

On behalf of Dr. Vichinsky and the Thalassemia Team, we wish you all a happy, healthy, and prosperous New Year!



PERSPECTIVES

NEWSLETTER OF THE NORTHERN CALIFORNIA THALASSEMIA CENTER - WINTER 2014

2013—A Year in Review: Thalassemia Outreach Highlights

2013 ICF Convention

The 82nd Annual Italian Catholic Federation convention was held in La Quinta, California (near Palm Springs), over Labor Day weekend. The blazing heat and humidity did not stop the fun events which kicked off Thursday night. Friday morning marked the second annual blood drive in honor of thalassemia, planned by the ICF's Live To Give Committee. Twenty-six people came ready to donate lifesaving blood, and 23 units were collected by the Desert Blood Services.

On Sunday morning, the ICF once again chose Cooley's anemia (thalassemia) as its national charity, and Grand President Jane Dianda presented Dr. Elliott Vichinsky and Laurice Levine with a check for \$68,000. Life Member Emeritus Nettie Descalco-Del Nero (pictured bottom right) presented an additional \$10,000, which she secured from the Kemp Trust. The \$78,000 will go a long way toward thalassemia research and patient programs, and we are eternally grateful to the ICF for its continued support.

Laurice presented outgoing Grand President Dianda with a plaque thanking her for her years of friendship and dedication to the thalassemia program, as well as a poster commemorating the Live to Give Committee that she began two years prior with the vision of providing more support to people with thalassemia while raising awareness of the importance of donating blood.

We would like to thank the ICF again for its immense generosity, dedication, and friendship.

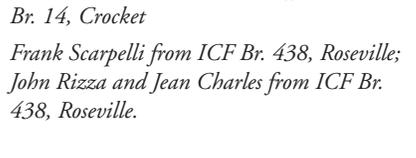
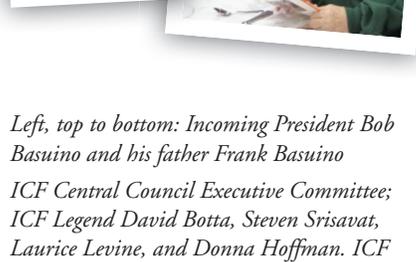
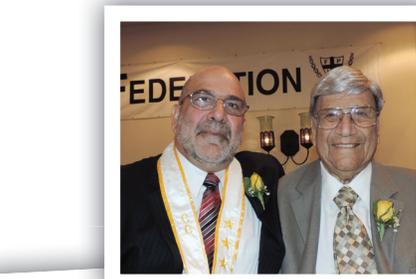
For more information on the ICF visit www.ICF.org or call 510-633-9058.

Right, top to bottom: Karen Rosson, Laurice Levine, and Dante Gallezzi, ICF Br. 390, Tracy.

ICF Live to Give Committee: Jim Acitelli, Nina Maline, Laurice Levine, and Lisa Crudo—with Dr. Vichinsky at the ICF Convention.

Outgoing President, Jane Dianda, received a plaque and heart poster from Laurice Levine. ICF Convention 2013, Palm Springs.

Laurice Levine, Nettie Descalco-Del Nero, and Dr. Vichinsky.



Left, top to bottom: Incoming President Bob Basuino and his father Frank Basuino

ICF Central Council Executive Committee; ICF Legend David Botta, Steven Srisavat, Laurice Levine, and Donna Hoffman. ICF Br. 14, Crocket

Frank Scarpelli from ICF Br. 438, Roseville; John Rizza and Jean Charles from ICF Br. 438, Roseville.

IN THIS ISSUE

Page 1: 2013 ICF Convention

Page 2: Blood Centers of the Pacific/Phi Delta Epsilon Thalassemia Blood Drive

Page 2: Rammeet Kaur Makes a Wish

Page 3: Walk with a Doc

Page 3: How to Find Trustworthy Health Information on the Internet

Page 4: An Interview with Chandan Das

Page 5: UC Berkeley Thalassemia Internship Program

Page 7: PHRESH Project Looks at the Impact of Thalassemia in California

Page 7: Upcoming Events

Page 8: Italian Young Adults: Honoring Past Traditions While Creating Their Own

Page 9: Iron Absorption Research Study

Page 9: Medic Alert Foundation

Page 10: Patient Care Perspective

Page 11: Holiday Party 2013

Page 12: Announcements

BLOOD CENTERS OF THE PACIFIC/PHI DELTA EPSILON THALASSEMIA BLOOD DRIVE—OCT. 8, 2013

by Rosheen Birdie

It is simply an amazing experience when students, community members, and service workers come together to organize an event that enriches the lives of so many in our community! On October 8, 2013, interns with the Thalassemia Outreach Program at Children's Hospital & Research Center Oakland worked alongside blood donation services workers from Blood Centers of the Pacific and members of the University of California, Berkeley, premedical fraternity, Phi Delta Epsilon, to run a blood drive on the UC Berkeley campus.

The drive attracted nearly 50 participants, of which 39 were able to successfully give the gift of life. Participants included Berkeley community members, as well as students from all backgrounds. For some, it was their first time donating, and the experience was made all the more meaningful when they were informed of the many ways that their blood would help those in need. Thalassemia interns Leslie Yeh, Wendi Gu, and Rosheen Birdie worked hard at preparing giveaways with essential thalassemia informational packets, as well as sweets, to keep the donors' glucose levels in check. Fred McFadden from Blood Centers of the Pacific worked closely with the students to design and distribute publicity materials and organize the logistics of the event. The event truly benefitted from teamwork as Melanie Wathugala, president of Phi Delta Epsilon, and numerous fraternity members were able to meticulously guide people through the process of registering and completing their



Blood drops and volunteers save lives.

paperwork prior to donating. The blood drive ran for a full five hours, from 10 a.m. until the last donor was accepted at 3 p.m. All in all, the day was a rousing success.

When blood is broken down into its components (red cells, platelets, and plasma), each unit has the potential to touch three different lives, which means that the generosity of the blood donors will make a difference in the lives of 117 Bay Area patients! We look forward to putting together future drives in order to expand on this success and to continue to keep the community informed about the necessity of blood—especially to help those living with genetic blood disorders such as thalassemia.

Rammeet Kaur Makes a Wish

Rammeet Kaur went on a \$3,000 shopping spree, thanks to the Make A Wish Foundation. She went to Best Buy and purchased a MacBook Pro, an iPod touch, and a Photoshop downloader. Then she went to the Stoneridge Mall in Pleasanton to go clothes shopping and also got a bicycle. Rammeet quotes, "It was an awesome day... I had such a great time, and I felt like a princess." She would sincerely like to thank the people at the Make A Wish Foundation for their kindness and generosity.



Highlights from Rammeet's day.



Walk with a Doc

by Mint Bhetraratana

On Saturday, October 19, 80 members of the community came out to support Berkeley's First Walk with a Doc in San Pablo Park, a free event that aims to encourage individuals to be more physically active and healthy. Participants were able to converse with representatives from various health organizations such as Lifelong Medical Care, 10 x 10 Wellness for Alameda County, Covered California, Diabetes and Sports Health Camp, Northern California Gastroenterology Consultants (NCGC), Bay Area Longevity Community, and our own Thalassemia Outreach at Children's Hospital & Research Center Oakland in order to learn more about health and wellness initiatives in the community.

Participants were also able to get their blood pressure checked by Heart 2 Heart, eat healthy snacks provided by generous sponsors, and interact with any one of the three visiting doctors, including Dr. Janet Berreman, MD, MPH, the City of Berkeley's health officer; Dr. Phuoc Le, MD, MPH, assistant clinical professor of medicine and pediatrics at UCSF School of Medicine; and Dr. Mehra Hosseini, MD, a gastroenterologist at NCGC.

Participants described the event as a "relaxing and engaging opportunity to learn more about health" and enjoyed learning about



Left: A group of dedicated volunteers and walk with a Doc organizer Mint Bhetraratana (third from the right)

Below: Thal interns from UCB Caroline Levan, Andrew Shieh, and Edith Yuan.



the importance of physical activity and nutrition from Dr. Berreman's keynote speech. To conclude the day's activities, physicians and community members walked side-by-side along a two-mile route around the city, which is enough daily physical activity to help improve one's immune system, strengthen one's heart health, and reduce one's risk of diabetes and obesity.

It was a great learning experience for me to be able to put on the Walk with a Doc and humbling to know that there are so many in the community, including my mentor, Laurice Levine, who supported my efforts. This event could not have been possible without their support! If you are interested in helping to host Berkeley's next Walk with a Doc, please email Mint Bhetraratana at wwad.berkeley@gmail.com.

How to Find Trustworthy Health Information on the Internet

If you are going to utilize the Internet as a resource for health information, it is vital to use trustworthy websites. While there is a wealth of helpful information online, there is also an abundance of misinformation. When it comes to your own healthcare concerns, it is important to talk to your doctor before following online medical advice. Consider bringing information that you find online to your medical visit so you can discuss any questions you may have with your medical provider.

Below are some guidelines to finding trustworthy health information:

- The website gives contact information for the person or organization that is responsible for the site.
- The website provides information only—nothing is being advertised or sold.
- If the website asks for your personal information, it details what it will/will not do with this information.
- The health information is based on results from medical research backed up by references and has been approved by medical experts.
- The website gives the source of the health information.
- Information is up to date, legitimate, unbiased, and objective.
- When multiple websites contain similar information, it is more likely to be accurate.

RECOMMENDED WEBSITES:

www.medlineplus.gov

This website is run by the National Library of Medicine and offers a medical encyclopedia containing detailed information on medical conditions, prescription drugs and herbal remedies, and access to publications and article summaries via Medline.

www.cdc.gov

This website is run by the Centers for Disease Control and Prevention and offers information on health conditions, information and advice for people traveling to other countries, and public health concerns.

www.healthfinder.gov

This website is run by the Department of Health and Human Services and offers health tips, information on diseases and medical conditions, and links to assist people in finding health-care providers.

www.ajrq.gov

This website is run by the Agency for Healthcare Research and Quality and offers consumer guides to help people understand and choose high-quality health care, tips on optimizing your medical care visits, and information on patient safety.





An Interview with Chandan Das

Dr. Chandan Das is an adult with thalassemia and resides in Cuttack, India. He is a professor of English at a local university.

Q: How many people in India have thalassemia?

A: India's population in 2012 was 1.22 billion. As of 2008, an estimated 100,000 have thalassemia major.

Q: How have you seen care for the disease change over your lifetime?

A: For one, there are now two specialty centers in the state of Odisha, both in the city of Cuttack, which is where I live. These two centers, at the Red Cross Blood Bank and the SCB Medical College and Hospital, serve Odisha's population of 42.5 million. Also, all the major chelating agents are now available, and most of the important tests, such as serum ferritin, can be performed. Bone marrow transplants are now fairly common. Professional blood donation has long been banned and has been replaced by solely voluntary donation, providing safer blood. In addition, transfusions are now performed with universal safe practices, such as using disposable, presterilized syringes, needles, sets, and blood pouches. Component separators are available in Cuttack and Bhubaneswar, and leucocyte filters can be purchased from Delhi. As always, rigorous and mandatory screening of blood is a statutory practice.



Q: What is your current method of treatment?

A: I personally take the oral iron chelator Kelfer (deferiprone/L1) and two units of leucoreduced, saline-washed packed red cells with a leucocyte filter twice a month.

Q: What was your life like growing up with thalassemia?

A: Because antenatal diagnosis was not available in the 1960s, as it is now, my parents did not risk a second thalassemic birth but resolved to give the one child thus born all the love and care possible in this world. My crisis-ridden life, for whatever it is worth, was thus protected at every stage by a compassion and tenderness—especially from my mother—that I would call nothing less than divine.

Q: How did you cope with the challenges of the illness?

A: I suctioned strength from the far blue mountains and the whole human world; I coped in the way that anyone anywhere copes who marches to the beat of a different drummer.

Q: What hopes and dreams do you have now?

A: That in some way, I can recompense the world for what it has given me in the shape of so many who have done so much for me for no other reason than that they were of the religion of humanity.

POETRY BY CHANDAN DAS

There's a stillness in the air
That cannot be called into question.
The swells that run beneath it,
Like autumnal leaves skittering in a wind
seeking its destiny in the moss-covered
courtyard,
Underlying the torn clouds of memory
And the occasional, random dream,
Have long been there and will be for a
time—
Not ours to measure, yours or mine.

When the summer and the sky become one
And the hawk in gaunt majesty climbs the
air, its wings presaging rain,
And the forest breathes a tremulous
prayer to the heavens that both punish and
forgive,
It is time, perhaps, to look on tomorrow,
An uncertain flame that flickers as it shines.

When they say to me, you must be used to
the pain,
How can I tell them? You must face each
pain anew,
One more stranger to be met all over again,
To be sensed, felt, known, experienced, and
Made to feel at ease with the old
ceremonies,
Who will depart in his own time, no amount
of suggestion withstanding;
Such is the force of his presence,
To be borne until he wills it otherwise.
When they say to me, you must be used to
the pain,
I do not tell them.
Only when I have finished counting
The stars of the sky,
The waves of the sea.



INTERN UPDATE

UC Berkeley Thalassemia Internship Program

by Sushrita Neogi

The Thalassemia Outreach Program at Children's Hospital Oakland is always doing its best to increase thalassemia awareness across the country, but it takes more than one person to do the job. In May 2013, Laurice Levine and UCB graduate and intern Sushrita Neogi recruited 4 students and one recent graduate and began the UCB Thalassemia Outreach Internship Program. Now in its second year, the program comprises 13 extremely talented, diligent, and innovative interns. These individuals have taken on projects ranging from conducting outreach at health fairs and blood drives to collaborating with various foundations such as the Blood Centers of the Pacific and the Alta Bates Asian Outreach group. Five of the interns have also taken the initiative to teach a DeCal about thalassemia at UC Berkeley. A DeCal is a student-led undergraduate class; the interns create a syllabus, gather lecture materials, and recruit guest speakers.

The thal interns are some of the most hardworking volunteers! The following biographies and images will give you a chance to get to know them a little bit better.

NIGINA ALI is currently a fourth-year integrative biology major at UC Berkeley. After her undergraduate studies, she is planning to attend medical school. In her free time, she loves being with her three-year-old sister. She also enjoys the outdoors and playing a lot of sports when she has the time. She got involved in the Children's Hospital & Research Center Oakland thalassemia outreach program because her friend has thalassemia. Learning about the dangers of the illness made her want to get involved and spread awareness in any way that she could.



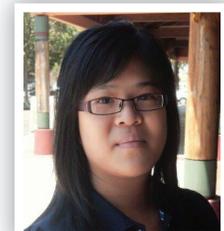
MINT BHETRARATANA graduated from UC Berkeley this past year with a B.A. in public health and integrative biology. While at UC Berkeley, she was involved in multiple community service groups, including Cal Habitat for Humanity, UNICEF at Cal, Supporting Peers in Laidback Listening (SPILL), and the YWCA's Pre-kindergarten Enrichment Program (PEP). She was also a teaching assistant for PH 116, an introductory public health course. She is currently studying for the MCAT—she hopes to attend medical school in 2015 and would like to pursue a dual MD/MPH degree. In 2014, Mint will work as a medical fellow at East Bay Ophthalmology under the mentorship of Dr. Scott Lee. Mint is excited to be joining the thalassemia outreach team and looks forward to working with Laurice Levine and her fellow interns. She hopes to help educate the general public about thalassemia, as well as increasing awareness about this genetic condition in local schools.



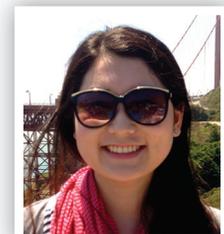
ROSHEEN BIRDIE is currently a junior at UC Berkeley majoring in molecular and cellular biology and public health. She is extremely interested in studying global health and health policy in order to better understand the broad divide in healthcare access and quality around the world. Due to her interest in healthcare advancement coupled with her understanding of the many diseases that afflict populations, she believes that her experience at CHRCO is an extremely valuable one. She has gained both knowledge about thalassemia and a better understanding of its prevalence and treatment techniques. This knowledge enables her to educate communities about the disease. She is very excited about this opportunity and is looking forward to the year ahead.



CHRISTINE DINH comes from a Vietnamese family in San Jose. Her recent studies at UC Berkeley earned her a B.A. in molecular and cell biology and a minor in music. She hopes to attend medical school in the near future and eventually pursue a career in pediatrics. As an intern, she facilitates a student-run class about thalassemia at UC, as well as doing outreach at local schools. In her spare time, Christine enjoys reading, listening to music, and arranging choral pieces.



WENDI GU graduated from UC Berkeley in May 2013 with a degree in neurobiology and a minor in Italian studies. During her time in college, she conducted research at the School of Optometry, volunteered at homeless clinics, and spent an entire semester studying abroad in Rome, soaking in the art, history, and culture of the Italians. Now that she has graduated, she is applying to medical school and working full time as an administrative assistant at One Medical Group, a series of primary care offices in San Francisco. However, she has not given up volunteering with the thalassemia outreach team due to her love for her fellow colleagues and also her desire to continue their success from the previous year. When she is not knee-deep in academics or extracurricular activities, Wendi likes to practice yoga, root for the Los Angeles Lakers and Oklahoma City Thunder, learn new languages, be a foodie, spend time with friends, and travel.



AMINA KHIMANI is currently a third-year student at UC Berkeley, double majoring in integrative biology and public health. This year will mark her second year as an intern for the thalassemia outreach



continued on page 6



INTERN UPDATE

UC Berkeley Thalassemia Internship Program continued from page 5

team and her second semester teaching a course titled “Thal at Cal” on UC Berkeley’s campus. When she is not spreading the word about thalassemia with her co-interns, she is volunteering at the on-campus clinic, the Tang Center, specifically in the optometry department. In addition, she is involved in international public health research on the correlation between pediatric malnutrition and oral hygiene, and she currently serves as philanthropy chair for UC Berkeley’s coed medical fraternity, Phi Delta Epsilon. In between all the academics and extracurricular activities, she loves running, dancing, playing/watching basketball, and traveling.

CAROLINE LEVAN is a second-year undergraduate student at UC Berkeley majoring in molecular and cell biology with an emphasis in genetics. She was first introduced to thalassemia at a UC expo for student-run classes (called DeCals) by last year’s amazing intern team. She knew next to nothing about thalassemia and gained insight into the diversity and complexity of this disease through taking the class. Caroline felt that she needed to put what she learned to good use by reaching out to others so she joined the thalassemia intern team. This fall, Caroline and fellow interns Christine, Andrew, and Amina will be facilitating the next DeCal. She is excited to see the growing popularity of the class and can’t wait to get started for the new semester. Aside from teaching the DeCal and performing outreach at health fairs and blood drives, she loves photography and graphic design, traveling, and baking.



SABA RAHMAN is a California-born and -raised Bangladeshi-American studying public health and neurobiology at UC Berkeley. She has aspired to be a doctor ever since she can remember and loves to participate in anything that makes her feel more involved in the field of medicine. Thalassemia caught her interest once she learned that the trait is spreading, yet people aren’t aware of the degree of prevalence. She wanted to take the upstream approach and participate in the thalassemia outreach program to spread awareness. During her free time, she enjoys watching her favorite TV shows, eating new foods, and meeting new people. Saba is always up for an adventure and loves to experience new aspects of life as much as she can.



ANDREW SHIEH graduated from UC Berkeley in May 2012 with a degree in molecular and cell biology. Since graduating, he has been actively involved with the thalassemia outreach team. His immediate contribution to the team was constructing a poster that is used in health fairs and blood drives. As an ambitious public speaker, he strives to attend as many health fairs as he can to raise awareness of the disorder in his community. In addition,



Andrew taught a DeCal class at UC Berkeley. Educating students about the biological, psychological, and social aspects of thalassemia has continued to motivate Andrew to learn even more about the disorder comprehensively and holistically. His accomplishments as an intern have shaped him into the leader he is today. Outside of reading literature on thalassemia, he can be found riding his longboard, playing basketball, and cooking.

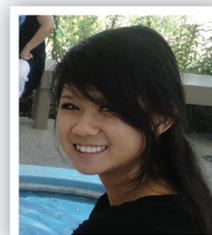
SHAGHIG TCHAPARIAN is a third-year UC Berkeley undergraduate majoring in nutritional science: physiology and metabolism. She recently joined the thalassemia outreach team as an intern, helping to spread the word and educate others about the blood disease. She has attended and will be attending blood drives and health fairs. The thalassemia program has helped her to understand the importance of educating people—once patients and others learn about the disease, they can take initiative to research more about it or to ask for help from their physicians. In addition, the program has offered her the full experience of working with others who are also dedicated to this project and with Laurice Levine, who she looks up to as an amazing role model. Shaghig hopes that this will be one of the best years for thalassemia outreach. During her free time, she likes to swim, run, draw, read, travel, cook, and come up with new healthy meals and recipes.



LESLIE YEH is in her third year at UC Berkeley. She is pursuing a degree in molecular cell biology with an emphasis in genetics and a minor in theatre, dance, and performance studies. She has enjoyed being able to gain so much knowledge about thalassemia while spreading awareness about the disorder throughout the Bay Area. Currently, she is working with other team members to teach a DeCal on thalassemia and to create literature for health fairs and blood drives. Through both, her team hopes to educate the public. In her free time, Leslie loves to sing and bake all types of desserts. She also teaches elementary school students music and hopes to be able to join Teach for America.



EDITH YUAN is a junior at UC Berkeley, studying molecular and cellular biology with an emphasis in neurobiology, as well as music. She loves being an intern for the thalassemia outreach team because it provides a myriad of perspectives in the medical field. She originally wanted to join because, as a regular volunteer for Children’s Hospital, she wanted to expand her experiences outside of the hospital walls and be part of a team that reaches out to the general public and attempts to make a difference through education.



PHRESH Project Looks at the Impact of Thalassemia in California

by Susan Paulukonis, MA, MPH, California PHRESH Project

Beginning in Fall 2012, the Centers for Disease Control and Prevention provided two years of funding to develop and share data about thalassemia in California. The project, titled Public Health, Research, Epidemiology, and Surveillance in Hemoglobinopathies (PHRESH) follows up on the earlier Registries and Surveillance for Hemoglobinopathies (RuSH) project, which used data from many sources to count those with thalassemias in the state. Surveillance in the project title refers to looking at a public health issues such as thalassemia over time to see if the impact of the condition, the type of care being delivered, and the quality of life and outcomes are changing.

PHRESH funding allows researchers to delve deeper into the collected data and determine its accuracy. Project staff will share the data with those living with the disorders and their families, healthcare providers, community-based organizations, and policy makers, as well as using it to continue to raise awareness of thalassemia in the state.

Among the types of information the project hopes to be able to publicize:

- How many people impacted by thalassemia (including alpha and beta thalassemia) are living in California? How old are they? What racial and ethnic groups are most affected? What types of insurance (private, government, self-pay) do these people have?
- What areas of the state are most impacted by thalassemia?
- What are the complications, procedures, and treatments most frequently associated with thalassemia, and when are they most likely to occur or be necessary in the lifespan? How do these differ between transfusion-dependent and non-transfusion-dependent individuals?

Partners in this work are Dr. Lisa Feuchtbaum at the California Department of Public Health's Genetic Disease Screening Program, Dr. Elliott Vichinsky of Children's Hospital & Research Center Oakland, and Dr. Tom Coates of Children's Hospital Los Angeles. In addition, Dr. Catherine Madigan at UC San Diego Rady Children's Hospital, Dr. Theodore Wun at UC Davis Medical Center, Dr. James Huang at UC San Francisco Children's Hospital, and Dr. Susan Claster at UC Irvine Medical Center are partners in the effort to determine the accuracy of the data. The project is set to conclude in September 2014.

For further information on the project, please contact:

Lisa Feuchtbaum at lisa.feuchtbaum@cdph.ca.gov.

UPCOMING EVENTS

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

JANUARY

January 28, 2014: ICF Br. 139 dinner/thalassemia presentation, Manteca, CA.

FEBRUARY

February 1, 2014: patient and family conference, Phoenix, AZ.

February 15, 2014: ICF Branch 52 Valentine's Day fundraiser benefitting thalassemia. Presentation and dinner, Healdsburg, CA.

MAY

May 3, 2014: thalassemia awareness concert, UC Berkeley, CA.

May 7, 2014: Blood drive in honor of World Thalassemia Day at Children's Oakland, Oakland, CA.

May 13, 2014: ICF Br. 14 dinner/thalassemia presentation, Crockett, CA.

May 16, 2014: "Evening under the star" benefitting thalassemia. Chabot Space and Science Center, Oakland, CA.

May 18, 2014, 8:30 a.m.: "A Root in the Boot" walk-a-thon benefitting thalassemia, Lafayette, CA. F or more information contact Chelsea Spencer at casp358@gmail.com

JUNE

June 14, 2014: World Blood Donor Day—this is a global celebration to raise awareness of the need for safe blood and to celebrate donors who give the gift of life. June 14 is also the birthday of Karl Landsteiner who won the Nobel prize for his discovery of the ABO blood group system. Sri Lanka is the host country for 2014.

JULY

July 28 – August 2: The Painted Turtle Camp Thalassemia/Hemophilia Week. To apply: www.thepaintedturtle.org.





Italian Young Adults: Honoring Past Traditions While Creating Their Own

by Chelsea Spencer

Oakland, CA—The Italian-American Federation (IAF) has been a part of the Oakland Italian-American community since 1935. At that time, there were several Italian-American clubs in the East Bay. Although the clubs progressed well individually, the leaders of these clubs felt that a federation would celebrate their shared heritage and gain recognition on a wider scale. Through the following decades, Italian Americans of great prominence and distinction have served as presidents of this federation. The members were the leaders of the Italian-American clubs in the East Bay.

Since 1935, a Columbus Day queen has been appointed to represent the clubs. In the early years of the federation, this queen was chosen by the number of raffle tickets sold in her name. The Columbus Day queen's coronation would be held every October and was viewed as an event of high prestige. Many parades and ceremonies were observed throughout the East Bay on the following day, thus concluding a joyous occasion, as well as a celebration of American and Italian heritage. However, in the present day, the queen is selected by a panel of

nonaffiliated judges based on multiple criteria. All prospective queens have to respond to a number of selected questions related to how they would conduct themselves if they were chosen.

In October 2011, Chelsea Spencer was honored to be chosen as 2012 queen for the IAF. Her main responsibilities were to represent the 13 Italian clubs in the East Bay and to attend their functions. In the past, this was the extent of a queen's participation, but as queen in 2012, Spencer chose to do more. She aspired to bring the Columbus Day Court, comprised of all the girls who ran for Columbus Day queen, together under a common goal. The intended result was to encourage young adults to involve themselves more in the clubs, and most importantly, to give back to the Oakland community where Italian-American ancestors originally established a new life for themselves. At the outset of her reign, Spencer organized a group brainstorming session with the princesses to decide what this common goal would be and how they were going to raise funds.

Thalassemia (Cooley's anemia) research at Children's Hospital & Research Center Oakland (Children's Hospital) was chosen as the charity that the Columbus Day Court would dedicate its free time to, and an initial goal was set. Thalassemia is a genetic blood disorder that can affect individuals of Mediterranean descent, such as Italians. The court more than doubled its original fundraising goal in 2012 and is close to surpassing its

2013 goal. The girls accomplished this by setting up and cleaning up for club events and waiting tables. Spencer also organized a small sponsored walk in 2012.

On Saturday, May 26, 2013, Spencer, in partnership with the Columbus Day Court, held the second annual "Root in the Boot's Fight Against Thalassemia" in another effort to raise funds and awareness for thalassemia research at Children's Hospital. The walk began at eight o'clock on a beautiful spring morning. Members of the 13 Italian-American clubs of the East Bay, as well as their families and friends, helped support 12 walkers at this year's event. The walkers completed the 2.7-mile course in a little under an hour and were motivated to cross the finish line strongly with energetic music. Everyone was then rewarded with donated goodie bags and recharged their batteries with homemade mini-muffins.

Each year, every walker is asked to contribute \$100 in sponsorships, with 100 percent of the proceeds going toward thalassemia research. This year, the group of walkers and club members was able to more than double last year's total contribution, raising \$2,800! Organizers are excited and hard at work on doubling the take for next year's event!

The Italian club presidents, officers, boards of directors, and members have all supported and embraced the goals and directives set forth by the courts. "I am humbled by the love and support of so many throughout the last few years. The goals we set and partnerships we developed with the 13 Italian clubs, along with the unconditional support of our families and friends, has truly been inspiring," says Spencer.

For more information, contact:
Chelsea Spencer
e-mail: casp358@gmail.com



Iron Absorption Research Study

by Monica Khurana

The purpose of this study is to determine if the body absorbs iron with the same or varied efficiencies when iron is in different chemical forms. Individuals with thalassemia who do not receive regular red blood cell transfusions absorb iron from food at very high rates, even to the point of iron overload and organ damage. This occurs because premature death of red blood cells results in oxygen-deficient tissues that signal the intestine to absorb more dietary iron, which is then delivered to the bone marrow to make more red blood cells with iron-rich hemoglobin.

By better understanding how the body absorbs iron specifically in individuals with thalassemia, we can better treat them and recommend dietary modifications that would decrease the risk for iron overload. Dietary iron has three chemical forms: (1) heme iron in meats; (2) ferritin iron in legumes; and (3) ferrous iron salts or chelates in fortified foods like cereals and breads. We know that patients at risk for iron overload should avoid red meats, but less is known about the iron from the other two sources. Commercially available iron supplements include ferritin iron, a natural

source from legumes or animal organs, and ferrous iron sulfate, which mimics iron in fortified foods. Previous research shows that although ferritin iron is absorbed slower than ferrous iron sulfate, both forms of iron reach the red blood cell precursor, which makes iron-rich hemoglobin, at the same time. By comparing ferritin iron and ferrous iron sulfate in this study, we will determine if these findings are also true in patients with thalassemia and if we should recommend changes in dietary legumes or foods derived from legumes.

We invite individuals of all ages with thalassemia who have a hemoglobin less than 9 g/dl, have not had a red blood cell transfusion in the past two months, and are able to swallow capsules to participate in this study. Individuals who are pregnant or have malabsorption/chronic diarrhea may not participate. Although participants need not live in Oakland to enroll, they must be able to come to Children's Hospital Oakland Pediatric Clinical Research Center for three visits during the next three to six months for blood draws. In addition to meals, we will provide compensation for your time and efforts. We look forward

to sharing the final results with you and anticipate that the results of this pilot study may serve as preliminary data to generate a larger randomized clinical trial.

We would like to thank in advance individuals who enroll in this study. Your willingness to participate enables us to learn more about iron absorption and improve care for all individuals with thalassemia.

For more information, please contact:

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MedicAlert Foundation

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Facts about MedicAlert

- MedicAlert Foundation is a 501(c)(3) nonprofit organization.
- MedicAlert received a grant to design a pet protection program in 2012—an emergency caregiver notification program to protect family pets.
- The IRS considers MedicAlert to be a “medical information plan,” and therefore, MedicAlert membership is tax deductible.
- MedicAlert membership qualifies as an expense that can be reimbursed under many flexible spending accounts (FSAs) and health savings accounts (HSAs).



Patient Care Perspective

by Shaida Samimi



For nearly two years, the Meena Health and Welfare Organization (MHW O) has devoted its energy to passionately advocating for the children of Afghanistan suffering from thalassemia. MHW O



is a non-governmental, nonprofit, self-governing organization established by the effort of the younger Afghan generation with the vision of making healthcare available for the children of Afghanistan who suffer with thalassemia. The organization provides family support and help to raise awareness of thalassemia. MHW O is one of the first established nonprofit organizations that provides basic thalassemia patient care needs.

MHW O was established in 2012 and located in Kabul, Afghanistan. Currently, the office is registered with the Ministry of Economy and Public Health in Afghanistan. The core mission of MHW O is to educate the public about thalassemia and its effect on society. Its focus is to provide treatment, find cures, and support the patients in every sector to enhance their quality of life.

Saqib Niazi is the founder of MHW O. Saqib's personal inspiration behind this cause was losing his beloved sister Meena after her fight with thalassemia ended at the age of 15 in 2008. Operating MHW O has enabled Saqib to try to fulfill his sister's last dying wish, which was to bring an end to thalassemia so other children don't suffer as she did from the age of three months. This is the sole rationale for why Saqib started his lifelong journey to help one child at a time to become thalassemia free. Saqib feels that he is very fortunate to be able to impact the lives of others, all while partnering with some of the most passionate and driven philanthropists on the globe.

Saqib hopes to spread global awareness of the horrible conditions that thalassemia patients suffer in Afghanistan. Afghanistan has been a war-ravaged country for over 30 years. All records that might put an exact number on how many Afghan children have thalassemia have been lost, destroyed, or misplaced. MHW O has between 500 and 600 patients registered with its office, and approximately 150 of the patients undergo

minor treatment on a weekly basis. There is no sustainable help, aid, or financial assistance for thalassemia from the government or the public in Afghanistan. Many rural areas lack education

regarding premarital blood testing to rule out the genetic disorder, and people continuously intermarry with relatives, which puts them at risk for thalassemia.

Financial challenges and burdens prevent MHW O from providing the necessary healthcare needs to help accommodate a larger pool of patients. Currently, there are thousands of innocent children suffering from thalassemia. Some are misdiagnosed, others who are diagnosed do not have the financial means to receive the necessary medical attention, and others are in need of a bone marrow transplant. Presently, there are no hospitals in Afghanistan that offer bone marrow transplants, because the country lacks proper healthcare professionals knowledgeable in the procedure, as well as medical equipment and proper facilities to proceed with these surgeries. Very few families who can afford the treatments will travel to neighboring countries such as Pakistan to obtain assistance for their sick children.

The condition of thalassemia patients in Afghanistan is so bad that left untreated, many patients won't see a birthday beyond the age of five. While life expectancy for thalassemia survivors in many developed countries is 60 years or older, in Afghanistan, it is currently the age of 15. Because Afghanistan is in a transition phase of rebuilding, its society does not have the financial means to make any philanthropic

contributions, and the government feels that it is not a major problem that requires its attention. On occasion, some individuals may volunteer to donate blood to help patients with the regular blood transfusions needed for survival—the only current form of assistance.

I urge all readers to take to their hearts the fact that many children are dying from thalassemia in Afghanistan on a daily basis. It costs less than \$3.00 a day to give them a chance for a normal life and a future beyond 15 years. Please visit the MHW O website to make your philanthropic contributions to a wonderful cause; your donations are the key to survival. Any educational courses, medical training, or equipment and necessary medication contributed towards MHW O will enhance the promise of a future for MHW O which will enable the organization to provide great care for the innocent and vulnerable children.

"Giving of any kind begins the process of change and moves us to remember that we are part of a much greater universe."

—Mbal Creazzo



Saqib Niazi, founder of the Meena Health Welfare Organization

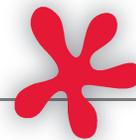
Shaida Samimi is an advocate for MHW O in Sacramento, California.

She may be reached by sending your e-mails to shaidasamimi@meenawelfare.org.

To contact Saqib Niazi, our founder, in Afghanistan, please e-mail him directly at saqibniazi@meenawelfare.org. You may also send questions or concerns to info@meenawelfare.org.

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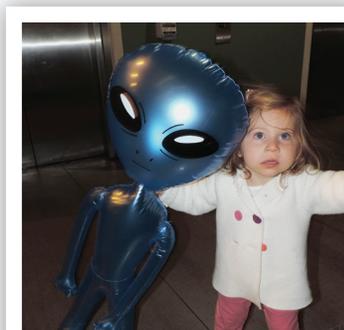


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Thank you to Straw Catering, San Francisco





PERSPECTIVES

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Perspectives is produced by Senior Thalassaemia Outreach Coordinator Laurice Levine, MA, CCLS, at Children's Hospital & Research Center Oakland. For questions regarding the newsletter or for more information on thalassaemia, call 510-428-3885, ext. 5427, or visit www.thalassaemia.com. If you no longer wish to receive *Perspectives*, please email Laurice at llevine@mail.cho.org.