CHILDREN'S HOSPITAL & RESEARCH CENTER OAKLAND

PERSPECTIVES

NEWSLETTER OF THE NORTHERN CALIFORNIA THALASSEMIA CENTER - SUMMER 2013

Project Thal

by Maggie Leinen

"Thalassemia is a genetic blood disorder that affects the production of the blood's hemoglobin." That was the standard answer I would give whenever someone asked me what thalassemia is. I have always aimed to become a physician when I am older and was interested when a friend of mine started working with thalassemia last year. I went with her to help at the thalassemia Valentine's Day party at Children's Hospital Oakland last year and had a great time. That was when I knew that I wanted to be involved with thalassemia.

When I started researching thalassemia, I was just trying to get a feel for the disease. I found an article, "Thalassemia: The Facts and the Controversies," that gave an overview about thalassemia and how it affects the families that carry the disease. The article gave descriptions of the different types of thalassemia and the treatments. It also discussed how the treatment not only affects the disease itself but also the lives of the people with the disease. The article gave me the base of information I needed to really start delving deeper into thalassemia. It familiarized me with the vocabulary associated with thalassemia and made me more comfortable researching it.

I didn't fully comprehend how affected the thalassemia community was by unawareness until I read an article about thalassemia patients' transition from childhood to adulthood. This article brought up the fact that while there are some pediatric thalassemia centers, there are no thalassemia treatment centers for adults in the United States. I was shocked to read this. How could there be no treatment centers for adults? The article went into detail about the issues that thalassemia patients have to deal with in adulthood, like finances, work, and treatment. It discussed the hardships that adults have to deal with during treatment because they can't do everything in one place anymore. It was this article that really gave me a purpose for my project. This was when I decided to focus on raising awareness.

Since thalassemia is most prominent in nations with high malaria rates, I wanted to research the global effect of thalassemia. I came across an article called, "The inherited diseases of hemoglobin are an emerging global health burden." I was intrigued by the title. This article got straight to the point of the huge issues that hemoglobin disorders touch on. It discussed how global health organizations have not done much to aid the growing population with inherited hemoglobin diseases. It discussed many things that could be done to help and explained that not a lot can be done without local governments' belief that the cause is important. The idea relates back to how significant awareness is. This was when I realized that my work went beyond some small project. I think that the United States, as a country, has a responsibility to reach out and help to encourage a global effort. For that to happen, the cause needs to be spread, and communities need to be educated.

After performing all of this research, and with the help of my mentor, Laurice Levine, I was ready to start educating in my community. My partner, Clara Knapp, and I started a project called Project Thal, which is centered on raising awareness in our community. We started giving presentations to grade schools and high schools in our area. The first talk I gave was at a school event for St. Eugene's, a local K–8 Catholic school in Santa Rosa, California. I am normally very nervous about speaking in front of crowds, and this time was no different, but I was able to talk with more ease than I normally can. I think that because this is something I feel so passionate about, I was able to forget about all of the people. I was surprised at how interested in thalassemia the kids were. They were very curious and asked a lot of questions. I don't know if it was the adrenaline from speaking in front of a school or just the project itself, but I felt amazing afterward—like I did something good for someone else.

Being my senior year, I have a case of "senior-itis" when it comes to school. Working with thalassemia gave me a purpose. It is something that fascinates me and doesn't feel like work. Project Thal has opened my eyes to the world around me and will make me a better worker in the future. It is my hope that I can help make a change in the thalassemia community like it has done for me.

Maggie Leinen is currently a senior at Cardinal Newman High School in Santa Rosa, California. After she graduates this May, she will be attending college at Baylor University in Waco, Texas. She plans on studying pre-medical and hopes to become a pathologist in the future.

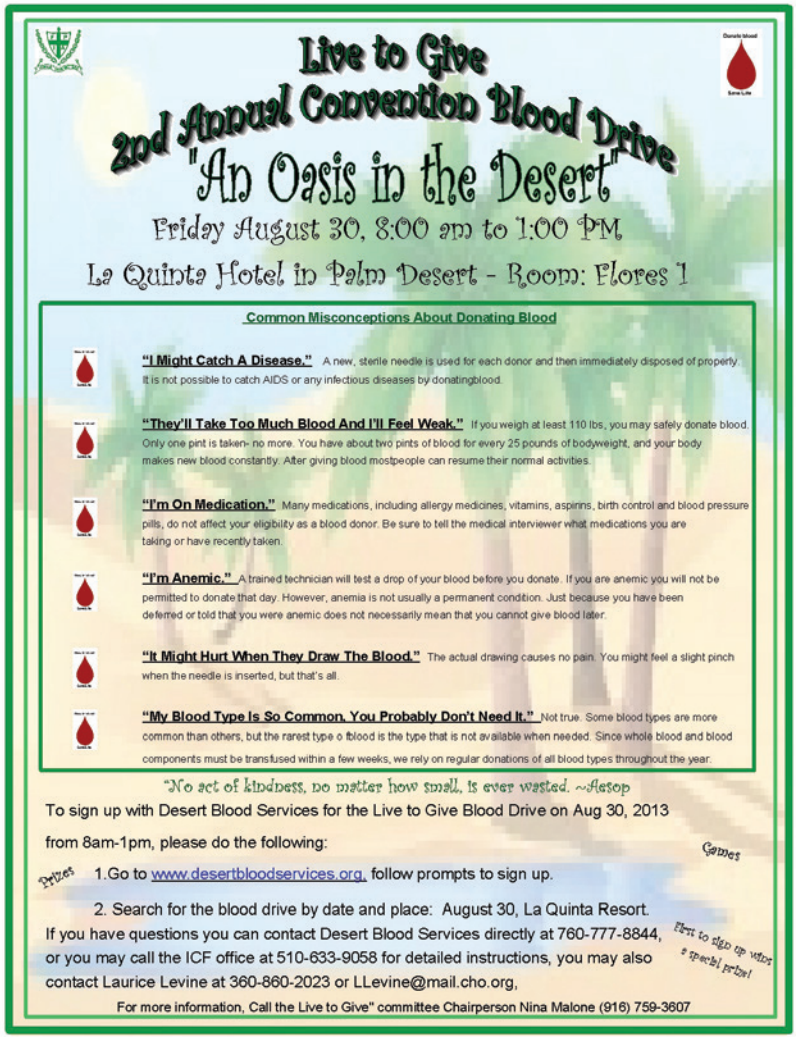
IN THIS ISSUE

OUR NEW AND IMPROVED WEBSITE IS NOW LIVE!

www.THALASSEMIA.com

- New look
- Updated information
- Improved psychosocial and resource section
- Patient stories
- Event calendar

Special thank you to Shanda Robertson for her work on the website.



Live to Give
2nd Annual Convention Blood Drive
"An Oasis in the Desert"

Friday August 30, 8:00 am to 1:00 PM

La Quinta Hotel in Palm Desert - Room: Flores 1

Common Misconceptions About Donating Blood

"I Might Catch A Disease." A new, sterile needle is used for each donor and then immediately disposed of properly. It is not possible to catch AIDS or any infectious diseases by donatingblood.

"They'll Take Too Much Blood And I'll Feel Weak." If you weigh at least 110 lbs, you may safely donate blood. Only one pint is taken- no more. You have about two pints of blood for every 25 pounds of bodyweight, and your body makes new blood constantly. After giving blood mostpeople can resume their normal activities.

"I'm On Medication." Many medications, including allergy medicines, vitamins, aspirins, birth control and blood pressure pills, do not affect your eligibility as a blood donor. Be sure to tell the medical interviewer what medications you are taking or have recently taken.

"I'm Anemic." A trained technician will test a drop of your blood before you donate. If you are anemic you will not be permitted to donate that day. However, anemia is not usually a permanent condition. Just because you have been deferred or told that you were anemic does not necessarily mean that you cannot give blood later.

"It Might Hurt When They Draw The Blood." The actual drawing causes no pain. You might feel a slight pinch when the needle is inserted, but that's all.

"My Blood Type Is So Common, You Probably Don't Need It." Not true. Some blood types are more common than others, but the rarest type o blood is the type that is not available when needed. Since whole blood and blood components must be transfused within a few weeks, we rely on regular donations of all blood types throughout the year.

"No act of kindness, no matter how small, is ever wasted. ~Aesop

To sign up with Desert Blood Services for the Live to Give Blood Drive on Aug 30, 2013 from 8am-1pm, please do the following:

Prizes Games

1. Go to www.desertbloodservices.org, follow prompts to sign up.

2. Search for the blood drive by date and place: August 30, La Quinta Resort.

If you have questions you can contact Desert Blood Services directly at 760-777-8844, or you may call the ICF office at 510-633-9058 for detailed instructions, you may also contact Laurice Levine at 360-860-2023 or LLevine@mail.cho.org,

First to sign up wins a special prize!

For more information, Call the Live to Give" committee Chairperson Nina Malone (916) 759-3607

CHILDREN'S THALASSEMIA DEPARTMENT IS LOOKING FOR:

- Volunteers for outreach office administration or events
- Writers for *Perspectives* and www.thalassemia.com. Have a story to share? Healthcare tips? We want to know!
- Fundraisers—we need to keep our program going! Please let us know if you want to help.

If you are interested, please contact Laurice Levine at LLevine@mail.cho.org or call 510-428-3885, ext. 5427.

Thalassemia International Federation (TIF)

Source: www.thalassaemia.org

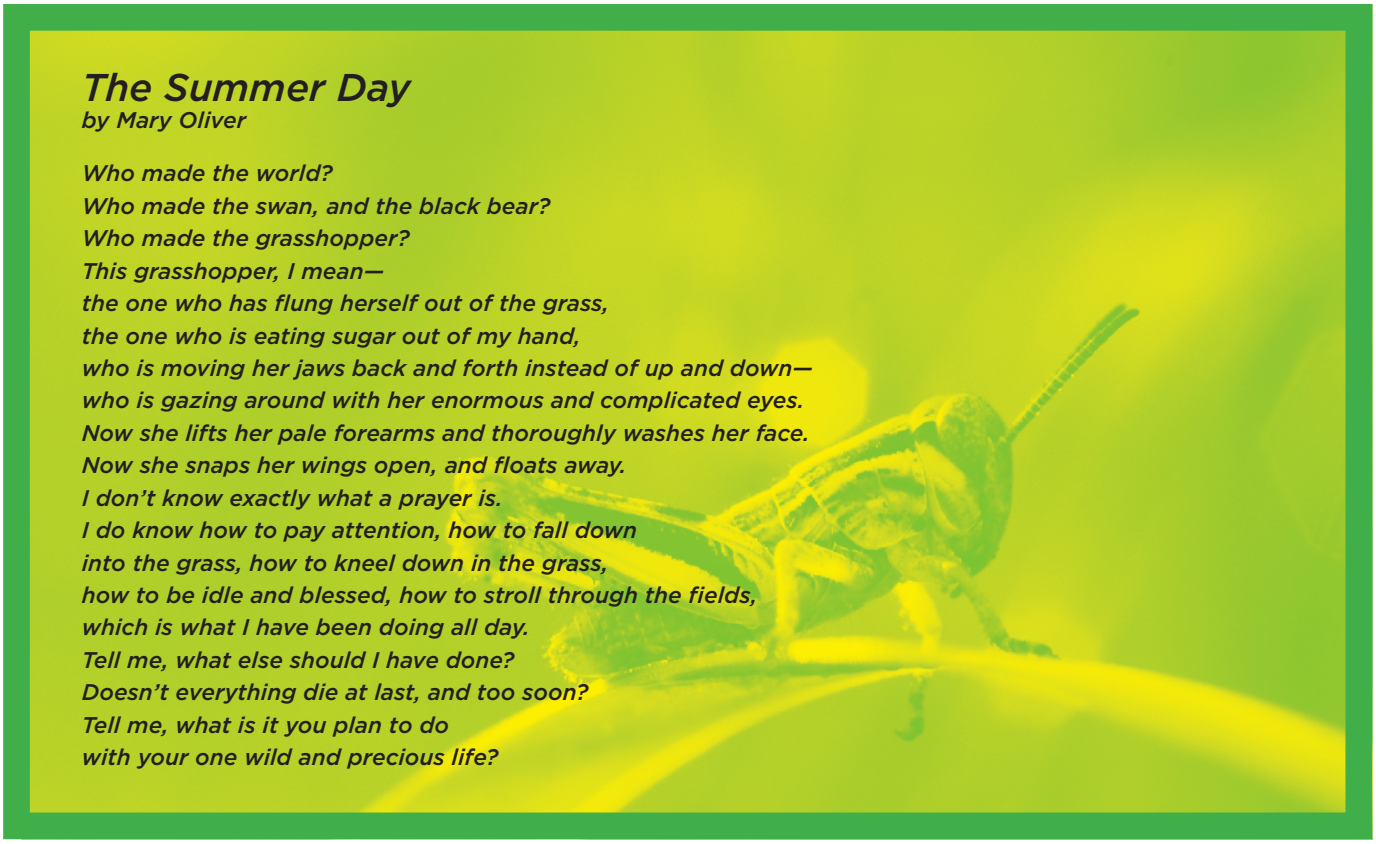
Our mission is the development and establishment of National Control Programmes [sic] for the prevention and quality treatment of thalassaemia [sic] and other haemoglobin [sic] disorders in every affected country and in particular where frequency, incidence and prevalence of these disorders are high.

Our vision is to ensure equal access to quality healthcare for every patient with thalassaemia and other haemoglobin disorders across the word.

We aim to:

- Promote awareness about thalassaemia, both its prevention, and its medical and other care.
- Cooperate with member associations, the medical community and health authorities in education, training, diagnosis and management of rare anaemias [sic].
- Promote and support studies and research for the continuous improvement of clinical care and prevention strategies and for achieving the total cure of thalassaemia.
- Identify experts and centres [sic] of expertise in thalassaemia and rare anaemias and create and consolidate global networks of experts and patients.
- Create internationally agreed guidelines for diagnosis and clinical management; develop quality and accreditation systems.
- Contribute to epidemiological surveillance, improve health information and create registries of thalassaemia.
- Disseminate the knowledge, experience and expertise gained from countries with successful control programmes to those in need.
- Situate thalassaemia and other Hb disorders in the wider context of rare diseases/chronic/genetic/non-communicable diseases.
- Promote haemoglobinopathies on national, regional, European and international health agendas, and
- Attain the right of every patient to equal access to quality medical care.

Contact/Subscribe to their newsletter/More information:
Thalassaemia International Federation
PO Box 28807, 2083 Nicosia, Cyprus
Phone: +357 22 319 129
www.thalassaemia.org.cy
Facebook: https://www.facebook.com/pages/Thalassaemia-International-Federation-TIF/430793140336625



The Summer Day

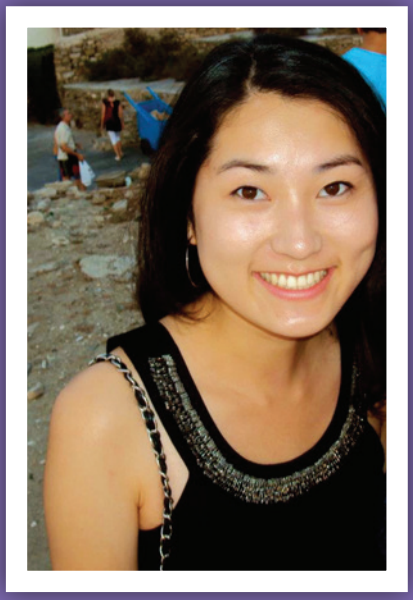
by Mary Oliver

Who made the world?
Who made the swan, and the black bear?
Who made the grasshopper?
This grasshopper, I mean—
the one who has flung herself out of the grass,
the one who is eating sugar out of my hand,
who is moving her jaws back and forth instead of up and down—
who is gazing around with her enormous and complicated eyes.
Now she lifts her pale forearms and thoroughly washes her face.
Now she snaps her wings open, and floats away.
I don't know exactly what a prayer is.
I do know how to pay attention, how to fall down
into the grass, how to kneel down in the grass,
how to be idle and blessed, how to stroll through the fields,
which is what I have been doing all day.
Tell me, what else should I have done?
Doesn't everything die at last, and too soon?
Tell me, what is it you plan to do
with your one wild and precious life?

VOLUNTEER'S PERSPECTIVE

Reach Out and Engage: Volunteering with the Thalassemia Outreach Team

by Wendi Gu



I still remember pulling my brand-new and incredibly oversized blue volunteer shirt for thalassemia outreach from the washer and dryer almost a year ago. It smelled like my favorite lavender detergent and was still warm from the drying cycle it had just been put through. It was the day of my first outreach event as a rookie thalassemia outreach team member, and on that summer day, I couldn't wait to drive through the Caldecott Tunnel from my small town of Lafayette to Oakland's Chinatown.

As I drove down to the annual Lion's Club Health Fair, organized for the Asian populations living in and around the city of Oakland, I recalled the moment, a month ago, when I received a call from Laurice Levine, coordinator of thalassemia outreach at Children's Hospital & Research Center Oakland welcoming me to the outreach team she had created recently to increase awareness of the genetic blood disorder in the San Francisco Bay Area. It was the end of my third year at UC Berkeley, summer was approaching fast, and I had been searching for a cause that I could become passionate about and dedicate myself to. Imagine my surprise and happiness when I heard the news that I would be joining five other Berkeley students and alumni on the team to inform the community about the existence of thalassemia, encourage people to get tested for the gene, and promote blood donations for patients who require chronic transfusions.

At the health fair, I joined my fellow team members, Sushrita Neogi and Jeff Nathan, ready for an entire afternoon of outreach. Being of Chinese descent, I naturally wanted to raise awareness in the Chinese populations, and I thought my knowledge of Mandarin would definitely come in handy when communicating with those in the Chinese community. However, I found it very difficult to explain all the medical symptoms and terms in Mandarin and was frustrated when I wasn't able to talk with the passersby who only understood or spoke Cantonese. Despite these little challenges, the conversations and interactions I had throughout the afternoon made all the frustrations disappear instantly. They opened my eyes to how many people were unaware of this condition—but they were willing to learn about it and pass on the information to their loved ones, inspiring and motivating me to dedicate even more effort to this cause and spread the word to as many communities as I can.

Since that first day, I have been doing outreach at other health fairs, cultural festivals, and blood drives, as well as on the UC Berkeley campus. Our team has even kickstarted a DeCal this spring—a student-run and student-taught class at Cal—titled Thal at Cal: Invisible No More, with the aim of inspiring passion for thalassemia outreach in our fellow students. I cannot put into words how much of an impact doing outreach for thalassemia and the Northern California Comprehensive Thalassemia Center has made on my life, and I am so grateful to be able to share this experience with six other equally caring and driven individuals. I am looking forward to setting and achieving new goals this year on spreading awareness and education about thalassemia. Go Team Thal!

Wendi Gu is currently finishing up her last year at UC Berkeley, pursuing a degree in molecular cell biology, with an emphasis on neurobiology, as well as a minor in Italian studies. She will be applying to medical school with the hope of one day becoming a pediatrician. She loves doing outreach and spreading the word about thalassemia with her team members at Children's and also loves volunteering with the Suitcase Clinic, an organization on the UC Berkeley campus dedicated to offering free health and social services to underserved and homeless populations in the Bay Area. In addition, Wendi is conducting research in a vision science lab that studies cataract formation in the eye and potential treatment options for this leading cause of blindness. When she is not knee-deep in schoolwork or extracurricular activities, she enjoys practicing yoga, rooting for the Los Angeles Lakers and Oklahoma City Thunder, learning new languages, being a foodie, spending time with friends, and traveling.

PATIENT'S PERSPECTIVE

The Thalassemia Support Foundation Conference—A Patient Perspective

by Perry Lai

Last October, I attended the Thalassemia Support Foundation (TSF) conference at Children's Hospital & Research Center Oakland. It was an enlightening and encouraging experience. I would like to share my perspective on the conference and its impact on me as a thalassemia patient.

TSF is a support group with the primary mission "to help improve the quality of life for all patients with thalassemia." TSF was founded by Paul DiLorenzo, an individual with Thalassemia, and his family. Paul organized and spoke at the conference. While there are several support groups dedicated to thalassemia in the country, as I learned, TSF is particularly active in California and on the West Coast. Prior to attending this conference, I was not aware that this organization, or any other thalassemia support group, existed, so my recognition that there are people and entire organizations to support the thalassemia experience was itself an eye-opener.

The primary focus of this conference was on health, best practices in daily life, and how patients can best take care of themselves. As important as updating patients on medical research and current standards of practice is, the emphasis on lifestyle and the personal concerns of everyday living is refreshing and useful. Topics included the importance of a holistic approach to treating thalassemia; changes that thalassemia patients can expect to experience through their lifespan; achieving balance in daily life; and nutritional and exercise tips specific to thalassemia. I found the information regarding the effects of tea and vitamin C on iron absorption very helpful, and I have started pairing tea with my meals while avoiding high–vitamin C and high-iron foods at the same time. Since attending the conference, I have also started exercising regularly (for cardiovascular and bone health, which are particularly important for thalassemia patients). This was something I had planned on doing anyway, but the information presented at the conference convinced me and gave me the push to actually do it. The presentations at the conference gave attendees a unique opportunity to learn from highly trained professionals in thalassemia, including world-class expert Dr. Elliott Vichinsky, and I certainly walked away feeling intellectually stimulated and excited about the many ways I can live a healthier life.

As the presentations fed my mind, the panel discussion on coping with thalassemia fed my heart. The panel members were all people living with thalassemia and included Paul, who is the president of TSF, as well as Children's own Laurice Levine. The panel members related their experiences growing up with thalassemia and how they continue to manage their lives as people with the disease. Most have experienced the trials of blood transfusions and the consequent chelation therapy for iron overload. Until the advent of Exjade, they endured countless needle-sticks and gave over innumerable hours to Desferal therapy. Some talked about feeling different than "the other kids" as children or being left out of activities due to the inability to keep up physically. Some also talked about suffering episodes of severe illness. One of the panel members related his perspective on being a father to a child with thalassemia, giving care to her while also coming to terms with the reality that she has to manage a chronic disease starting at such a young age.

While we understand that people with chronic diseases have experienced challenges, we may not anticipate the resiliency and strength forged by a lifetime of meeting those challenges. Such cases, related by the panel, are inspiring. Thuy, a teenager with thalassemia, developed a love for swimming and swims for her high school team despite not being able to keep up in PE in her earlier years. She also keeps a contagious smile on her face, as well as a sunny outlook on her future. Paul and Laurice have not allowed transfusions, chelation, and the vicissitudes of life to deter them from achieving great academic and professional success—both have earned graduate degrees and charted promising careers. Both have transcended their disease by dedicating themselves to improving life with thalassemia for the rest of us who have it. For Paul, this means his founding and running TSF; for Laurice, it is her work in research and education for Children's. Far beyond sharing a medical diagnosis, the members of this panel shared the experience of overcoming obstacles. They have embraced the challenges imposed by thalassemia, drawn lessons from their personal experiences, and applied the skills, strength, and wisdom found in those lessons to not only living healthier lives with thalassemia, but to life itself. Learning to work with needles and drugs, unpleasant as they may be, has become a skill of life. The attention and care given to one's own body have become the discipline needed to meet one's responsibilities. Health setbacks and disappointments have provided the training ground for cultivating tenacity and courage. Although I think of myself as fortunate for having a relatively mild form of thalassemia,

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PATIENT'S PERSPECTIVE

The Thalassemia Support Foundation Conference—A Patient Perspective

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the management of which is not nearly as intensive as that experienced by these panel members, I also believe that I have missed the opportunity to learn about myself in the reflection of thalassemia and to forge the kind of character that can only be achieved in the acceptance, and then transcendence, of disease. In my eyes, the panel members have accepted and transcended thalassemia, and I thank them for sharing their experiences and for their inspiration.

And I am inspired. The conference helped me make the decision to take better care of myself. Because I had not had direct or significant health problems since becoming an adult, I made the lazy assumption that my tussle with thalassemia was in the past and that I was not going to be affected in adulthood. After attending the conference and reading the literature I received, I now realize that I do have a higher risk for infections, blood clots, tissue damage from iron overload, osteoporosis, and even low testosterone. Fortunately, many of these risks can be managed with simple lifestyle practices, including exercise, diet and smart supplementation, daily aspirin, and extra vigilance to avoid getting sick. Iron overload is a problem that requires treatment by a physician, however, and attending the conference motivated me to finally start taking care of this problem after several years of moderately elevated iron levels. Even though I had not developed obvious signs of damage from excess iron, it is undeniable that simply waiting was not an optimal course of action, so I sought treatment from a hematologist in my city. Although my treatment has seen setbacks, in that it has not worked for me so far, I have learned much from this experience. I have learned that doctors—even specialists—are not always knowledgeable about thalassemia, and that we need to take responsibility for the management of our own care. We can be the bridge between the doctors who care for us where we live and the experts at Children's Hospital. Indeed, the issue of transition of care affects many adult patients and was another topic informatively discussed at the TSF conference.

Although my iron level is still high, I am not discouraged. I continue to be buoyed by the success of fellow thalassemia patients like Thuy, Paul, and Laurice and by the dedication and compassion in medical providers like Dr. Vichinsky and Nurse Practitioner Dru Haines, whose full support I know I have as I seek further treatment. It is a great relief to know that a smooth transition to adult care is possible and that the wonderful staff in the hematology clinic is committed to sharing knowledge and coordinating care with other doctors, in addition to conducting research and generating advances in practice. Irrespective of geography or age, the highest standard of care is available to us all. That is a powerful realization!

I feel lucky that I made the decision to attend the TSF conference. Not only did I learn useful tips and new findings on thalassemia, I met many extraordinary people, most of whom have thalassemia! They inspired me to take better care of myself and thus live more fully. It is interesting how life unfolds. A day spent with Paul and TSF has turned into something more—a new journey that is meaningful and hopeful. Should you have a chance to attend such a conference in the future, or to simply acquaint yourself with TSF, I encourage you to indulge in your curiosity and discover something new about thalassemia—and maybe even yourself.

STAFF UPDATE: **Welcome, Wendy Murphy!**

My name is Wendy Murphy, and I am a licensed clinical social worker who joined the thalassemia team in August 2012 after spending six years in the Oncology and Neuro-Oncology Department at Children's Hospital & Research Center Oakland. I was honored to be offered the social worker position in thalassemia.

I grew up in San Francisco but left the Bay Area for college and graduate school. I attended the University of Michigan for a graduate degree in social work. As a child, I always wanted to be a teacher, but after volunteering in college with programs to help pregnant teens and women in prison, I decided that my passion is social work. After completing my MSW, I returned to the Bay Area and worked in foster care— residential and day treatment programs for emotionally challenged children—before coming to Children's.

I really enjoy working with the patients and staff at Children's. My goal is to help thalassemia patients live a healthy life and address whatever issues may be impeding their care, whether it is to find stable housing or assistance with a bill. I also want to encourage patients to take advantage of opportunities like the Painted Turtle Camp and CoachArt.

When I am not at the hospital, I am busy with my family. I have two sons, ages 12 and 15. We love doing outdoor activities, especially camping, whenever possible. It has been a pleasure getting to know all the patients, and I am looking forward to working with you in the future.

wemurphy@mail.cho.org
510-428-3268

The Magic of Camp!

by Rosalyn Skelton

Everyone deserves to experience the magic of camp. But what about children who need special medical attention in order to be away from home? That is where a place called The Painted Turtle comes in.

The Painted Turtle is a medical specialty camp that provides a year-round, life-changing environment and authentic camp experience for children with serious medical conditions. As a member of the Serious Fun Children's Network, an international family of camps founded by Paul Newman, it is the only camp of its kind in California, serving children across the state with a variety of serious illnesses. The best part is that it is free! There is no billing department—campers and their families will always attend camp free of charge.

Located in the hills just north of Los Angeles, The Painted Turtle hosts eight week-long summer camp sessions and eleven family weekend programs for over 2,500 children, ages 7 to 16. In addition, The Painted Turtle reaches another 2,000 children each year in hospitals across California through its hospital outreach program, The Painted Turtle Outpost.

With the on-site support of some of California's top pediatric medical professionals and a state-of-the-art medical facility, The Painted Turtle's adaptive programming makes it possible for children with serious medical conditions to enjoy traditional summer camp activities such as fishing, boating, horseback riding, archery, high ropes, arts and crafts, woodshop, and much more. Through these programs, campers gain self-confidence and independence and form a community of friends with other children who face similar medical challenges, helping them to realize that they are not alone in their illnesses. Each session is medical-condition specific. Throughout the year, The Painted Turtle welcomes children with over 30 different illnesses.

Medical conditions served at The Painted Turtle this year include: cerebral palsy, spina bifida, kidney disease and transplant, liver disease and transplant, primary immunodeficiency diseases, rheumatic diseases, skeletal dysplasia (dwarfism), hemophilia, thalassemia, inflammatory bowel diseases, neuromuscular disorders, genetic and metabolic conditions, and many more.

To learn more about The Painted Turtle and how to apply, please contact Camper Admissions Manager Rosalyn Skelton at 661-724-1768, x 203, or visit our website at www.thepaintedturtle.org.

Camp magic awaits!

Rosalyn Skelton
Camper Admissions and Database Manager
The Painted Turtle
17000 Elizabeth Lake Rd.
P.O. Box 455
Lake Hughes, CA 93532
Phone: 661-724-1768, x 203
Fax: 661-724-1566
Email: rosalyns@thepaintedturtle.org

UPCOMING EVENTS

Dates subject to change and events are added frequently. For the most current updates please refer to our website.

JUNE

June 9: Oakland Chinatown Health fair, Oakland CA.

June 18: Thalassemia presentation to ICF Branch 61, Larkspur, CA.

June 23: 2nd Annual Let's Get Healthy Health fair sponsored by GILEAD Community Health and Co-Hosted by the VACCEB (Vietnamese American Community Center of the East Bay); Alameda County Public Health Dept. Oakland CA

June 28-30: Cooley's Anemia Foundation 2013 Patient-Family Conference; Philadelphia, PA. For more information: www.thalassemia.org

JULY

July 29 – Aug. 3: Painted Turtle Camp for children with Thalassemia, Hemophilia, other blood disorders, Lake Hughes, CA.

AUGUST

Aug. 28-29- Sept. 2: Italian Catholic Federation 86th Annual Convention, Palm Springs, CA.

Aug. 30: "Live to Give" Blood Drive sponsored by Children's Hospital Oakland, The ICF and Desert Blood Services.

SEPTEMBER

Sept. 15: 5thAnnual Health and Wellness Fair: "Your Path to Wellness". Sponsored by theAlameda County Public Health Dept., Oakland, CA.

Sept. 27-29: San Genaro Italian Festival, Los Angeles, CA.

OCTOBER

October 20-13: 13th International Conference on Thalassaemia & Haemoglobinopathies and the 15th TIF International Conference for Patients & Parents, Abu Dhabi National Exhibition Centre, UAE. For more information and to apply for patient sponsorship: http://www.thalassaemia.org.cy/conferences/

NOVEMBER

Nov. 2: ICF Testimonial Dinner for Grand President Dianda, Location TBA.

DECEMBER

Dec. TBA: Thalassemia Holiday Party, Oakland, CA.

Dec. 7-10: American Society of Hematology (ASH) Annual Meeting and Exposition, New Orleans, LA.

My Incredible Journey to Raise Awareness

by Andrew Shieh

Before I joined the thalassemia outreach team at Children's Hospital & Research Center Oakland in May 2012, I had never heard of thalassemia. After doing my own research online prior to my interview with Laurice Levine, I became motivated to unravel this genetic disorder even further. It wasn't until after my initial meeting that I realized what a great opportunity this was for me to immerse myself in projects dedicated to raising awareness of this disorder. I contemplated how I could contribute to expanding our opportunities for outreach in the Bay Area. A week later, I received a packet of primary literature and pamphlets about thalassemia in the mail from Laurice and proceeded to educate myself through background literature. Little did I know that my journey had only begun.

My immediate involvement with the outreach team began when I reviewed the plethora of literature and proceeded to organize all the material in a concise and presentable manner for the rest of the team, including myself. I will be honest: it was an arduous task, simply because there was a lot of information. It wasn't long before I realized that thalassemia is not merely a disorder—it creates a lifestyle composed of biological, social, and psychological elements. After two weeks of dedication, my project was complete. I constructed a poster that would follow the rest of the team to all future events. Aside from doing my own research to learn about the disease, I attended the Thalassemia Support Foundation conference at Children's in October 2012. This conference proved to be one of the most educational health conferences I have ever attended. The inspiring doctors, nutritionists, and patients shared insights unrivaled by any from reading research papers. The conference gave me new knowledge and stories to share at future events and has definitely shaped the trajectory of my involvement with this team.

As an ambitious outreach team member, I have strived to attend as many health fairs as I can to raise awareness in my community. One notable fair I attended was the 2012 Summer Health Fair hosted by the Vietnamese American Community Center of the East Bay. It was my first time presenting at a health fair, and I felt empowered to educate those of Vietnamese descent who had not heard of thalassemia before. Most people attended the fair for free health screenings and immunizations, so it felt rewarding to see people leave my display with smiles on their faces while holding the pamphlets and Band-Aids exhibited on my table. With the low prevalence of thalassemia in the Bay Area, it was especially gratifying to speak with individuals who knew thalassemia patients living in Vietnam. Another memorable health fair I attended was the USF Health Promotion Services Community Student Health Fair in March 2013. Among all the students and representatives from other organizations that I conversed with, five students identified themselves as carriers. In the Bay Area, approximately one out of eight people in the Asian community are carriers of thalassemia. Immediately, I felt that it was my responsibility to be proactive and encourage students who plan to have children to share that they have the trait with their future spouses. Outside of community wellness fairs, I have attended blood drives sponsored by Blood Centers of the Pacific and the American Red Cross both on and off the UC Berkeley campus. These events have given me an avenue to personally thank those who take time from their day to donate blood.

As a member of the thalassemia outreach team at Children's, my elation regarding our success cannot be expressed in words. We have managed to spread awareness beyond the community to a class of students at UC Berkeley. Currently, our class consists of ten dedicated students who are motivated to learn about thalassemia comprehensively and holistically. Instead of confining themselves to the classroom, the students have also become motivated to attend blood drives on campus to do outreach. A few students have also expressed great interest in joining members of the outreach team at future health fairs. Furthermore, the students are working closely with the entire team to coordinate a benefit concert in May 2013 at UC Berkeley to help raise awareness of thalassemia in the community. The students' eagerness to get involved with events in the community and the benefit concert is a testament to how much the outreach program has evolved.

While everyone on the team, including me, can attest to the fact that we have definitely met many goals and stretched our boundaries, we all still have goals we want to achieve. Personally, I would like the outreach program to have a chance to present at middle schools and high schools. Such an opportunity would not only be another avenue to raise awareness, but it would demonstrate to students in the community that what they learn in school is applicable to their futures. This would also allow the outreach team as a whole

to gain more exposure in the Bay Area. However, given that our current team is only a year young, I simply cannot ask for more. I have not only become an educator for my community, but a role model for children and students, reminding people to ignore stigmas and social barriers regarding chronic disorders. My accomplishments as an intern have certainly shaped me into the leader I am today. Words cannot express how grateful I am to be an intern for this program. I personally want to extend my thanks to everyone who has helped build the program into what it is today.

Originally from Cupertino, California, Andrew Shieh graduated from UC Berkeley in 2012 with a degree in Molecular and Cell Biology, concentrating in neurobiology. This summer, he hopes to ride some new roller coasters, learn new recipes, and go hiking weekly. Andrew enjoys playing and watching basketball, running, cooking, riding his longboard, and playing saxophone. As an undergraduate, he participated in numerous community service projects on campus, around the Bay Area, and even in Jamaica. Furthermore, he is passionate about teaching, which consequently has molded him into a mentor for his students. He also has extensive involvement in the medical field as a volunteer and a certified EMT. All of his previous experiences have helped him aspire to attend medical school in the future.

Necessities of Life—Blood and Ice Cream

by Sushrita Neogi

As we all know, ice cream is an essential part of life. To individuals with thalassemia, blood transfusions are another essential, lifesaving part of life. How are these two related, you ask? On January 30, 2013, the Thalassemia Outreach Department at Children's Hospital & Research Center Oakland (Children's) collaborated with Blood Centers of the Pacific (BCP) and a local Berkeley ice cream store called C.R.E.A.M (Cookies Rule Everything Around Me) to host a successful blood drive in honor of thalassemia.

Blood drives truly are very important for patients with thalassemia, because there really isn't a proper synthetic replacement for human blood. If kindhearted, socially conscious altruists did not take the time and effort out of their day to come and donate blood, people with thalassemia would not be able to receive their necessary, periodic blood transfusions.

We had over 20 such philanthropic individuals come to the bloodmobile, literally ready to roll up their sleeves and give the gift of life. There were medical and research staff from Children's and Children's Hospital Oakland Research Institute (CHORI), there were students from UC Berkeley, and there were members of the local Berkeley community.

However, despite so many individuals coming into the bloodmobile ready to donate, not everyone was able to actually donate due to height and weight restrictions, and more importantly, low iron levels. The level of iron required for a blood donor is slightly higher than average. Iron levels in our blood fluctuate and might be different on any given day, depending on the amount of iron we have recently consumed through diet and supplements. As such, temporary anemia, the leading cause of donors being turned down at this specific blood drive, can easily be reversed. Those who are not able to donate the first time around should not be disheartened. Consuming iron-rich meals in the days leading up to donating blood can raise their blood iron levels up to the proper range. Some foods that are high in iron include shellfish, fish, leafy green vegetables, strawberries, and tomato juice. To view a more comprehensive list, visit www.bloodcenters.org/docs/iron.pdf. Also, to learn more about the general requirements for blood donors, you can visit www.bloodcenters.org/blood-donation/am-i-eligible/.

Another vital key to the success of this blood drive, in addition to the wonderful donors, was the diligence of the blood-collecting team. These professionals were exemplary. Their skill at phlebotomy and their friendliness and upbeat spirits helped the entire day to run smoothly.

All in all, I must say that planning and executing my very first blood drive was a thrilling experience. The representatives from C.R.E.A.M and BCP, Gus Shamieh and Fred McFadden respectively, were stellar individuals to work with. Gus can be contacted at cream.gus@gmail.com, and Fred can be reached at FMcFadden@bloodcenters.org. And of course, the head of the thalassemia outreach team, Laurice Levine, is the best mentor for outreach and education involving this disorder.

The World Thalassemia Day Blood Drive is approaching on May 8 and will be located at Children's. Another thalassemia-centered blood drive is in the works for September 2013 at UC Berkeley! I can't stress the importance of blood donation enough. Without donors, the blood supply in hospitals would dwindle, and those suffering from traumas, those undergoing surgeries, and those with chronic diseases that require blood transfusions, such as sickle cell disease and thalassemia, would be completely lost. Next time you hear about a blood drive, please think about taking part and donating. The world always needs more lifesavers.

Despite all your efforts, if you are not physically able to give blood but have the desire to contribute nonetheless, another aspect of blood donation to consider is hosting. We are always looking for individuals and companies to host blood drives and help by recruiting donors from among their family, friends, neighbors, and coworkers. If you are interested in organizing a blood drive, please feel free to contact us at LLevine@mail.cho.org for more information.

A Decade of SQUID

by Marcela Weyhmiller, PhD

For the past 10 years, the SQUID-ferritometer, or just "SQUID," has been an important part of care for the Thlassemia community at Children's Hospital Oakland. Quick, painless and, we admit, a little weird, SQUID is an instrument dedicated to the measurement of iron concentration in the liver and spleen. Children's's SQUID remains the only site in the United States (and one of four in the world) to perform the measurement clinically. We are fortunate to offer our patients access to this technique! In the last decade over 2400 clinical and research scans have been performed in Oakland. The switch to data from the SQUID by our clinical teams has greatly reduced the need to perform liver biopsies and has been an important tool to monitor iron chelation therapy. This great accomplishment could not have been possible without the teams of people who have supported the technology for the last 10 years, the patients who have been involved in SQUID research studies and the Children's staff who have been dedicated to providing SQUID assessments for our patients.

Debut of the SQUID in December 2002.

Drs. Harmatz and Fischer demonstrate the SQUID.

The SQUID Technology

SQUID is an acronym that stands for Superconducting QUantum Interference Device and refers to the super sensitive magnetic detector at the heart of the measurement. The technique works because of the principle of electromagnetic induction—the same concept behind those forever shake flashlights and the alternator in your car. The slow, downward movement of a patient lying on a bed induces a voltage proportional to the concentration of iron in the liver. The more iron, the higher the voltage.

The Patients

Patient participation in SQUID based research laid the foundation for SQUID to be used as a clinical measurement for hundreds of other patients. In 2004, 4 patients with thalassemia, 5 with sickle cell disease and 3 healthy controls flew from Oakland to Torino, Italy and Hamburg, Germany to be assessed by the SQUID instruments housed there. The "SQUID Calibration Study" was necessary to make sure that all the machines came up with the same result. From 2003 – 2007 several of you volunteered to have a biopsy along with your SQUID in order to make sure that the SQUID was giving an accurate result. Additionally, your participation has helped bring new chelators to market and establish the efficacy of combination chelation.

The People

So many people have played a role in the SQUID program during the last 10 years—here I highlight only a few. Drs. Paul Harmatz and Elliott Vichinsky initiated the momentum to bring the SQUID to Oakland. Together with Dr. Roland Fischer they lead the teams to set up the technology. Tristan Technologies (San Diego, Calif.) built the SQUID and have continued to be involved in keeping it running the over the years. Before the SQUID was sent to Oakland, three patients, Huythong, Nguyen, Laurice Levine and Sierra Randall travelled to San Diego to be the first patients measured to calibrate the machine.

Many individuals and organizations, such as the Italian Catholic Federation, Cooley's Anemia Foundation, and the Kalmoanovitz Foundation were involved in raising the money to purchase the SQUID and the building to house it. Children's's Biomed department, especially Kevin Lautenschlager, have been devoted to keeping the SQUID filled with liquid helium each week. Ellen Fung, Lisa Calvelli, Zahra Pakbaz, Matt Hertz, Catherine Gariepy and me, Marcela Weyhmiller, have worked to establish the SQUID program, help it grow and perform the countless tasks needed to provide SQUID assessments for our patients.

Ellen and Lisa shared their perspective as part of the original SQUID team and what the technique has meant to patient care. Lisa states, "I was thrilled to learn there were only four of these machines in the world and I would be a part of a new team at Children's Hospital, Oakland involved in starting up the program.

Zahra, Ellen and Lisa in 2004.

I remembered hearing how much easier this would make life for our patients, who would no longer need a liver biopsy." Ellen, who no longer works directly with the SQUID program, was working at the Children's Hospital of Philadelphia the first time she heard about "ferritometry." She met Dr. Harmatz at a meeting and she thought he was talking about measuring ferrets!

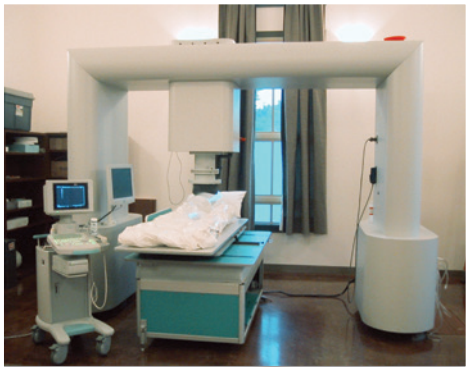
Both Lisa and Ellen agree that the SQUID has made a huge impact on the quality of care for our patients. Ellen recalls that "10 years ago Children's really pushed liver biopsies, knowing that serum ferritin was such a poor indicator of total body iron burden. Although many of our younger patients never had to be subjected to a biopsy, the parents and adult patients know that a non invasive procedure is always welcome over an invasive one." Lisa added that "SQUID is easy to schedule at their convenience, pretty much anyone can do it, as often as every 6 months, so it can really monitor change. You don't need to wait 1-2 years for your next liver biopsy to find out how you are doing with your chelation!!!"

"Being able to follow the same group of wonderful patients over the last ten years" is one of the best parts of the job for Lisa. She states that "watching them grow up, go through awkward teen years and mature into fine adults, trying their best to live healthy, normal lives is very inspirational." Ellen has maintained her connections with patients over the last decade when they come for their DXA scans and states that her relationship to the patients "feels like a family." Although I have only worked as the SQUID Program Coordinator for a year and a half—I totally agree.

Do you have a SQUID story that you would like to share? We would love to hear it! Please share them by emailing Marcela at mweyhmiller@mail.cho.org

SQUID BY THE NUMBERS

2460+	Research and clinical SQUID measurements performed
800+	Number of people who have had a SQUID at Oakland
1 y 11 months	Age of youngest patient measured
87	Age of oldest patient measured
3	Number of SQUID detectors. For each scan three measurements are taken
-321° F	Temperature of liquid helium that keeps the SQUID magnets superconducting
31,200	Approximate number of liters of liquid helium used to cool down the SQUID over the last decade
900,000	Number of 9" helium balloon that could have been filled with that helium or about 45 Macy's day parade balloons
8,075	Miles largest distance traveled for a SQUID
37° C	Temperature of water inside the SQUID



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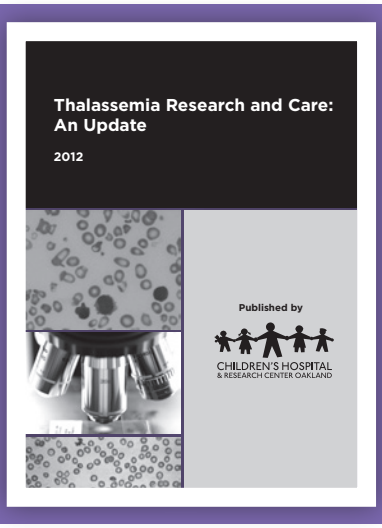

Thalassemia Standards of Care, Third Edition, 2012
Research and Care—An Update

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Perspectives is produced by Thalassemia Outreach Coordinator Laurice Levine, MA, CCLS, 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. If you no longer wish to receive *Perspectives,* please email Laurice at llevine@mail.cho.org.