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### Upcoming Events

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<td><strong>61st American Society of Hematology Annual Meeting and Exposition</strong></td>
<td>Dec. 7–10, 2019</td>
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<td><strong>Third Annual Thalassemia Holiday Party</strong></td>
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<td><strong>Thalassemia Support Foundation Patient/Family Conference</strong></td>
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### Resources

Interested in learning more about thalassemia? Join the Thalassemia International Federation’s mailing list to receive updates about current and upcoming activities, research developments and more: [http://eepurl.com/drd5Fb](http://eepurl.com/drd5Fb)
12 Ways to Have a Healthy Holiday Season
From the Centers for Disease Control and Prevention

Brighten the holidays by making your health and safety a priority. Take steps to keep you and your loved ones safe and healthy—and ready to enjoy the holidays.

1. Wash hands often to help prevent the spread of germs. It’s flu season. Wash your hands regularly with soap and clean running water for at least 20 seconds.

2. Bundle up to stay dry and warm. Wear appropriate outdoor clothing: light, warm layers; gloves, hats, scarves and waterproof boots.

3. Manage stress. Give yourself a break if you feel stressed out, overwhelmed and out of control. Some of the best ways to manage stress are to find support, connect socially, and get plenty of sleep.

4. Don’t drink and drive or let others drink and drive. Whenever people drive drunk, they put everyone on the road in danger. Choose not to drink and drive and help others do the same.

5. Be smoke-free. Avoid smoking and secondhand smoke. Smokers have greater health risks because of their tobacco use, but nonsmokers also are at risk when exposed to tobacco smoke.

6. Fasten seat belts while driving or riding in a motor vehicle. Always buckle your children in the car using a child safety seat, booster seat or seat belt based on their height, weight and age. Buckle up every time, no matter how short the trip, and encourage passengers to do the same.

7. Get exams and screenings. Ask your health care provider what exams you need and when to get them. Update your personal and family histories.

8. Get your vaccinations. Vaccinations help prevent diseases and save lives. Everyone 6 months and older should get a flu vaccine each year.


10. Practice fire safety. Most residential fires occur during the winter months, so don’t leave fireplaces, space heaters, food cooking on stoves, or candles unattended. Have an emergency plan and rehearse it regularly.

11. Prepare food safety. Remember these simple steps: Wash hands and surfaces often, avoid cross-contamination, cook foods to proper temperatures and refrigerate foods promptly.

12. Eat healthy, stay active. Eat fruits and vegetables, which pack nutrients and help lower the risk for certain diseases. Limit your portion sizes and foods high in fat, salt and sugar. Also, be active for at least 2 ½ hours a week and help kids and teens be active for at least one hour a day.

The Hematology Section at Children’s Hospital Los Angeles wishes you a safe, healthy and happy holiday season!

Words of Encouragement From a Patient with Thalassemia

Growing up diagnosed with beta thalassemia major, I felt that I was different from all my peers in school. While in elementary school, a cloud of lethargy always hovered over me; I couldn’t run to play tag or basketball, I couldn’t keep up in PE without special treatment from the teachers, and sometimes I wouldn’t even show up to school, which caused some resentment from my classmates. In their eyes, I was the kid who wouldn’t try.

Later I would find out that my thalassemia was not being managed as well as it should have been. Today, I don’t let my disability define me or use it as an excuse, as I did in the past. Being accepted into University of California, Irvine’s School of Engineering and being placed on the Dean’s Honor List showed me that I can do almost anything people without thalasssemia can do, and be even better at it than they can. If you are suffering from thalasssemia, always keep in mind that every triumph you experience will be increased tenfold because not only have you accomplished something, you’ve achieved it even though fate has put you at a disadvantage. Do not allow this to define you or be your crutch. You can make your dreams come true, and with a team of doctors, nurses and social workers that genuinely cares, they will come true.

Onward,
Christopher Jhaveri

Meet Our Staff: Christopher Denton, MD

Christopher Denton, MD, is an attending physician in Pediatric Hematology and an assistant professor of Clinical Pediatrics at Children’s Hospital Los Angeles. A native of Seattle, Dr. Denton completed his undergraduate degree at Stanford University and his medical training at Oregon Health Sciences University. During his residency at Seattle Children’s Hospital, he became interested in pediatric hematology, which led him to pursue a fellowship at CHLA. Dr. Denton served as Chief Fellow during his third year of fellowship, and subsequently joined the CHLA provider team as an attending physician.

Dr. Denton is committed to his patients and strives to treat them with dedication and confidence. In addition to providing clinical care, he is engaged in research to improve patient outcomes. His current research project involves looking at the protective role of alpha thalasssemia trait in patients with sickle cell disease.

An avid runner, Dr. Denton has participated in over a dozen marathons. He also enjoys live music, snowboarding, and fancy dinners with his wife, Audrey. We are fortunate to have such a bright and committed physician on our team.
If you decide to participate in this study, you are being asked to participate in a research study. Participation in this study is completely voluntary. This study is being conducted by the Division of Cardiology and the Division of Hematology, Oncology, and Blood and Marrow Transplantation at Children’s Hospital Los Angeles, to try to understand whether blood transfusions and hydroxyurea improve resting and maximum brain blood flow, measured by magnetic resonance imaging (MRI). By learning this, we may be able to identify patients at high risk for stroke or discover better ways to protect the brain from stroke in patients with chronic anemia.

Study participation requirements:
- If you or a guardian signs a consent form, you will be scheduled for blood tests, research testing including an MRI scan at the hospital, and a neuropsychiatric test with a psychologist. The study visits will each last three to four hours. Depending on your anemia, your participation in the study could require monthly visits for three to eight months, or you may be asked to come in two or three times within three months.
- All research visits will be conducted at Children’s Hospital Los Angeles, located at 4650 Sunset Blvd., Los Angeles, CA 90027.
- To be eligible, patients:
  - Must have a known diagnosis of sickle cell disease (SS, SC or Sβ0 genotype) or chronic anemia
  - Must be 7 years of age or older
  - Must be able to follow instructions
  - Must be able to participate without needing sedation for an MRI scan
  - Must not be pregnant
  - Must not wear metal braces
  - Must not have a history of seizures

Payment
- Participants will receive $100 per study visit.

Principal Investigator:
John C. Wood, MD, PhD
Phone: 323-361-5470
Email: jwood@chla.usc.edu

Contact Person:
Cobalio Carreras
Phone: 323-361-4663
Email: ocarreras@chla.usc.edu

Why We’re Thankful
Expressing thanks is a healthy practice. Here’s what our staff members are grateful for this season.

I am thankful for a job that I love.
- Susan Carson, NP

I am thankful for dear friends and family that support me.
- Michelle Lahat, LCSW

I am grateful for people who donate blood and save lives like mine. Without them I would not be here and I am eternally grateful.
- Laurice Levine, CHLA consultant and Italian Catholic Federation liaison

I am thankful for the perseverance of our patients and families.
- Kelly Russell, project coordinator

Embracing Your Dark Thoughts While Living With Thalassemia
By Josephine Bila, LMSW

Think back to your earliest memories of what it was like to receive treatment for thalassemia as a child. I primarily remember not wanting to go to the hospital to get stuck with needles.

My resistance to needle sticks was met by nurses who would hold me down to avoid getting kicked and punched. They’d press their body weight down on my legs and arms while saying “You’re doing a great job” and “being so brave.” Then one nurse would count down from 5 and insert a needle into my vein.

Early on, I remember realizing that I had no way to stop myself from needing transfusions. This understanding forced me to embrace what was happening during my hospital visits. I learned to cope with needle sticks by becoming the “brave girl” who always tried to “do a great job.” That brave girl who did a great job wore a smile on her face to show everyone how well she accepted life with thalassemia. She giggled to brush off her painful experiences. She denied and suppressed the very part of herself that wanted to kick and punch her nurses and doctors.

The part of my mind that I rejected was the “negative thinker” and the “weak one.” The self that, when expressed, made other people sad or uncomfortable. Those of us who are forced into such vulnerable positions can’t have the very people in charge of their care feeling sad or uncomfortable, can we? No, because doing so might make them not want to be around us, which could end our care and, thus, our lives.

The anger, hurt and sadness we feel as a result of living with thalassemia becomes buried into our subconscious minds. As we smile through our pain for the sake of everyone else’s comfort, we bury the truth of how we feel. This often causes us to experience passive-aggressive relationships with other people and live inauthentically, for the sake of other people’s happiness. We also begin to distrust our own feelings about things, which sometimes gives rise to anxiety.

So, how do we change? We begin to recognize, accept and comfort our darker thoughts. We take note of the pieces of ourselves that we turn away from. We tell ourselves, “No, I’m not going to deny the truth of how I feel about this anymore.” We cry when things hurt, no matter who else is in the room. We own our feelings of anger, frustration and rage. We tell people the truth of what’s on our minds when it really matters and trust ourselves to make good decisions. We also honor our bodies and minds equally and begin to love ourselves from within.

Release yourself from the burden of burying your shadow thoughts, because the only way to resolve them is to bring them toward the light of your conscious mind.

Josephine Bila, LMSW, is a thalassemia major patient who lives in New York City with her husband. She is a licensed master social worker and front-end website developer, and holds multiple certificates in health and wellness. Visit her blog, ThalassemiaDiet.com, for more information.

While Living With Thalassemia

Embracing Your Dark Thoughts

Josephine Bila, LMSW, is a thalassemia major patient who lives in New York City with her husband. She is a licensed master social worker and front-end website developer, and holds multiple certificates in health and wellness. Visit her blog, ThalassemiaDiet.com, for more information.
The stunning natural surroundings of Tucson, Arizona, served as the backdrop for the 89th Italian Catholic Federation (ICF) Convention. The Thalassemia Program at Children’s Hospital Angeles, which has benefited from a philanthropic partnership with the ICF, was once again named the organization’s charity of choice and presented with a $62,000 donation.

The event took place Aug. 29 to Sept. 2, 2019, and kicked off with a welcome dinner followed by a successful blood drive. Thirty-three pints of blood and two pints of plasma were collected, which will help save 101 lives. We are grateful to everyone who volunteered to donate and would like to thank the following individuals for giving the gift of life:

Lorraine Acuña
Colleen Alfieri
Denise Antonowicz
Michelle Antonowicz
Paul Cook
Tom Cook
Monica Crowley
Lisa Crudo
Jerry Farrugia
Dante Galeazzi
John Gillie
Anna Gonzalez
Bill Greco
Colleen Alfieri
Bobbie Lizarraga
Lou Mages – Power Red (2 units)
Pat Mages
Elizabeth Marshall
Ken Marshall
Lucy Olsen
Robert Pachinger
Andy Pappani
Sid Pappani
Debbie Piro
Terrie Rhodes
Melissa Rodriguez
Terri Rolleri
Marcie Rossi
Mike Rossi
Karen Rosson
Joan Ryder
Carmelo Sabatella
Sandra Sarerika
Tad Shaw
Kate Shimshock
Ric Shimshock
Estrella Sistual
Alicia Trevino
Ronnie Urbe
Judy Wellbeloved
Andrew Zasoski
BG Zasoski
Joey Zasoski
Leonard Zasoski – Power Red (2 units)

Saturday featured an evening banquet where ICF members were able to meet and chat with Thomas Coates, MD, Section Head of Hematology at Children’s Hospital. During the Sunday session, Dr. Coates and Laurice Levine, MA, CCLS, who serves as CHLA’s liaison with ICF, received a check donation on behalf of the Thalassemia Program.

For more information on the Italian Catholic Federation please visit: ICF.org

In Memoriam: David Botta

At its recent national convention in Tucson, the Italian Catholic Federation honored David Botta who served as ICF Grand President and was a Life Member Emeritus. Before his passing in November 2019, Mr. Botta was presented with a special award at the ICF’s branch meeting in Crockett, California. We thank President Botta for his many years of service to the ICF. He will be missed by many, and our thoughts are with his family and friends.

The award reads:

In Honor of David Botta

On behalf of Dr. Thomas Coates, Laurice Levine, and the patients and families in our care, we would like to thank you for changing the lives of countless Cooley’s anemia patients. By adopting Cooley’s anemia as the ICF’s National Charity during your Grand Presidency, you changed the direction of thalassemia research and care. Your support and dedication to Cooley’s anemia has been unwavering. We have been touched by your humor and kindness, and we cherish your friendship. With love and gratitude, we thank you.
Step Right Up and Join Us for a Carnival
To Celebrate the Third Annual Thalassemia Holiday Party

When:
Sunday, Dec. 15, 2019  |  Noon – 2 p.m.

Where:
Children’s Hospital Los Angeles
Stauffer Conference Room
4650 Sunset Blvd., Los Angeles, CA 90027

RSVP:
By Sunday, Dec. 1 to Kelly Russell
323-361-3269 or krussell@chla.usc.edu

Please let us know the names of everyone in your group and the ages of guests who are under 18 years old.

We hope to see you there!

Keep in touch!
If you would like to get thalassemia news and information via email, please write to krussell@chla.usc.edu. Thanks!

This newsletter is made possible through the kind support of the Italian Catholic Federation. Visit ICF.org for more information.