

IN THAT VEIN

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Winter 2021-2022



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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>



COATES' CORNER

**Dear Members of the Clergy, Grand President Vincent Piro,
Central Council members and ICF members,**

First, I want to convey the sincerest wishes of the Hematology Section of the Cancer and Blood Disease Institute at Children's Hospital Los Angeles, and from me personally, for a successful and productive convention this year and for success in all your endeavors. The members of the Thalassemia Program at CHLA remain deeply honored to have been selected by the Italian Catholic Federation to be a member of your team carrying out the mission of helping others.

I am very disappointed not to be there at the ICF Convention in person. I look forward to the convention every year, meeting old friends and making new acquaintances. As I have said before, it gives me great pleasure to listen to all the presentations, and in general just to hear about your successes and see the enthusiasm of your members as they relate their projects to help others. I hope by next year the pandemic will be behind us. However, for now, all my travel remains canceled.

I hope that all of you have been vaccinated by now and that you will continue to spread the word that COVID-19 vaccinations are very effective and safe. One of the problems we are facing now is that vaccinated people can be infected and not know it. Thus, they can unknowingly spread the disease. I suspect that is why the virus seems to be spreading so much faster now and why wearing masks and social distancing remains important. Wearing a mask helps you protect others.

This has been an amazing year in the world of thalassemia. First, our Thalassemia Program continues to get many new referrals from across California and the country of children and adults with thalassemia-related disorders. Laurice Levine continues to be an important ambassador in this regard along with the Cooley's Anemia Foundation and other community organizations.

Another exciting development is that Luspatercept was approved by the Food and Drug Administration (FDA). This medicine, given

by an injection every three weeks, can significantly reduce the transfusion requirement in transfusion-dependent thalassemia patients. It will likely be approved by the FDA this year or in early 2022 for thalassemia patients who do not require routine transfusions. Children's Hospital Los Angeles was the first site in the world to open the clinical trial for this drug.

Currently, we are opening clinical trials at CHLA for two additional new drugs for thalassemia that act by a completely different mechanism and are administered orally. If these agents prove effective, there will be three medications to improve the lives of transfusion-dependent thalassemia patients as well as non-transfusion-dependent patients. It is possible that with these new medicines, many patients with mild forms of thalassemia may never need to go on chronic transfusions.

Last, but certainly not least, there has been tremendous progress in curative approaches to thalassemia. At least 16 patients have now been treated with gene-editing approaches, whereby a patient's own bone marrow cells are collected, the abnormal thalassemia gene is corrected, and then the patient undergoes a bone marrow transplant with the corrected bone marrow. All of the patients treated survived and became transfusion-independent. These approaches are still experimental but hold great promise.

The pace of scientific progress is breathtaking in the genetics era. Think of it: Within days of receiving the genetic code of COVID-19, drug companies were able to start producing an effective vaccine and save millions of lives! Now, we can cure certain genetic diseases previously thought to be fatal. We still need compassionate caregivers. However, it is a pleasure to tell worried new thalassemia families not to Google the disease because the online data is misleading and frightening. Current data is clear that the outlook for thalassemia now is excellent. The worst-case scenario is a normal life expectancy except for transfusions. (By the way, speaking of "normal," we welcomed two new babies of thalassemia moms in our practice this year!). In the future, we hope to cure all patients early in life.

Thank you again for all the wonderful things that ICF does for thalassemia patients and families and for the positive spirit you convey and share.

I hope to see you in person next year.

Thomas Coates, MD
Section Head, Hematology

ITALIAN CATHOLIC FEDERATION DONATES \$41,000 TO THE THALASSEMIA PROGRAM

After 18 months in “virtual” isolation, the Italian Catholic Federation (ICF) met in person in early September for the 90th annual ICF Convention in Santa Clara, California.

It is no small feat to fundraise, and during a pandemic, it is nothing short of miraculous. ICF donated \$41,000 to the Thalassemia Program at Children’s Hospital Los Angeles.

Thomas Coates, MD, Section Head of Hematology at Children’s Hospital Los Angeles, the Thalassemia Program team, and especially the children and families in our care, are truly thankful for the support of the ICF. Thalassemia has been the official ICF National Charity since 1982, and CHLA has been the honored recipient of these funds since 2015. ICF makes a vital difference to the thalassemia community.

The 10th annual Live to Give convention blood drive, in honor of thalassemia, was also an immense success and especially important in light of the continuing blood shortage. Thirty units of blood and one unit of plasma were collected by the incredible team at Vitalant Blood Bank, whose staff, led by Pamela Moore, Donor Recruitment Representative, was professional, dedicated and compassionate. As a result of this blood drive, 91 lives will be saved!

We would like to thank everyone who donated blood and gave the gift of life:

Joseph Aguilar
Mahmoud Ahmadi
Thomas Cook
John Gillio
Steven Hong
Arthur Kao

Patty Litts
Nancy Lukas
Lou Mages
Elizabeth Marshall
Robert Pachinger
Andy Pappani

Sid Pappani
Marcie Rossi
Mike Rossi
Karen Rosson
Dean Santiago
Patricia Segarini

Nanette Metz
Jacob Sharir
Ric Shimshock
Citlalie Tello
Gianna Rosine Valero
Patricia Whelan

Kyung Yi
Leonard Zasoski

We are incredibly grateful to the Italian Catholic Federation for its generous contributions. For more information or to join the ICF please visit: www.ICF.org



On behalf of Thomas Coates, MD, Laurice Levine, MA, CCLS, accepts ICF's donation from Grand President Vincent Piro.



Welcome Deborah Rodondi, incoming ICF Grand President and the Executive Officers of the Central Council: Top Left – Right: Bob Basuino, Pat Mages, Perry Shurko, Vincent Piro, Leonard Rossi and Lisa Crudo Bottom Left – Right: Franklyn Lopes, Denise Antonowicz, Deborah Rodondi, Father George Aranha (Diocesan Chaplain of the ICF Santa Clara Valley District) and Lauren Kilcullen

IT IS POSSIBLE! WE CAN STILL HAVE A BABY!

The thalassemia community at CHLA is happy to announce the birth of a son to Vilay, one of our long-time patients. Vilay recently sat down for an interview with social worker Michelle Lahat to share her experience.

Vilay always thought she wouldn't be able to have a child because she has thalassemia major. She remembers family members telling her that she would have a very hard time or maybe not be able to get pregnant naturally. Vilay did not think about having a baby until she got married, and then together with her husband, they decided to try to conceive. After testing confirmed that Vilay's husband was not also a carrier of thalassemia, they were able to get pregnant. Unfortunately Vilay miscarried, and for a time they considered adoption due to their concern that Vilay could never bring a baby to term.

As it turns out, Vilay and her husband were able to conceive again, and baby Asher was born their healthy rainbow baby. Vilay searched for an obstetrician who understood the needs and risks of an expectant mother with thalassemia. Eventually, she found a physician who knew about thalassemia and was able to refer her to a high-risk fetal medicine specialist. Both doctors monitored Vilay very closely throughout her pregnancy.



Baby Asher with his proud parents



Vilay cherishes every moment with her family.

Vilay's primary complication was gestational diabetes. Due to being over age 35 with thalassemia, she knew she was at higher risk for this particular complication. Throughout her pregnancy, Vilay gave herself finger pricks to monitor her blood sugar, took insulin injections and adjusted her diet.

Vilay wants others with thalassemia to know it is possible to have a healthy baby naturally. She stresses the importance of finding physicians who are willing to do the research and coordinate care with other specialists. Vilay's high-risk physician and her obstetrician had a plan for transfusion both before and after the c-section delivery so that Vilay was not anemic before or after giving birth. Vilay says there was a "Plan B for everything," and the physicians were communicative with her about those plans. Vilay knows she is fortunate that her insurance company allowed her to be followed by knowledgeable and caring physicians who communicated with each other.

The Thalassemia Program team at CHLA could not be more excited for Vilay as she lives out her dream of being a mother. Thank you to Vilay for sharing this story and the adorable pictures of Asher!



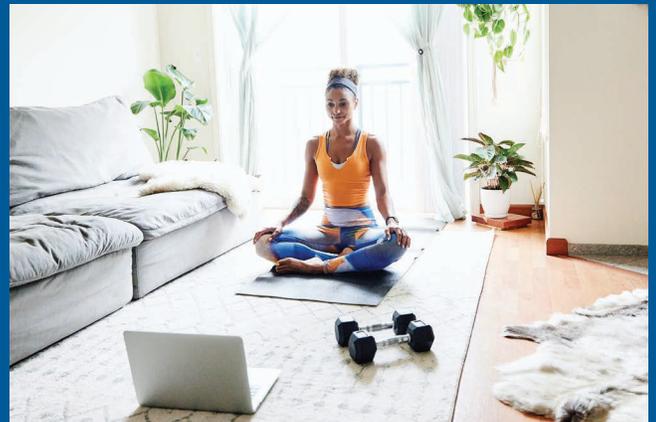
MARK YOUR CALENDAR!

Ongoing Events hosted by Cooley's Anemia Foundation

Thursdays at 9 a.m. PST

10-minute mindfulness and breathing exercises

This is a virtual event. For more information or to register for this Zoom meeting, please email Kathleen Durst at kdurst@thalassemia.org.



We'd like to hear from you!

If you have any questions about caring for a patient with thalassemia or suggestions for the newsletter, let us know. Please contact Michelle Lahat at mlahat@chla.usc.edu.

KIDS HELPING KIDS!

Members of the Thalassemia Program at CHLA like to recognize peers who support each other. It is inspiring and makes a vital difference in the lives of our patients and families.

Girl Scout Troop 4116

By Eliza Higgins

Ciao! We are Girl Scout Troop 4116. Girl Scouts is a worldwide organization founded in 1912 by Juliette Low, in Savannah, Georgia. It was created to empower girls through compassion, leadership, character and confidence. Our troop has bonded over the Italian culture and heritage. We are actively learning the Italian language and taking many field trips to promote learning about the culture and community!

We try to meet once a month (mostly over Zoom right now) to bake and do science projects together to earn badges and learn new skills. Before COVID-19, we participated in many field trips around the greater Los Angeles area. Some of our favorite activities were a campout at the Santa Barbara Zoo and a tour of the Getty Villa in Malibu.

The most rewarding part of Girl Scouts is being able to use our resources to help others. This past year we created and colored children's books to support a sister Girl Scout who was building a library in Tijuana, Mexico. Participating in the CHLA Christmas party was another rewarding experience for us because we were able to be together and meet a lot of other kids and families while making crafts alongside them.

It is something that we hope we will be able to do again in the future.



Girl Scouts Sophia, Livia, Bella and Veronica at CHLA



Near the hospital's main entrance, the scouts posted encouraging messages for patients with thalassemia.



Thalassemia Holiday Party 2019

Junior Italian Catholic Federation Branch 218

By Katharine La Corte

My name is Katharine La Corte, but I am known simply as Katie. My doctor diagnosed me with thalassemia trait when I was a baby. Thalassemia can be traced to my Southern Italian family. My family and I are members of the Italian Catholic Federation (ICF) Branch 218 at Holy Angels Catholic Church in Arcadia, California. ICF has consistently supported thalassemia research and the dedicated team at Children's Hospital Los Angeles.

In 2017, I was asked by my Branch President if I would volunteer for CHLA's 1st Annual Thalassemia Holiday Party. I was so excited! And this is how I met Laurice Levine. She is so much my hero, as well as everyone's. Before the pandemic, I helped collect toys before the party and volunteered as a Santa helper on the day of the celebration. Helping and volunteering gives me so much joy and happiness.

A little bit about me. I was born in Arcadia, California. I live with my mother and father. I have no pets, but I love dogs and cats—I hope to have a cat one day! I attended elementary and middle school in the Monrovia Unified School District. Currently, I am a junior at Alverno Heights Academy. I have been involved in the Alverno Singers, the Alverno Ambassador Program, the Harry Potter/Movie Club and the Art Club. Last year I served in the Alverno Congress as a Congressional Liaison and currently I am a Representative in the Junior State Assembly. I have received the honor of being a member of the California Scholar Federation (CSF) as a sophomore. Lastly, I am a Girl Scouts Ambassador and am currently working on my Gold Award. My Gold Award project is about working with foster children in art therapy.



ICF member Jerry Farrugia, Laurice Levine, Katie La Corte and Dr. Coates at CHLA's annual Thalassemia Holiday Party

My passion is art studies and animation because I love drawing and creating characters as well as storytelling through story boarding. I hope to attend an art school or a college/university studying media or animation. I love classic Disney and Pixar films, especially "Alice in Wonderland," "Luca," and Tim Burton's "The Nightmare Before Christmas." I enjoy listening to classic rock and roll (my dad is a musician) and modern artists such as Billie Eilish, Lady Gaga and Melanie Martinez. I have a collection of vintage dolls, which comes from my grandmother's love for dolls. I enjoy going to the beach and searching for hermit crabs. But most of all, I love volunteering and working with CHLA. I am very honored to be featured in this newsletter and am excited to return to the hospital for the next holiday party when we can come together again.



KEEP IN TOUCH!

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

This newsletter is made possible through the kind support of the Italian Catholic Federation.

Visit ICF.org for more information.