

Love and Blood: Uncovering Thalassemia

by Rilee Hakola and Denise Corriveau

How is it that a majority of Americans have never heard of thalassemia, a chronic blood disorder, yet two million people in the United States carry the genetic trait for the disease? This fact will be the opening statement of our Community Based Service Learning (CBSL) project which we will present in May 2012. A CBSL project is designed to send students out into the community with the universal goal of improving our world.

Choosing a CBSL project takes much thought and consideration, because it not only affects our English and Religion grades, it is required to graduate from Cardinal Newman High School in Santa Rosa, California. We teamed up together in May 2011 due to our shared love of children and common interest in working in a hospital. Our first inclination had been to work with cancer patients, because cancer was a well-known disease and a noble cause, but after many failed attempts at the hospitals and organizations in our area, it became clear this was not our calling. Through the Italian Catholic Federation (ICF) branch in Healdsburg and our mentor, Julie Tomasin, we discovered thalassemia and began researching the details. It was not until our first tour of Children's Hospital & Research Center Oakland, and meeting Laurice Levine, that we wholeheartedly wanted to improve the lives of those with Thalassemia.

The name of our project is Love and Blood: Uncovering Thalassemia. We are targeting three main areas: fundraising, raising awareness, and most importantly, volunteering at the hospital.

Our first encounter with children who



Rilee Hakola and Denise Corriveau with Marine World raffle winners Rammeet and Amrit.

had thalassemia was at the Holiday party, which we helped Laurice plan and execute. Along with making a presentation to St. John's Elementary School, we ran a toy drive, collecting around 200 toys for the party, which was a great achievement. Prior to the event, we had expectations of what patients would be like but no personal experience to develop opinions, which contributed to an open mind. The party was hectic, bustling with volunteers, patients, and families, which aided our comfort level, but we did not develop the deep personal connections we were striving for. We instantly wanted to throw another party ourselves, but upon seeing all the hard work and time Laurice devoted to the Holiday party, we understood that it had to be on a much smaller scale.

Thus far, our Valentine's Day party has been our greatest achievement, smaller yet effective. It has been our first experience organizing something of importance instead of plainly helping someone else organize, which is normal growth for a CBSL project. We could never have imagined the preparation required to throw a party for approximately 35 guests. Our first step in the process was fundraising, which began at

Mary's Pizza Shack (www.maryspizzashack.com). They offered a percentage of earnings for our cause, so we asked all around and gathered a large group to enjoy pizza with us. After we gave a presentation, the student council at St. Rose Elementary School in Santa Rosa, California, generously donated to our Valentine's party, as well. With our funds, we purchased four tickets to Marine World as a raffle prize, flowerpots for decorating, and many other supplies to ensure that the party ran smoothly. We can still recall the names of the children who made an imprint on us personally and after that party, we truly appreciate that working with thalassemia was the right decision for CBSL.

We began our effort to spread awareness of thalassemia by going to our elementary schools, St. Rose and St. John's. We made multiple appearances with different age levels through St. John's, including fourth graders who made Valentine's Day cards for the children at that party. The St. Rose seventh graders spoke to Laurice virtually after our presentation by using Skype, allowing them to see and hear about thalassemia firsthand.

continued on page 2

IN THIS ISSUE

Page	
1	Love and Blood
2	"Live to Give" - ICF Organ donor program
3	Thank you, Volunteers and Donors
4	Painted Turtle Camp
4	Medic Alert
5	Thalassemia Awareness—A Volunteer's Experience
6	Staff Spotlight: Gabe Wong
6	ICF Highlights
7	Staff Update
7	Event Calendar

Love and Blood: Uncovering Thalassemia (continued from page 1)

We have publicized our project all around our high school, Cardinal Newman. We asked the students to bake sugar cookies that could be decorated at the Valentine's Party, hung flyers, and spoke in classrooms. The graphic design classes made Holiday cards for the Holiday party, and we bring along younger volunteers to events in hopes that they will take on our project and carry on our mission of service. The ICF's national charity is thalassemia, so we gave a speech during their Ravioli fundraiser (for thalassemia) concerning our project, spreading awareness not only to our generation, but to others', as well.

Every time we present our project, our audience is completely unaware of the effects of thalassemia. It is shocking to see the number of children and adults alike who are unaware of this disease, but we were in that same category until our project began. Before

Our naïve expectations of changing their lives were instantly demolished after our first engagement, when we knew they had touched our hearts more than we could ever touch theirs.

beginning our project, we were required to write out all our goals for the upcoming months. Now that we are over halfway done, we are amazed by not only the number of goals we have achieved, but also how much they have changed. Our goals adapted to the many things we learned during talks with the patients about their home lives, hearing the true details of thalassemia that research cannot capture. Prior to actually encountering the hospital experience and working with the children, our goals involved brightening their lives and making them happier but now have evolved into being good listeners and stable friends they can confide in. Our naïve expectations of changing their lives were instantly demolished after our first engagement, when we knew they had touched our hearts more than we

could ever touch theirs. Simple pleasures such as the balloons we use as decorations can fill them with such pure joy that it is impossible not to overlook their disease and view them as the kind, strong, and willful children they really are. We have long passed the 25 hours required for CBSL, but it is no longer just a project—it is a life-changing experience we are not ready to give up, which is why our future plans include volunteering in the hospital playroom. Love and Blood: Uncovering Thalassemia has not only helped us discover a disease in need of assistance but also to discover aspects of ourselves and the blessings in life only a thalassemia patient can show you.

Denise Corriveau and Rilee Hakola are both seniors at Cardinal Newman High School in Santa Rosa, California. Denise and Rilee both have plans to work in the medical field in the future that involve working in the medical field. Denise would like to become a pharmacist and Rilee would like to become a pediatric nurse. They enjoy every experience they have at the hospital and always look forward to coming back.

Italian Catholic Federation Update

“Live to Give” Breathes New Life into Organ Donor Program

by Michelle Feldman, Bollettino Editor, ICF

Italian Catholic Federation (ICF) Grand President Jane Dianda recently renamed and restarted the federation's Organ Donor Awareness Program under the name “Live to Give.” This isn't necessarily a new program to the ICF, but a restructuring of the committee formerly led by the late Past Grand President Richard Valli. Live to Give expands on Richard's mission, working to increase understanding and knowledge of not only organ and tissue donation, but also the bone marrow/stem cell registry and how to set up blood drives at local ICF branches and districts. Heading this committee is

Central Council Life Member Nina Malone. Serving on the committee are Al Teglia, Past Grand President and Central Council Life Member Emeritus; Lisa Crudo, Member-at-Large from Branch 343 Castro Valley; and Laurice Levine, Thalassemia Outreach Coordinator for Children's Hospital & Research Center Oakland. One goal of the committee is to set up a Live to Give branch program in 2012 and find eager and willing members to serve as branch chairpersons for the committee.

There are three ways to start living out the mission of this new committee: (1) sign-up to be an organ and tissue

donor; (2) donate blood; and (3) register as a stem cell donor. Being a blood donor can directly help Cooley's anemia/thalassemia patients. Becoming an organ and tissue donor is as easy as registering with the DMV and placing the sticker on your driver's license. One donor can give life to eight people and enhance the lives of up to 50 more. As of right now, the Live to Give committee is also exploring options with stem cell registration, specifically to benefit thalassemia patients. Stay tuned for more information.

Many thanks to our volunteers and donors (holiday party and beyond) for their hard work, generosity, and support!

Volunteers

The Titan Group:

Jessica Ancheta
Jackie Callo
Gracel Catacutan
Kevin Chow
Jerry Comyn
Chelsea Cunningham
Randy Duran
Sharmeen Fatehi
Ned Gorges
Kevin Haskell
Pedro Lepe
Marcia Loeffler
Ron Manuel
Sherry McClure
Heather McGuire
Mildred McKinney
Tisha Rosenbaum
Elizabeth Taylor
Veronica Viera
Riane Welch

Tammy Buntman
Denise Corriveau
Rilee Hakola
Kelsey Honeychurch
Shani Litwin
Sushrita Neogi
Zoe Oppenheim
Ivanna Pincilotti
Maansi Shah
Ashley Steward

Special Thanks to our Vendors and Entertainment

Braxton Boxes Desserts
Mavericks Catering
DJ Mark Chicoin
Gotta Sing Performers

Special Thanks to Children's Hospital Staff

Mary Lekich, Volunteer Department
Steven Srisavat, Thalassemia
Outreach
Gabe Wong, Thalassemia Social
Worker

Special Thanks To Our Donors

Charles Abela
Anonymous member of ICF Br. 227
Rose and Don Arnaudo
Bob Basuino
Donald & Helen Bonnel
Marlene Farber
Darlene Fitzgerald
Genworth Financial
Italian Catholic Federation—
members and branches
Jelly Belly
Jim & Janice Jones
Charlene Kramer
Joseph & Jo Macaluso
Mary's Pizza Shack
Ivanna Pincilotti
Rosa Radicchi
Terry Rosser and Project Linus
Mike and Marcie Rossi
Gerald Salsbury
Sonoma State Student California
Teacher's Association, Sonoma
Chapter
Mary Sperrazzo
The Titan Group
Richard and Valerie Vote



The Titan Group



*Jessica Ancheta and Santa's helper
decorate cookies.*



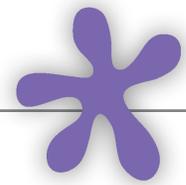
*The ICF makes the
holidays merrier.*



Gotta Sing Performers



Rockin' at the holiday party.



PATIENT'S PERSPECTIVE

The Painted Turtle Camp

by Thuy Carpenter

My name is Thuy Carpenter. I am an ordinary 16-year-old girl who has been going to the Painted Turtle Camp for two years, and I really enjoy it. I have a disease called thalassemia. Thalassemia is a blood disorder that makes an abnormal form of hemoglobin (I lose energy). I'm really the only one in my family who has it, because I was adopted from Vietnam by an American family, and I love them very much. But on with my fantastic story about the Painted Turtle.

I never knew anything about this camp until Gabe Wong told me about it, and it sounded so interesting that I tried it for my first time in 2009. I wanted to try it because I thought that it would be fun to go and meet new people that have my disease and other diseases, too. My mom and dad decided to fly me down to L.A. and have me meet with my driver to take me to Lake Hughes, where the campground is. There were other people that flew in, as well, and instantly, I made friends with them. When I finally got to the campground about an hour or two

later, everyone was welcoming, and they all made me smile. I knew immediately that it was going to be a fun week at this camp.

After we all introduced each other, we split up into boys and girls and went to our cabins. Each cabin had a name that we got to make up. The campground was amazing, and the cabins were really nice. There were probably about 10 cabins, and each cabin had 10 beds in it. There were two bunk beds and four solo (single) beds. We were all split in to age groups. The youngest would go to Yellow cabins 1 to 4, ages 7 to 9 went to Red cabins 1 to 4, and ages 10 to 15 went to Blue cabins 1 to 4. I went to cabin Blue 3, because I was the oldest—when you're in Blue 3 and 4, you get to do fun stuff at night when everyone goes to bed. The night events are really fun to do with your cabin mates and the other cabins, as well.

For breakfast, lunch, and dinner, we would all eat at our cabin table in



the Dining Hall, and each cabin would chant its chant in there. The activities we did, such as, boating, fishing, horseback riding, high ropes, swimming, and many more, were fantastic and fun.

At lunchtime, we would all rush to the dining hall and start eating. Then after that, we

would clean and dance. Next, we got in a circle and gave awards for the people who just poked themselves for the first time. The award was a little stick with great designs that were designed by the older kids, and you sat in a chair, and the older boys pushed you around the circle and had everyone give you a high five. It was awesome to watch little kids be so happy after they poked themselves for the first time!

I had a really great time at the camp. Since I'm too old to attend as a camper, this coming year, I will train to be a counselor there. It is an absolutely great camp to send your kids to. They would have a lot of fun and make tons of friends—everyone makes it fun for you. It would be a great summer week for your kids to enjoy before school starts. I hope you send them there, and I hope they love it!



MedicAlert—Be Prepared

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Reference: MedicAlert Magazine and website, 2011-2012



VOLUNTEER'S PERSPECTIVE

Thalassemia Awareness— A Rewarding Volunteer Experience

by Sushrita Neogi

Thalassemia is a genetic blood disorder with which patients cannot make a normal form of hemoglobin. Over the years, being a pre-med student and having an ardent interest in biology—especially biology pertaining to the human body—I had read about thalassemia in textbooks, but my knowledge had never gone further than the aforementioned concise definition. I knew about the physical and biological conditions of the disease to some extent, although it is usually overshadowed in books by other blood disorders, such as sickle cell disease and hemophilia, but I hadn't really considered it on a community or global level. That changed this previous summer. I was working in the Ames Lab at Children's Hospital Oakland Research Institute (CHORI) when my primary investigator (PI), Dr. Ash Lal, introduced me to Laurice Levine, the thalassemia outreach coordinator at Children's Hospital & Research Center Oakland (Children's).

Together with Laurice and other veteran spokespeople for thalassemia, Mr. Vijay Talwar and his son Sid, I spent a weekend in August setting up a booth at the Festival of India (FIA) and talking to the multitude of people at the fair about the disorder. I had been surprised to learn myself that thalassemia is especially common among the South and Southeast Asian communities. Some of the visitors to our booth had heard about thalassemia before, and some even had friends or family who were affected by it, but the vast majority of people were completely unaware of the disease. Among these people, there was a wide range of interest. Some had come to our booth because they or their children wanted the free merchandise we were handing out. Others saw the Children's sign and wondered whether we were providing health testing services. And yet others only wanted directions. Most of these latter people were not the least bit interested in hearing about thalassemia. However,

for every unresponsive visitor, there was another who made my volunteering experience more positive. Such people were eager to learn and receptive to the information we provided. Some were even generous enough to offer on-the-spot donations. Informing the heavily Indian crowds at the FIA of the prevalence of thalassemia in their community and urging them to seek testing for the gene was a simultaneously exhausting and rewarding experience. Throughout the weekend, Laurice and the Talwars were at my side, inspiring me with their desire to spread the word and their dedication to the cause.

My next events were at two local Bengali events—the Pashchimi and Prabasi Durga Pujas. Both were solo events where I had to handle the crowds on my own. It was nerve-racking at first, knowing that if there were questions I couldn't answer, there was no one to refer the visitors to. I also wondered if I'd be able to generate much interest in the booth. However, both events went off smoothly, and my apprehension proved to be unfounded. What surprised me most during both these events was the number of people who had encountered thalassemia before, whether at a personal level or via distant acquaintances. It really brought home to me the reason why it's so important to raise awareness—while these people usually knew someone with thalassemia and knew the consequences of being a patient, they were curious about how the disease actually arose in the body, and most did not know that it is passed on genetically. I feel that it is really important to make the genetic component of thalassemia known to more people so they can prepare themselves better.

I realized that if I wanted to raise awareness on a more widespread scale the first steps would be to recruit more



volunteers to help me and to build partnerships with organizations that have goals and ideas similar to ours. Thus I opened up a dialogue with the HepB Project, a student-run group at the University of California, Berkeley, that raises awareness and provides vaccinations for Hepatitis B. I also found another volunteer, Maansi Shah, a recent Berkeley grad, to work with me in widening our sphere of outreach. Our first event together was a health fair at a local Thai temple. In addition to talking to the public at the health fair, we were able to make many connections with other groups who work in outreach. We met many health professionals and volunteers there who have goals similar to ours: raising awareness about particular diseases.

I look forward to increasing our numbers in spreading the word about thalassemia and to building a support system in the health awareness community. Despite utilizing dedicated personnel, the thalassemia outreach program at Children's is small. We have a lot of work in front of us, and I don't expect to put an end to thalassemia. But I would be glad if I could just make a small impact on this seemingly gigantic mission and hopefully touch a few individual lives in the process.



STAFF SPOTLIGHT

Gabe Wong: Thalassemia Social Worker

My name is Gabe Wong, and I am the social worker for the thalassemia program at Children's Hospital & Research Center Oakland (Children's). I was born in Hong Kong and spent my childhood and young adult years in Canada. While living in Toronto, Ontario, I earned my BA in Political Science and was gearing up for law school when my volunteer and personal pursuits directed me toward a career in social work. After earning my MSW, I worked as a child abuse investigator for two years in Canada before moving to the Bay Area to work as a case manager for children with developmental disabilities at the East Bay Regional Center.

I have been working as a medical social worker at Children's since 2005,

and I also worked for Kaiser Permanente. My passion for social work is founded on my desire to advocate for and serve those who are facing adversity and to help empower them toward positive change and self-fulfillment. I particularly enjoy working with the thalassemia patient population, and I truly relish my diverse roles, including supportive counseling, referrals for practical resources (food, shelter, or transportation), and advocacy for financial needs (resolving medical insurance or billing issues), educational needs (Individualized Education Plans and 504 plans to prevent academic penalty due to health status), and legal matters (immigration, housing, or custody issues). Recently, I have been working alongside Laurice Levine in

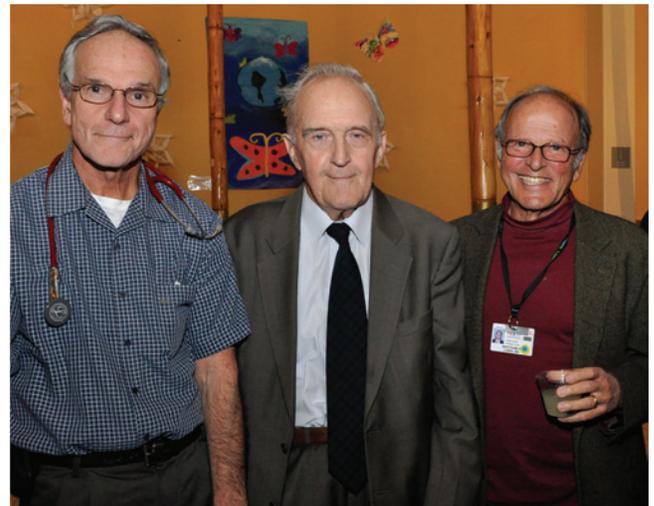


the thalassemia outreach program at Children's.

In my spare time, I enjoy playing and teaching piano, volunteering at a homeless mission in downtown San Francisco, and participating in outdoor sports, including backpacking and marathon running.

OUTREACH HIGHLIGHTS

Sir David Weatherall visits Children's



Clockwise: Dr. Weatherall with the Thalassemia Team: (l-r) Ash Lal, MD; Gabe Wong, MSW; Dru Haines, PNP; Sir David Weatherall, MD; Donna Edwards, LVN; Elliott Vichinsky, MD; Laurice Levine, MA, CCLS

Dr. Weatherall with Elliott Vichinsky, MD, and Bertram Lubin, MD, Children's Hospital's President & CEO.

The Maimonides Award is presented to Sir David Weatherall, MD, for International Achievement In Science, Medicine and Ethics, on November 10, 2011 at Children's Hospital & Research Center Oakland.

STAFF UPDATE A Familiar Face Joins the Thalassemia Team

Joining the thalassemia team this past fall was Steven Srisavat. He has been a long-time volunteer in the outreach program and is now employed in the Hematology Department as a general clerk, primarily helping in the thalassemia outreach program. Steven is instrumental to everything outreach, from assisting with events to developing literature and educational materials, and, of course, providing peer support. Welcome, Steven!



*ICF Branch 285
President Gail Rocca and
Steven Srisavat at the
February 18 Bingo Bash
for Thalassemia.*



UPCOMING EVENTS

MARCH

March 8, 2012: Thalassemia workshop for providers (in collaboration with the Community Health Interventions and Sickle Cell Agency—includes outreach to local churches and 6 hour training workshop), Charlotte, NC

March 9, 2012: “An Evening of Information and Outreach” for people with thalassemia, Charlotte, NC

March 15, 2012: ICF Branch 390 Dinner Meeting/Thalassemia Presentation, Tracy, CA

March 17, 2012: ICF Branch 218 Dinner Meeting/Thalassemia Presentation, Arcadia, CA

March 18, 2012: Thalassemia Support Foundation Meeting, Burbank, CA

March 19, 2012: ICF Branch 352 Dinner Meeting/Thalassemia Presentation, Danville, CA

March 20, 2012: ICF Branch 61 Meeting/Thalassemia Presentation, Larkspur, CA

March 21, 2012: ICF Branch 214 Dinner Meeting/Thalassemia Presentation, Concord, CA

APRIL

April 12, 2012: ICF Branch 395 Dinner Meeting/Thalassemia Presentation, Stockton, CA

April 12, 2012: Thalassemia Inservice for Asian Community Health Group, Alta Bates Summit Medical Center, Oakland, CA

April 16, 2012: ICF Branch 52 Dinner Meeting/Thalassemia Presentation, Gilroy, CA

MAY

May 6, 2012: ICF Branch 261 Dinner Meeting/Thalassemia Presentation, San Diego, CA

May 8, 2012: WORLD THALASSEMIA DAY!

May 8, 2012: ICF Branch 17 Dinner Meeting/Thalassemia Presentation, Crockett, CA

May 9, 2012: 11th Annual Thalassemia Blood Drive, in collaboration with Blood Centers of the Pacific, Oakland, CA

May 10, 2012: ICF Branch 343 Dinner Meeting/Thalassemia Presentation, Castro Valley, CA

May 19, 2012: Annual Mark Santos Motorcycle Run benefitting thalassemia, Gilroy, CA

JULY

July 23, 2012: ICF Branch 127 Dinner Meeting/Thalassemia Presentation, Petaluma, CA

July 30–August 4, 2012: Painted Turtle Camp for children with thalassemia and hemophilia, Lake Hughes, CA

AUGUST

August 30–September 2, 2012: Italian Catholic Federation Annual Convention, Reno, NV

SEPTEMBER

Date TBA San Genaro Italian Festival, Los Angeles, CA

OCTOBER/NOVEMBER

Date TBA: Thalassemia Retreat

October 6, 2012: Thalassemia Support Foundation / Children's Hospital's Thalassemia Outreach Program present the Wellness Conference for people with thalassemia and their families

DECEMBER

December 1, 2012: Thalassemia Holiday Party, Oakland, CA

Date TBA: ICF Branch 367 Holiday Party/Thalassemia Presentation, Los Vegas, NV

December 8–11, 2012: American Society of Hematology (ASH) Annual Meeting and Exposition, Atlanta, GA



PERSPECTIVES

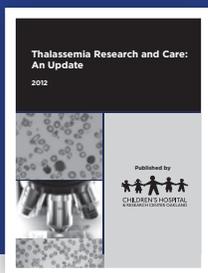
Northern California Thalassemia Center
Children's Hospital & Research Center Oakland
747 52nd Street, Oakland, CA 94609

Address change requested

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

To order hard copies, additional copies, or PDFs, please send your information to LLevine@mail.cho.org or call (510) 428-3885, ext. 5427:

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New look • Updated information • Improved psychosocial and resource section • Patient stories • Event calendar • More.

LOOKING FOR:

- Volunteers for outreach projects
- Writers for Perspectives and thalassemia.com. Have a story to share? Healthcare tips? We want to know!
- Fundraisers

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

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.