought home to the international attendees.

The second session was intended to produce an agenda to provide direction for improvement of the care of thalassemia patients in India and to identify chief areas for Indo-U.S. collaboration in basic science and clinical care.

The Indo-U.S. symposium on hemoglobin disorders marked the first collective and definitive effort to establish an infrastructure for dealing with the problem of hemoglobinopathies in India.

Thalassemia Outreach at the University of California, Santa Cruz

by Michelle Ma

Kappa Gamma Delta—what do those three words mean to you? Like many people, the words probably make you think of sorority girls, party nights, formal banquets and bake sales. However, Kappa Gamma Delta goes beyond being a social outlet; those three words represent aspirations of countless women who share the same hope and dream of one day becoming medical doctors.

Kappa Gamma Delta, as a premedical sorority, offers women a chance to be in an environment where they are encouraged and motivated by each other to succeed. As a member, I went out to seek potential ways we could expand our resources while simultaneously helping our community. That's when I met Laurice Levine from Children's Hospital & Research Center Oakland. Laurice gave me an opportunity to be an intern at the hospital and work with her in the Hematology/Oncology department. With her mentorship, as well as that of other friendly and helpful staff members, I was able to gain a lot of knowledge about thalassemia.

The more I found out about this illness, the more I realized how little about it was known to the general public. Since our sorority was hosting a women's health fair on February 14, we decided to educate our community by taking surveys, passing out literature, and informing the public about thalassemia. We hope that by taking small steps like this, our sorority, in conjunction with the thalassemia outreach program at Children's, can continue to heighten the general public's awareness of thalassemia.

Michelle Ma is a senior at U.C. Santa Cruz. Her major is Molecular, Cell and Development Biology with a minor in Chemistry. She is an active member of Kappa Gamma Delta.