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Upcoming Events

CAF Annual Care Walk

Sunday, May 5, 2019 | 10 – 11:30 a.m.

Point Vincente Interpretive Center
31501 Palos Verdes Drive
West Rancho Palos Verdes, CA 90275

Note: Meet at the whale-watching area facing the Pacific Ocean before 10:15 a.m. If you are late, you'll find us on the trail to the north wearing our CareWalk T-shirts.

Contact: Thomas Cheng, tmcheng@verizon.net

Cooley's Anemia Foundation Patient Family Conference

July 12 – 14, 2019
Marriott San Francisco
Airport Waterfront
1800 Old Bayshore Highway,
Burlingame, CA 94010

Register at: docbw.com/meet/caf

Italian Catholic Federation 2019 Annual Convention

Aug. 29 – Sept. 2, 2019
Hilton El Conquistador Resort
10000 N. Oracle Road
Tucson, AZ 85704

For more information:
ICF.org/about/convention

Save the Date! Thalassemia Holiday Party

Dec. 15, 2019 | 1 – 3 p.m.
Children's Hospital Los Angeles
John Stauffer Conference Room

A Magical Evening

There certainly was magic in the air at the second annual Thalassemia Holiday Party at Children's Hospital Los Angeles. With over 100 guests present, our families enjoyed entertainment that included magicians, clowns, face painting and a photo booth. Delicious food and dessert was a highlight, as was the opportunity to meet Santa Claus and get special gifts. For the second year in a row, Marie Antonowicz, longtime member of the Italian Catholic Federation (ICF), which sponsored the event, led the party in the famous Chicken Dance—a real crowd-pleaser provoking lots of laughter. Many people won raffle prizes of games and stuffed animals, and everyone had the chance to make magic wands and holiday decorations at the arts and crafts tables.

The Thalassemia Program at CHLA is fortunate to be supported by the Italian Catholic Federation, which sent over 60 members to celebrate with us and serve as Santa's helpers. ICF support, both fiscal and physical, is invaluable in making the event a great success. The Thalassemia team would like to express our thanks to CHLA consultant and ICF liaison Laurice Levine for her masterful organization of the party along with Pat Mages, Los Angeles District ICF President. We also would like to thank everyone who came to celebrate the magic of the season with us. ☺



Members of the Italian Catholic Federation, L.A. Archdiocese District

Special thanks to:

Joyce, Natalie and Liam Allesandro
Dianna Amper
Marie, Denise, Germaine and Michelle Antonowicz
Connie Bohanon
RoseMary Brougher
Marianne Cannetti
Karen and Michael Cerri
Marty and John Cirone
Maria DeSalguero
LuAnne Donahue and family
Rita Downey
Charlene, Steve and Mary Margrette Drobeck
Carol Eller
Annemarie Ellington
Ginny and Gary Ethier
Linda Fabry
Carol and Jerry Farrugia
Nancy and Ludwig Fraines
Anne Interante
Kristine Kaiser
Eric LaBree
Aileen and Katie LaCorte
Andrea Linn
Pat and Lou Mages
Adriana and John Maggiora
Renee Mata
Ryuko, Helena, Amanda and Mickey Murano
Julia and William Mussatio
Fiora Murphy
Jean Ornelaz
Aileen Painter
Mary Pavia
Dave and Shelley Petrelli
Claudia Pirozzi and her lovely sister!
Mary Poe
Diane Riga
Pam Roemer
Linda Sabatella
Nenette Saldana
Frank, Crocetta and Leonardo Salomone
Julia Scalise
Adele, Gabby and Rob Schilling
Patrick Scott family
Theresa Shaw
Perry Shurko
Della and Gino Spinelli
Trish and Emily Thompson
Barbara Tweedy
Nancy Valdez
Margaret Valdez-Gallardo
Irene Vallini
BG and Leonard Zasoski
ICF L.A. Archdiocese District
ICF Branch 14
ICF Branch 102
ICF Branch 108
ICF Branch 111
ICF Branch 115
ICF Branch 118
ICF Branch 169
ICF Branch 237
ICF Branch 317
ICF Branch 319
ICF Branch 362
ICF Branch 374
ICF Branch 380
ICF Branch 443
ICF Branch 444
ICF Branch 447
Sacred Heart Council
Knights of Columbus

There are countless people to whom we owe our gratitude. Please forgive us if we have inadvertently left out the name of a volunteer or a branch. If your name is missing, please let us know. Thank you!

Thalassemia Support Foundation

by Paul and Melissa DiLorenzo



Mission Statement

The Thalassemia Support Foundation (TSF) is a nonprofit organization founded by patients, parents, loved ones and friends affected by thalassemia. The foundation provides hope, comfort and encouragement to

those battling this disorder. At the heart of the organization is a strong desire to help improve the quality of life for all patients with thalassemia. We volunteer our time to organize conferences, raise funds to educate the community, ensure patients and parents know the latest in care, and donate to the work of researchers. The foundation maintains a strong relationship with the medical community that provides diagnoses, treatment and care.

Background and Activities

The Thalassemia Support Foundation was founded in January 2005 by a group of patients, parents and loved ones with over 30 years of nonprofit experience in previous organizations. We started the organization with the belief that there is more to helping a patient than research, drugs and blood tests. We understand that patients and their families also need hope, hope that living a full, productive

and happy life is possible. With this hope instilled in them, any obstacle can be overcome. As patients and families face these obstacles, TSF aims to provide them with support and a helping hand along the way.

Specifically, TSF is focused on providing support to the thalassemia community in California and neighboring states. We want to help people in their own backyard. To this end, we hold conferences in the Los Angeles and San Francisco areas, where patients and families are able to connect with doctors, nurses and patient advocates. Additionally, local gatherings provide an opportunity for members of the thalassemia community to meet and connect with one another. For many patients and families, our conferences are their only opportunity for this type of interaction. To date, we have held seven conferences, with our next one planned for some time in 2019.

To best serve the thalassemia community, we are always looking for new ideas. If you have an idea or would like to help, please contact us at: helptals.org/blog/contact-us-by-e-mail.html. With your help, we can ensure a bright future for thalassemia patients.

To learn more about TSF, please visit: helptals.org, where you can find news, events and conference information. You can also join our mailing list!

Thank you for taking the time to learn about our organization. ☺

Make plans to attend Thalassemia Week at The Painted Turtle!

A fun-filled camp experience awaits your child this summer. The Painted Turtle is a camp for children with serious medical conditions. High-quality medical professionals help staff the camp to ensure that all children are able to engage safely in the full range of camp activities.

When: July 23-28, 2019

Where: Lake Hughes, California

Camp is free for all campers!

To learn more about The Painted Turtle and how to apply: thepaintedturtle.org

Camper Admissions Manager: admissions@thepaintedturtle.org or 661-724-1768, ext. 203

Camp magic awaits!





Relieve Your Parking Woes With SAPE – Search Available Parking Everywhere

by Sikandar Bangash



Everyone has the same annoying problems they have to deal with, and just about everyone finds that finding parking can be annoying. This has certainly been the case for me. Finding a parking space that is not restricted has become a big problem. Street parking typically has a two-hour maximum.

I was at my doctor's appointment in Los Angeles, and when I left the hospital after treatment, I noticed my car was missing. The hospital has a small parking lot that fills up fast. Without any other option, I was fortunate enough to find an open spot for metered parking on the street. I'd parked at the same location multiple times without any problems, but this time the parking enforcement changed street-parking times by a few hours without warning. The day was miserable for me since I had to call a taxi to get a ride home (which cost \$80), and the following day I had to pay \$700 to get my car out of impound. All of this could have been avoided in just a few seconds if I had a tool to notify me of the street-parking times and even help me find available parking nearby.

This horrible experience was my breaking point, and I started building a tool to help others like me: SAPE (Search Available Parking Everywhere). SAPE is a smartphone application that provides drivers with real-time parking availability, and gives the driver a chance to reserve and pay for the parking space before leaving home. SAPE manages difficult tasks like guiding drivers to available parking spaces in large parking lots or structures, saving a driver precious time finding parking and eliminating all the pain of paying for a parking space. Drivers will receive street-parking rule alerts in just seconds after arriving at a street-parking location, and best of all every user will have a parking space to park in. SAPE achieves this by welcoming all types of parking owners to list parking spaces on the platform. Whether you're a commercial parking space owner or a homeowner with unused parking spaces, SAPE will list your parking spaces for drivers to reserve. SAPE became available for download on both Apple and Android phones starting earlier this year. For details about the app downloading process, or if you are interested in becoming a Parking Host, please visit our website at sapeeverywhere.com.

SAPE Features:

1. Searches, reviews and reserves parking from anywhere.
2. Guides drivers to available parking spaces.
3. Manages parking in large parking lots.
4. Saves drivers time finding parking.
5. Allows homeowners to rent out unused parking space for cars, trucks or RVs.
6. Curb alerts! Provides instant street-parking rules notifications.
7. Sweeping reminders! Reminds drivers to move their cars for upcoming scheduled street cleaning.

Sikandar (Andy) Bangash is founder and CEO of SAPE. He is currently studying bioinformatics at University of California, San Diego. To learn more about SAPE, please email Andy at sibangas@ucsd.edu.

A Battle of Positivity

Cesar Chavez once said, “[We] draw our strength from the very despair in which we have been forced to live. We shall endure.” My name is Maria Bangash, and in my 24 short years of my life, I have learned to be persistent and strong. As a patient with beta thalassemia, I have encountered many obstacles with my health and education, but I have overcome them with great strength.



Maria Bangash and family

I graduated from University of California, Irvine, with a degree in biological sciences in June 2017. My biological sciences degree not only required the completion of science courses, but it also required me to study when my blood level was low, competing to be the same as a student without thalassemia. I had to struggle through the effects of Benadryl and try to study during grueling transfusion appointments. Yes, grueling, because when the blood enters the veins it is very painful. But I did it.

My blood transfusions are part of my routine. I have to go in every three weeks to receive two to four units of blood (depending on my hemoglobin level, which the majority of the time is low), and at home I have to manage taking my

chelator (Jadenu) every day. A chelator helps remove excess iron from the blood. Many would think that that's the extent of my care, but it is not. I have to make sure that I do not have iron buildup in my heart or other organs, so I have to attend MRI and bone density appointments, as well as handle the fatigue and pain away from the hospital when my blood level is low. Through these struggles, I not only gained my degree, but I also showed that I was worthy enough to be on the Dean's Honor Roll by taking four major science classes in the midst of going to the hospital for transfusions. I showed that with persistence and the support of my family, I can do anything I dream of doing.

After graduating, I started to apply right away to medical colleges. I found out that, as a patient, I do have boundaries. Yes, we are free to dream of anything we want, but sometimes we have to realize our restrictions, and I realized mine. It was not very pleasant because my dream of becoming a doctor was my life, something I set in stone. I was going to travel abroad for my studies. I applied to a few colleges near me, but unfortunately was not accepted because they questioned my ability to handle more units. I knew that this was not going to stop me. I applied out of state and out of the country, and I was accepted into two medical schools. One was St. George's University (in Grenada), and the other was a medical school in Poland through a U.S.-based program in Virginia.

At this point, my concern was how to get my blood transfusions while attending medical school. It was as if ice cream had been served to me, but I could not have it. Well, it was more than ice cream; medical school was my dream. Unfortunately, I had to decline attending medical school because of my health concerns as well as my inability to get insurance due to my sickness and treatment.

I felt very weak emotionally, but in those hard times my family was always there to support me. They told me to look for something else that I would enjoy, and to search for something in which I could stay healthy and also complete my education. I researched careers and stumbled upon a chiropractic program, and I saw that I would be able to help relieve patients' pain with a healing touch. I thought to myself, “What more do I want?” This was exactly what I wanted. It was a program in California. I applied right away, was called for an interview and was accepted. Now I have completed a year of the chiropractic program and cannot be thankful enough. I know that I was not able to complete my dream of going to medical school, but sometimes life reroutes you to something better. And this doctorate program through the Southern California University of Health and Sciences rerouted my life for the best. I am able to go to the hospital for my blood transfusions and attend my classes without any concern about my health or insurance.

We all have faced obstacles, but the strongest individuals are those with positive minds and attitudes. I decided to take my challenge positively and to appreciate every aspect of it, because my end goal will always be to give hope and strength to my patients and to others around me. ☺



Maria Bangash resides in Southern California and receives treatment at Children's Hospital Los Angeles.



Managing Screen Time

The following is an excerpt from a New York Times article called "How (and When) to Limit Kids' Tech Use," by Melanie Pinola. A few basic parenting guidelines will help you establish ground rules and maintain tech harmony at home.

Aim for Balance

"The most important step is to establish a balanced or sustainable relationship with tech," says the social psychologist Adam Alter, author of "Irresistible: The Rise of Addictive Technology and the Business of Keeping Us Hooked." You can liken it to aiming for a healthy diet, Dr. Alter explains: "Older kids understand the concept of balance intuitively—they know that it's important to eat healthy foods alongside candy and dessert, and the same is true of the 'empty calories' that come from spending too much time passively gazing at screens. There's a time for screens, but not at the expense of time for physical activity and connecting with real people in real time."

Some things to keep in mind as you try to strike this delicate balance:

There's no single recipe for success, but you'll know it when you see it. Balance for your family will look different than it will for your neighbor because every family is unique and parenting styles and values vary.

Watch for the warning signs of unhealthy tech usage. The psychologist Jon Lasser, who co-wrote "Tech Generation: Raising Balanced Kids in a Hyper-Connected World," says parents should note when:

- Kids complain that they're bored or unhappy when they don't have access to technology
- Tantrums or harsh resistance occur when you set screen time limits
- Screen time interferes with sleep, school and face-to-face communication

Be prepared to revisit this topic again and again. As your children grow, so will their involvement with technology. Also, it's difficult to predict what the digital world will look like even just a few years from now. Your definition of healthy and unhealthy tech usage will need regular updates. Fun times ahead!

Some tips to evaluate the quality of your children's digital interactions (which you should do regularly):

- Are they accessing age-appropriate content?
- Are the apps they use interactive and thought-provoking rather than passive? Not all screen time is equal. Going back to the food analogy, 100 calories from a doughnut is not the same as 100 calories from a salad; an hour watching YouTube videos isn't the same as an hour spent in a digital art program.
- Are the privacy settings for older children's social media and other online accounts set to restrict what strangers can see and who can contact your children?



Still set screen time limits to balance online and offline activities. Although quality is most important, you'll probably still want to set some screen time limits for your family to preserve time for activities beyond screens and tech. While the debate on exactly how many hours kids can spend on their screens before it becomes unhealthy rages on, you can draw firm lines for tech-free times, such as during dinner, in the car, or on school nights.

Be a Role Model

Technology draws in parents as much as it does kids. We check our phones every hour, log late hours working or surfing the internet on our laptops, binge watch our favorite shows, and even engage in dangerous "distracted walking." Children are likely to not only copy our behavior, but they also are likely to feel like they have to compete with devices for our attention.

Set boundaries for work time and family time. A few key times to stay unplugged include:

- When picking up or dropping children at school, as this is a transitional time for them
- After coming home from work, as that's time to reconnect with your family
- During meals, including when dining out
- During outings like trips to the park or zoo, or vacations when the focus is on family time

As with most parenting topics, constant, open communication is key to helping your family reap the benefits of technology without experiencing too many of the negative effects. 

Ginny's Journey

A CHLA nurse was once a CHLA thalassemia patient.

My name is Ginny and I have beta thalassemia major. I have been getting chronic blood transfusions for the last 22 years of my life at Children's Hospital Los Angeles. During this time I have had approximately 382 blood transfusions, 127 clinic appointments, and a Port-a-Cath insertion and removal. CHLA's clinicians have closely monitored my iron levels, and I have seen three generations of advancement in chelation medications. I can say that my journey thus far has been relatively smooth with just a few bumps along the way.

With each obstacle I discovered something new about myself. Having to understand my diagnosis and to explain to friends and family why I often missed school taught me to be patient when speaking to others. Having to balance my appointments, school, work and everyday life taught me to be mature and to learn time management at a young age.



My experiences during my journey as a patient helped me to better understand my own patients throughout my time in nursing school, and those experiences continue to guide me now that I am a nurse myself. I am so happy that I had the privilege to meet all of the exceptional nurses, providers and patients throughout my time as a patient at CHLA.

I am proud to say that I have accomplished my goal of becoming a Hematology-Oncology nurse at the very hospital where I have received care. For the last three months, I have been a part of CHLA's

Versant™ RN Residency Program. It has been a wild ride and now that I am more than halfway through, I can say the learning curve has been steep. Yet, everyone has been very supportive and I have already learned so much. Being on the other side and providing care to patients was not what I expected. I had no idea how tough it would be to be the one providing care; to be the one who sits with family members while they receive bad news. It has been such an eye-opening experience, and I am looking forward to cultivating my skills as I continue to build my nursing career. 

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 Rauch Family Foundation and the Italian Catholic Federation.

Visit ICF.org For more information.