

Brief Overview of the Affordable Care Act

by Wendy Murphy, LCSW

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (P.L. 111-148). The Affordable Care Act (ACA) is also known as "Obamacare."

Important consumer protections under the ACA:

- Children can remain on their parents' insurance plans until age 26.
- Insurance companies can no longer deny coverage for a preexisting health condition.
- There is no lifetime limit to coverage.

The ACA wants to protect consumers from underinsurance and junk insurance, so health plans have to provide 10 essential benefits:

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Lab services

- Preventive and wellness services, as well as chronic disease management
- Pediatric services for dental and vision

State Exchanges

Many states have established their own health insurance exchanges; others are using the federal marketplace. See the following website to find out about your state: www.commonwealthfund.org/interactives-and-data/maps-and-data/state-exchange-map.

Affordable Options

Medicaid is a no-cost federally funded insurance program. Medicaid is available in all the states; however, 25 states have expanded income eligibility to 138 percent of the federal poverty level (FPL) to allow more people to get coverage, including single adults who were previously unable to qualify. For example, a single person with no dependents can qualify for Medicaid if he or she makes less than \$15,586 (which is 138 percent of the 2013 FPL).

There are also other affordable programs, such as premium assistance to reduce the monthly cost, and cost-sharing assistance that reduces the cost for copays and deductibles. These programs provide assistance to anyone who makes less than

400 percent of the FPL. For example, a family of four could qualify for assistance if together they make under \$94,200.

Open Enrollment

- Open enrollment for 2015 starts on November 15, 2014, and ends on February 15, 2015.
- Open enrollment for 2014 is now closed. To buy marketplace insurance outside open enrollment, you must qualify due to a qualifying life event such as marriage, birth or adoption of a child, or loss of health coverage.

Penalties

The ACA requires that most adults have public or private health insurance by January 2014. Fines increase over three years:

- Fines will be 1 percent of yearly income or \$95 per person whichever is greater.
- For children, the fine for lack of coverage is \$47.50 per child.
- By 2016, fines are projected to increase to 2.5 percent of income or \$695 per person, whichever is greater.

continued on page 2

CONNECT WITH US:

The thalassemia program at UCSF Benioff Children's Hospital Oakland is now on Facebook and Twitter.



<http://www.facebook.com/CHRCOTHAL>



<http://www.youtube.com/user/ThalassemiaOutreach>



<https://twitter.com/ThalassemiaCom>



<http://thalassemia.com/blog.aspx>
<http://NorCalThal.blogspot.com>

Visit us at www.thalassemia.com

The thalassemia is always being updated. Please refer to it for new stories, resources, an event calendar, and more.

IN THIS ISSUE

Page 1: Brief Overview of the Affordable Care Act

Page 3: All You Need to Know about Transition

Page 4: Welcome Kirin Salman

Page 5: 5 Steps to Break Ego at the Doctor's Office

Page 6: Gene Therapy Study for Beta-Thalassemia Major Patients Now Enrolling

Page 7: Exploring Gene Therapy

Page 8: An Interview with Christine Arias

Page 9: Events

Corrections from the Winter 2014 Issue, from the Interview with Chandan Das: Chandan Das is a reader, not a professor, and teaches English at S.B. Women's College in Hyderabad, India.

Brief Overview of the Affordable Care Act

continued from page 1

Example of Covered California Plan Options and Co-pay	Bronze Covers 60% average annual costs	Silver Covers 70% average annual costs	Gold Covers 80% average annual costs	Platinum Covers 90% average annual costs
Primary Visit Co-pay	\$60 for 3	\$45	\$30	\$20
Speciality Care Co-pay	\$70	\$65	\$50	\$40
Emergency Room Co-pay	\$300	\$250	\$250	\$150
Lab Testing Co-pay	30%	\$45	\$30	\$20
X-ray Co-pay	30%	\$65	\$50	\$40
General Medicine Co-pay	\$19 or less	\$19 or less	\$19 or less	\$5 or less
Annual Out-of-Pocket	\$6,350 individual \$12,700 family	\$6,350 individual \$12,700 family	\$6,350 individual \$12,700 family	\$4,000 individual \$8,000 family

Exemption from Penalties

- **Affordability exemption**—if the insurance plan will cost more than 8 percent of household income.
- **Hardship exemption**—such as homelessness, bankruptcy, domestic violence, large medical debts, utility shutoff notice, or death in the family.
- **Policy cancellation**—if your individual insurance policy is cancelled.

Resources

- Complete information on the ACA: www.healthcare.gov; or
- Call customer service 24 hours/day (800) 318-2596/TTY: (855) 889-4325.
- Facts about the Affordable Care Act: obamacarefacts.com.

California-Specific

- Health Care Consumer Advocacy: www.health-access.org.
- Health Consumer Alliance: www.healthconsumer.org.
- California's Health Exchange: www.coveredca.com.
- Call service center: (800) 300-1506/TTY: (888) 889-4500
- 8 am to 6 pm Monday to Friday and 8 am to 5 pm Saturday.

The following two programs provide insurance for patients with thalassemia. CCS is income-based; GHPP does not have this limitation.

1. Genetically Handicapped Persons Program:
www.dhcs.ca.gov/services/ghpp.
2. California Children's Services:
www.dhcs.ca.gov/services/ccs.

Please feel free to contact:

Wendy Murphy, LCSW
Medical Social Worker
Thalassemia Department
UCSF Benioff Children's Hospital Oakland
wemurphy@mail.cho.org

All You Need to Know about Transition

by Liz Morasso, MSW

Within the last couple of years, transition has become a huge buzzword in the medical community, with transition-related programs popping up in the nation's largest medical centers. But what is transition, and how does it relate to thalassemia care and patients' overall well-being? This article is part 1 of a two-part series on transition relating to thalassemia. Part 1 will focus on the topic of transition and its relation to the care of thalassemia patients across the lifespan. Part 2 will address considerations for developing and sustaining transition programs in comprehensive thalassemia care centers.

What is transition anyway, and why is it important?

Transition is a fancy word for change or development. Within medical literature, transition is usually described as relating to both transition, or change, to adulthood, and the actual transfer of medical care to an adult facility or adult-centered care within a pediatric care center. Many have differing opinions on when transition starts; however, most facilities have recognized that transition begins at diagnosis. A patient (and/or family) is told that he or she (or their child) has a health condition, and from that point on, there will be many transitions.

Transition has become an area of interest for many researchers and clinicians, especially as so many patients with complex health conditions are responding to new treatments that have extended their lifespans beyond what was ever imagined. Conditions previously thought of as mainly pediatric diseases, including thalassemia and sickle cell disease, are now being seen in much older populations due to these improvements in disease management. Patients are living, even in the simplest way, with these conditions and experiencing new areas of life!

Transition and thalassemia

For many years, most transition programs focused on transfer—moving young adult patients to adult medical facilities. For some conditions, this is a relatively



Liz Morasso, MSW, is a clinical social worker for the My VOICE Transition Clinic in the Division of Adolescent Medicine at Children's Hospital Los Angeles (CHLA). She received her BA in psychology/education studies from Catholic University and Masters of Social Welfare from UCLA. Upon obtaining her MSW, Ms. Morasso served as clinical social worker for the Division of Hematology/Oncology at CHLA, where she specialized in psychosocial considerations for patients/families with genetic blood disorders. In 2013, Ms. Morasso became clinical social worker for the My VOICE Transition Clinic, a multidisciplinary transition-preparedness service located in the Division of Adolescent Medicine at CHLA. In addition to her clinical work, Ms. Morasso is also involved in initiatives across CHLA focusing on transition/transfer to adult healthcare systems, insurance and access to care, and various advocacy projects aimed at transition-related capacity building for clinicians in the CHLA community. In her free time, she enjoys indoor cycling, swimming, and spending time with her husband and two cats, Gregory and Carla.

easy transition. A pediatric rheumatology patient moves to an adult rheumatologist who continues the patient's care. Treatments and disease maintenance for thalassemia have exploded (in a good way) over the last few years, much to the surprise of adult hematologists never trained in complex care of thalassemia patients. While moving to an adult specialist familiar with adult disease processes has its own complexity, moving

patients to adult specialists with little knowledge of their disease can be even more difficult. In response to the emotions and logistics involved, the medical community has accepted that transition includes not only the physical transfer of care to an adult facility, but also preparing patients for all of the changes that they will experience throughout their transition to adulthood and other lifelong milestones. Examples of such changes may be a patient discussing more mature topics during a medical visit, going to college, starting a family, getting a job, navigating the healthcare system, and enhancing relationships with family, partners, friends, and coworkers. It is now widely accepted that without transition preparedness, or preparation for the emotional and more tangible changes as we develop, transfer or change in focus to adult-centered care is even more difficult. Also, when patients aren't feeling good about other areas of their lives, it decreases motivation to be an advocate or expert and follow through on medical needs.

How do I—or how does my child—get started on transition?

It is never too early, or too late, to start thinking about transition. Transition also looks different for each patient and family. As mentioned above, transition planning ideally starts at the time of diagnosis. In early stages of life, it may include ensuring proper insurance coverage, incorporating your child into medical visits, teaching your child about his or her disease, or connecting with other parents or advocacy groups for support. Early to mid-teens is a perfect time to hone in on issues around transition and transfer. It is never too early to ask your medical team about what adult care will look like for your child. This age group is ready to learn, especially if it is about themselves and their bodies. Education around patients' disease process, as well as areas such as sexual/reproductive health and substance use is also helpful at this time. Patients in their late teens can begin to take on many responsibilities related to their

continued on page 4

All You Need to Know about Transition

continued from page 3

health care. Though the parents are certainly not out of the picture, and really never will be, patients can begin to fill their own prescriptions, learn about their insurance, or consult with vocational rehab or their school counselors about educational and career interests. It is crucial to discuss adult care with your (and your child's) providers at this time. Is there an adult facility that I will be changing to? What do I need to do to prepare for transition? How is adult care different, or if I am not changing to an adult facility, how might my care change? Adulthood is a perfect time for organization and exploration: organization, in terms of you and your child's medical needs—do I have an ID? Health passport? Health records?—and exploration, in terms of, what are my relationships going to look like? Am I communicating my needs to those around me like my employer, healthcare team, or partner? What does my support system look like? This stage never ends.

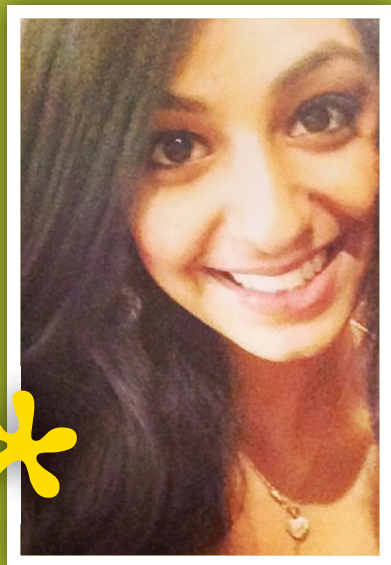
Thalassemia and celebration

Milestones throughout the lifespan that represent transition remind us that we are still here! By recognizing the importance of preparing for, and reflecting on, issues surrounding transition to the next phase of life or change in our medical care, we can better take in what is given to us—the good and bad. Transition is a reminder to celebrate. It is a reminder that we have come this far in our, or our children's, journey. For everyone, whether they have a complex health need or not, this includes emotional and logistical successes and failures! As the medical community expands its interest in transition and transfer, it is important that thalassemia patients have a voice in what this looks like. This may mean becoming more vocal during your medical visits about planning for your or your child's care or speaking with hospital representatives about incorporating more support around transition into your clinic. It can also include

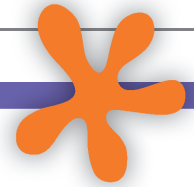
using the support systems around you to guide you through life's toughest transitions. Child life specialists, social workers, or psychologists may help navigate difficult systems or situations for you and your family. Advocacy groups such as Cooley's Anemia Foundation or Thalassemia Support Foundation also provide a community to assist with your transition and discuss issues related to transition and transfer for thalassemia patients. Remember, we are always transitioning, whether we like it or not. Let's celebrate the ability to do so!

INTERN UPDATE

Welcome, Kirin, to the Thal Intern Team!



Kiran Salman is currently a junior at UC Berkeley majoring in molecular environmental biology and psychology. She is extremely interested in becoming a pediatrician and wants to travel the world in favor of stopping world poverty. She has high interest in healthcare advancement and helping children receive better healthcare and a higher standard of living. This is why she believes that her time at UCSF Benioff Children's Hospital Oakland is extremely valuable. By taking a class on campus, Kiran has learned about thalassemia—something she never knew about in her prior experiences. She has a better understanding of the treatment techniques and wants to educate the general public. She is very excited to learn more about thalassemia and to work with a team whose members are as passionate as her!



5 STEPS TO BREAK EGO AT THE DOCTOR'S OFFICE

by Josephine Bila, MSW

Have you ever been around someone who thinks that their status entitles them to receive special treatment in certain situations? An example is when a shopper yells at a sales clerk, demanding services, simply because he or she feels that "the customer is always right." This type of ego-driven dissatisfaction doesn't stop in retail stores. I've seen people act this way towards medical professionals in hospitals, too.

As a kid who grew up requiring tri-weekly transfusions to treat thalassemia major, I became hyper-aware of the way that patients' word choices and behaviors helped or hindered them in their relationships with medical staff. As anyone might guess, the most disliked patients are the ones who are difficult, if not impossible, to appease. These patients go to their doctor appointments making statements like, "I should be getting seen faster," or, "I should be out of here already." They are constantly at odds with whatever is happening in the present moment.

I'm not saying that patients shouldn't stand up for themselves if the occasion calls for it. What I am saying is that patients should realize that hospitals are dealing with an increasing number of patients and a decreasing amount of staff members. Sure, accommodating people is good practice for medical facilities, but when patients huff and puff, expecting priority over others, they are unwittingly creating a hostile environment for themselves and everyone around them. And why would any patient want their doctor or nurse to feel agitated during a time when the patient is feeling most vulnerable?

This brings up an important point: unconscious feelings of vulnerability sometimes cause patients to push communication boundaries with medical staff too far. Through this article, I want to help patients have a better experience with doctors and nurses by teaching five effective techniques to reduce ego-driven, passive-aggressive tendencies.

Ego is a word used to describe a part of the mind that always seems to want more, have more, be more, or confirm its place in the world. When you hear stories of actors saying, "Don't you know who I am?" if they go unrecognized in a public setting, it is their egos talking. This part of the mind causes a lot of unnecessary emotional stress and suffering.



Josephine Bila, MSW, is a life coach, motivational speaker, and the author of "Transfusion: A Patient Survival Guide." She passionately advocates for those who live with chronic illness. Please visit transfusionsurvivalguide.com to learn more about her book and to download a free guided audio meditation. Connect with her on Facebook: [facebook.com/josephinebilafan](https://www.facebook.com/josephinebilafan) and Twitter: @josephinebila.

Let's break the ego's response to being in the doctor's office using these **FIVE STEPS**

1 Patients need to step back and examine where their demands are coming from. Are those emotions called for, or are there alternative methods of expressing feelings of anger, fear, and/or sadness? Understanding one's own emotions about the experience of being in a doctor's office will help reduce the ego's negative stress reaction from being there.

2 Try your best to stay present and not drift into thoughts about the future. Unless you're planning out a specific course of action for a future goal, don't go there. Future planning tends to get us in trouble, regardless of where we are. If you're the type of patient who says, "I should have been seen already!" recognize that you are creating stress that you can control. Focus on your surroundings instead of the inner turmoil of your mind. You will eventually get to where you need to go. Don't project yourself there beforehand.

3 Be considerate. If you are in an open area where other patients are also receiving services, please make your arguments private. No one likes to be around people who are openly airing their disdain for others.

4 Distract yourself. If by chance you know deep down that you are making a mountain out of a molehill, take out your phone and talk to a friend, read a magazine, or take some type of positive action to get your mind off things. This is a much better option than sitting around and allowing your grievances to fester.

5 Be grateful that you have the ability to receive medical care. I gave a speech at the Thalassemia International Federation's conference in Abu Dhabi this past October and learned about the extremely poor conditions in which the people of third-world countries receive care. Most of us are fortunate enough to never know what it's like to stop receiving treatment because the Taliban forced us from our hometown. These things are happening in other parts of the world, so don't take your good care for granted.





GENE THERAPY STUDY FOR BETA-THALASSEMIA MAJOR PATIENTS NOW ENROLLING

by Andrea Giovanelli, CRA, PA-S

A clinical research study, called the Northstar Study, at UCSF Benioff Children's Hospital Oakland is now enrolling patients between the ages of 18 and 35 who are diagnosed with beta-thalassemia major. The purpose of the study is to determine if a one-time investigational treatment, known as gene transfer, is safe and well-tolerated and can decrease or eliminate the need for continuous blood transfusions.

Northstar Study participants should satisfy the following criteria:

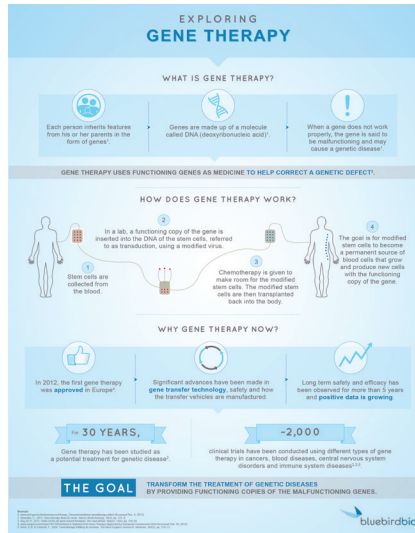
- Must be transfusion-dependent with a history of at least 100 mL/kg/year of packed red blood cells (pRBCs) or ≥8 transfusions of pRBCs per year for the prior two years.
- Treated and followed for at least the past 2 years in a specialized center that maintained detailed medical records, including transfusion history
- No active bacterial, viral, fungal, or parasitic infection
- No Hepatitis B, Hepatitis C, or HIV
- No uncontrolled bleeding disorder

Beta-thalassemia is caused by a malfunction in the gene that makes beta-globin, a protein necessary for normal red blood cells. The goal of the investigational treatment is for modified blood stem cells to become a permanent source of blood cells with a functioning copy of the beta-globin gene.

The study involves collecting blood stem cells, transferring a functioning copy of the beta-globin gene into the collected blood stem cells in a laboratory, and then transplanting these cells back into your body, where they are expected to grow and produce new cells that will contain the functioning copy of the beta-globin gene.

If you are eligible and agree to participate in the Northstar Study, you can expect to undergo these procedures:

- **Mobilization**—you will receive medication to make blood stem cells circulate in the bloodstream.
- **Apheresis**—blood stem cells will be collected from your blood through an intravenous catheter.
- **Transduction**—functioning genes will be transferred into your blood stem cells in a laboratory.
- **Myeloablation**—you will be admitted to the hospital and will receive several days of treatment with chemotherapy to remove



existing bone marrow stem cells to make room for the new ones, which contain the functioning gene. The treatment is intended to allow modified blood stem cells to engraft and multiply.

- **Transplantation**—modified stem cells will be reintroduced into your body via an infusion.
- **Maintenance**—you will recover from the procedures in the hospital and be monitored closely in the hospital by study teams for approximately four to six weeks. After you are released, you will periodically return to Children's for check-ups to evaluate your health and the outcome of the investigational gene therapy treatment.

Participation in the Northstar Study will last for two years after treatment, and participants will be asked to take part in a separate long term follow-up study as the long-term risks of gene therapy are unknown. All costs associated with participation in the study will be covered by bluebird bio, the sponsor of the Northstar Study.

bluebird bio is a biotechnology company dedicated to developing innovative gene therapies for severe genetic disorders. bluebird bio is also the sponsor of an ongoing study in France that is similar to the Northstar Study and has been used to treat three study participants with beta thalassemia. One of these participants is no longer transfusion-dependent.

For more information, please contact:

Cyrus Bascon, Study Coordinator
Department of Hematology/Oncology
UCSF Benioff Children's Hospital Oakland
cbascon@mail.cho.org or (510) 428-3885, ext. 6953

Andrea Giovanelli, Study Coordinator
Blood & Marrow Transplantation Program
UCSF Benioff Children's Hospital Oakland
agiovanelli@mail.cho.org or (510) 428-3885, ext. 5306

To learn more about investigational gene therapy for beta-thalassemia major and the Northstar Study, or to determine participation eligibility, visit www.northstarstudy.com.

Visit www.bluebird.com to sign up to receive future updates about bluebird bio's gene therapy program for beta-thalassemia.



An Interview with Christine Arias

by Laurice Levine, MA, CCLS

LL: When did you becoming involved in the Italian-American Federation?

CA: I became involved with the Italian-American Federation last August. Everyone was so welcoming and supportive, and I feel like I am truly part of a big family.

LL: Can you describe the process of becoming the Columbus Day queen?

CA: Becoming queen starts out with an application. One must fill out information about oneself, get a club to fund them, and turn it in by a deadline. After that is done, there is a dinner where the selection process takes place. Each girl running for queen is expected to come wearing formal wear. They are not allowed to say their name; each girl has a number (candidate 1, 2, etc.). After dinner is served, all the girls are taken to a separate room. One by one, each girl is called out where she goes through the "interview" process. Each girl is unaware of what the questions will be, and there are three judges that score the answers given. After every girl has spoken, the judges discuss and decide on a new queen. After dessert, the girls go back on stage, and the emcee announces who the new queen is. A couple of months after the queen is picked, there is a formal coronation. It is actually an exciting procedure!

LL: What are your duties as queen?

CA: As queen, I am expected to attend all events/dinners the different clubs have. When attending any event, I am expected to wear my crown and sash, and I usually will say some words. I am also expected to do work with a charity of my choice. I am choosing to focus on thalassemia, which affects those of Italian descent, as well as other cultures. So far, I have participated in the walk for thalassemia which was hosted by past queen Chelsea Spencer, and I have co-hosted—with my princess Gina—a blood and toy drive. All the blood and toys we received from donations are going to UCSF Benioff Children's Oakland thalassemia department. Helping the local community is important to me, and I am thrilled to be helping by giving blood for life and toys for joy.

LL: Had you heard about thalassemia before this endeavor?

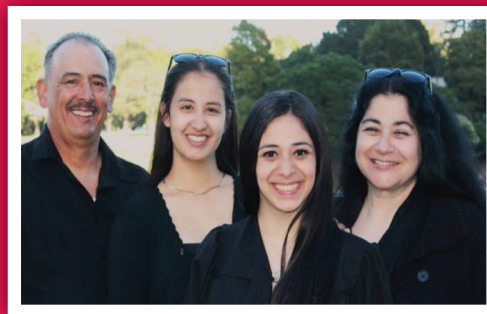
CA: Before I became queen, I had not heard about thalassemia. It is actually because I hadn't heard about it that I wanted to focus on it during my reign as queen.

LL: Why did you continue to dedicate your time to thalassemia?

CA: Raising awareness is crucial to fighting it together as a community.

LL: You have done a lot of activities so far this year for our cause. Can you describe them and what they have meant to you?

CA: I have truly enjoyed all the work done for thalassemia. I have gotten to meet great people [and] work with some truly dedicated individuals, and I feel that we are really starting to spread awareness about thalassemia.



Christina was born and raised in Oakland. She went to Bishop O'Dowd High School and Saint Mary's College of California for both her undergraduate and graduate education. Christine graduated cum laude and majored in history. She enjoys playing the piano, reading, and spending time with loved ones. She is a history teacher, and as she quotes, "I love what I do."

Since the time of this interview Christina landed her first job as a history teacher at Saint Joseph's Notre Dame High School in Alameda. Congratulations Christina!

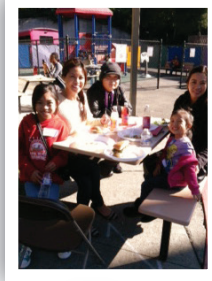
Events, Events, Events

Find out what has been going on for patients, families, and the community



Family Conference

The thalassemia patient/family conference held on January 18, 2014, at UCSF Benioff Children's Hospital Oakland was a success. Approximately 45 patients, families, and professionals attended to hear experts speak on the following:



(Clockwise, top left) Mia Armas playing Bingo;
The Armas Family Enjoying Lunch; Medical play.

Thalassemia Care and Research Update

Elliott Vichinsky, MD, UCSF Benioff Children's Hospital Oakland

Chelation

Ashutosh Lal, MD, UCSF Benioff Children's Hospital Oakland

Health Insurance Update/Affordable Care Act

Wendy Murphy, LCSW, UCSF Benioff Children's Hospital Oakland
Sabahat Rahman, University of California Berkeley

Bone Marrow/Stem Cell Transplant/Gene Therapy

Mark Walters, MD, UCSF Benioff Children's Hospital Oakland

PHRESH Grant Update

Lisa Feuchtbaum, California Department of Public Health

A children's program for ages three and older was run by two child life specialists. Activities included developmentally appropriate teaching on thalassemia and health, medical play, and art projects such as sand art, picture frames, and beading to name a few.

Conference attendees enjoyed lunch catered by Gira Polli of Mill Valley and dined al fresco.

Special thanks to our speakers for sharing their expertise. We would like to thank our volunteers: Sofia Dhanani; Stacey Wong; Kelly Stewart, MA, Children's Program; NNenna Okezi, MA, Children's Program. Special thanks to Nancy Anderson and Apo-Pharma for making this conference possible.

B.A.T.S. High School STEM Career Fair

The B.A.T.S. High School STEM Career Fair was a hands-on career event for all Bay Area high school students to learn cool information about college and career opportunities in the science, technology, engineering, and mathematics (STEM) fields. The event was held on Saturday, March 1, 2014, at Balboa High School in San Francisco. Almost 400 Bay Area high school students attended and had the opportunity to meet and discuss their interests in STEM with undergraduate and graduate students, researchers, and STEM education professionals.

Dinner at BUILD Pizzeria to Benefit Thalassemia

On April 30, University of California at Berkeley students, UCSF Benioff Children's Hospital Oakland staff, and community members dined at BUILD to benefit thalassemia. Ten percent of the proceeds from each meal went to the thalassemia program at Children's. Good food, great conversation, and a lot of laughter made fundraising for a great cause easy as a pizza pie. Thank you to Mint Bhetraratana for organizing this event and to BUILD for their generosity.

www.buildpizzeria.com



UCB interns and friends enjoy dinner at Build.



Annual Mark Santos Motorcycle Run Benefitting Thalassemia

A motorcycle and poker run, delicious food, a raffle, and incredible fun were had by all. Thank you, Roger and Kathy Santos, for your hard work in planning this event.



(Top to bottom) Roger and Kathy Santos standing with myself in front of the motorcycle; Louis and Pat Cordich from ICF Gilroy

Oakland Chinatown Learns about Thalassemia at the Lion's Club Health Fair



Thank you,
Kenny Chen,
for educating
the community.



Thank you, Edith Yuan, for translating
the thalassemia poster to Chinese and for
raising awareness.

Blood Drives

The importance of planning blood drives must especially be emphasized throughout the thalassemia community. The average person with thalassemia receives approximately 30 units of blood a year. It is vital to give back by planning blood drives and encouraging friends and family to donate blood.

The Blood Centers of the Pacific supplies blood to over 50 local hospitals (including UCSF Benioff Children's Hospital Oakland). The blood collected by this organization helps patients throughout our community as they undergo lifesaving surgeries and transfusions. Planning blood drives and donating blood are rewarding and meaningful ways to give back and truly help to save lives!

For more information on how to plan a blood drive, contact:

Laurice Levine, MA, CCLS at LLevine@mail.cho.org or (510) 428-3885, ext. 5427.

Or contact: Blood Centers of the Pacific, 270 Masonic Ave.,
San Francisco, CA 94118, www.bloodcenters.org



Find the Hero in You. Give Blood Three Times a Year.

May 7 marked the Thirteenth Annual Blood Drive for International Thalassemia Day. Thirty-three units of lifesaving blood were collected. Many thanks to the following:

Rosheen Birdie—for helping plan this successful drive and volunteering on that day.

Mint Bhetraratana and American Medical Student Association (AMCAS)—for volunteering on the day of the drive.

Blood Centers of the Pacific—especially Fred McFadden, blood drive coordinator, and the fabulous collections crew.

The donors—who saved lives by giving blood.



Root in the Boot Walkathon

Eager walkers gathered early on May 17 at the Lafayette Reservoir to raise money for the thalassemia program at UCSF Benioff Children's Hospital Oakland. Chelsea Spencer and her sister Bri organized this special event. Thank you to all the walkers and to the Spencer family for their incredible dedication and hard work.



(Top to bottom) Root in the Boot Walkers; Event coordinator Chelsea Spencer waits to give the walkers their goodie bags.

Donations

Students' Hard Work Spans Generations

Victoria Miksis, Elea Davison, and Juli Buehnerkemper—recent graduates from Cardinal Newman High School—completed a very unique and special senior project. The three young women spent countless after-school hours knitting teddy bears with people in nursing homes. Stories were shared, friendships were formed, memories were made...and two adorable baskets of teddy bears were donated to the thalassemia program at UCSF Benioff Children's Hospital Oakland. Victoria, Elea, and Juli, along with Victoria's mother and uncle, came to the hospital and took a tour with Laurice Levine. They all agreed that they were proud to pick such a wonderful program to which to donate their handmade bears. The teddies are adorable and will bring smiles to countless faces.



Teddy bear donation.

Thalassemia Intern Dinner

The UC Berkeley internship program is going strong at the end of its second year. A celebration at Fenton's Ice Cream Parlor marked a semester of dedication, passion and hard work. Congratulations to Wendi Gu for her acceptance into UCSF Medical School and Andrew Shieh for his acceptance into University of Pennsylvania Medical School. While we will miss them, we sincerely thank them for their two years of dedication to the thalassemia program—for pioneering the DeCal program and volunteering countless hours of time. We wish them happiness and much success in their future endeavors.



A Special Visit from Thailand

Nattiya Teawtrakul, MD, and Professor Arunee Jetsrisuparb (l to r) visited from Khon Kaen University in Thailand to tour the hospital and collaborate with the thalassemia team on providing care for their many patients.



(l-r) Franz Kuypers, PhD; Titi Singer, MD; Elliott Vichinsky, MD; Ash Lal, MD.

Italian-American Federation Thalassemia Awareness Blood and Toy Drive

June 14 was the Italian-American Federation Thalassemia Awareness Blood and Toy Drive at the Colombo Club in Oakland, California. Thank you to Christina Aria and her family for volunteering to plan this drive. The drive collected 21 pints of blood. Since each unit of whole blood can be separated into three different components, the blood our staff collected at the location Saturday can help up to 63 patients here in our wonderful Bay Area community.



Gina Arias donate blood and saves a life.

Evening Under the Stars

One hundred forty people gathered at the Chabot Space and Science Center (www.chabotspace.org) on May 3 to support thalassemia. The outer space feel provided a unique sense of excitement, as did the candy bar, which was one of the highlights of the event (www.SFCandyBar.com). Guests enjoyed cuisine by Red Door Catering (www.reddoorcatering.com/). After the thrill of a silent auction and raffle, everyone filed into the planetarium for the debut of a video on thalassemia that celebrated the progress that has been made over the decades. Guests then viewed a celestial show called, "We Are Aliens." We would like to extend gratitude to everyone who supported the event by attending and for the following volunteers and donors who made it possible.



Thank you to Fabiola Ortiz, owner of Pinot's Palette, for donating a multitude of paintings for Children's clinics and the Evening Under the Stars.

www.pinotpalette.com/danville

VOLUNTEERS

Wendi Gu—thank you, Wendi, for co-planning the event. You are a superstar!

Nigina Ali
Eleonor Baldwin-Brown
Mint Bhetraratana
Rosheen Birdie
Beverly Hoh
Diane Jung
Caroline Levan
Cheryl Mar
Andrew Shieh
Steven Srisavat
Pang Vang
Christine Yao
Leslie Yeh
Edith Yuan

DONORS

Trader Joe's, El Cerrito
Yoga Garden SF
Mancini's Sleepworld
Southwest Airlines
Huythong Nguyen
Nancy and Karl Seppi
Miria Garfagnoli
Denise Sangster
Terry and Imma Rosser
Thalassemia Outreach
Jackie Tribolet
SF Candy Bar
Fred and Carolyn Wood
Pinot's Palette
Oakland Raiders
Chabot Space and Science Center
Thalassemia Support Foundation
Hafner Vineyards

Studio Grow
Josephine Bila
Shadowbrook Restaurant
Dharma's Restaurant
San Francisco Opera
Another Planet Entertainment
Leslie Yeh
Theresa and Robert Dianda
Semifreddi's
California Academy of Sciences
Six Flags Discovery Kingdom
Renaissance ClubSport Walnut Creek
Pave Fine Jewelry Design
Lalime's Restaurant
Fine Arts Museums of San Francisco
Diablo Trophies and Awards
Lovejoy's Tea Room
Chris Randal
Julie Tomasin
Supple Integrative Skincare
Albany Bowl
Rockwall Winery
Music One Studios
Jackson Chiropractic
Michael Merrill Design Studio
Stefanie Lum
Beverly and Tony Compagno
Edible Arrangements
La Note
Café Clem
San Francisco Playhouse
Ice Chamber

Susan Winner
Berkeley Repertory Theater
San Francisco Ballet
Joseph Jewell Wines
Canvas on Demand
Maria Zanetich
Chelsea Spencer and Family
Ann Friedman
Albany Bowl
California Canoe and Kayaks
Claremont Resort and Spa
Scandia
Hotel Healdsburg
Oakland Zoo
Noah's Bagels
PF Chang's
Matt Levine
An Nguyen
Gil and Stacy Jackson
Molly Langdon
Greetings
Andronico's
Bay City Bike Rentals and Tours
Children's Discovery Museum of San Jose
Paul Diloranzo
A Step Forward
Blue and Gold Fleet
The Warfield Theater
Cal Berkeley Athletics
Hotel Shattuck
Children's Fairyland
Fenton's Creamery
Sandy Larkin
Autopia
Golden State Warriors
Molly Langdon
Alameda County Firefighters
Venus Restaurant

CORPORATE SPONSORS:

bluebirdbio™
ApoPharma
USA INC

UPCOMING EVENTS

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

SEPTEMBER 2014

September 6: Thalassemia Patient and Family Picnic at Minnehaha Park, Minneapolis, MN.

September 20: 10am-3pm Blood Centers of the Pacific 104 Heroes Blood Drive, Oakland, CA.

September 21: UCB 2014-2015 Internship meeting and Team Building Event, Pinot's Palette, Danville

September 26-28: Feast of San Gennaro Italian Festival, Los Angeles, CA.

DECEMBER 2014

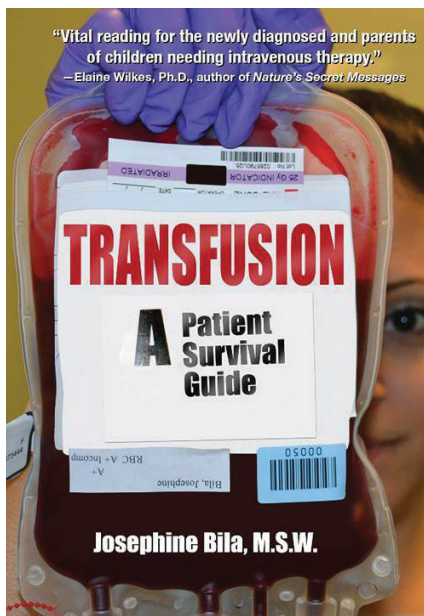
December 14: Annual Thalassemia Holiday Party, Oakland, CA.

PERSPECTIVES

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

Address change requested

"Vital reading for the newly diagnosed and parents of children needing intravenous therapy."
—Elaine Wilkos, Ph.D., author of *Nature's Secret Messages*



TRANSFUSION
A Patient Survival Guide


Josephine Bila's words of wisdom and compassion are like having a guardian angel with you as you enter the sometimes cold and clinical world of needles, transfusions and doctors. This book will keep you safe. Carry it with you at all times.

—Neil F. Neimark, M.D. Founder & Medical Director of *StimulusTherapy.com*

To all who have found themselves squirming at the sight of a needle or fearing the need for intravenous therapy, *Transfusion: A Patient Survival Guide* offers new insight into coping and a ray of hope to those in pain.

Josephine Bila, M.S.W. has received blood transfusions every few weeks over the course of her life to treat a rare disease called beta thalassemia major. Ms. Bila's bone marrow cannot produce functioning red blood cells, so she receives blood donations in order to survive.

Ms. Bila's life-long experience has given her insight into how to live as a powerful patient. Josephine hopes to impart this knowledge onto you by sharing her own personal stories of pain and triumph.



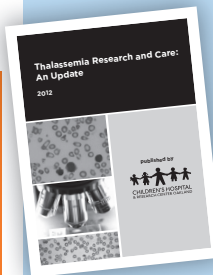
josephinebila.com

Visit us at www.thalassemia.com

The thalassemia is always being updated. Please refer to it for new stories, resources, an event calendar, and more.

Managing Thalassemia during Pregnancy

New guidelines for managing thalassemia in pregnancy announced at the Royal College of Obstetricians and Gynecologists (RCOG) World Congress in India. To view the guidelines: www.rcog.org.uk/womens-health/clinical-guidance/thalassaemia-pregnancy-management-beta-green-top-guidelines-no66.



Scan this with a QR reader app on your smartphone for the new mobile version of the Thalassemia Standard of Care Guidelines.



Perspectives is produced by Senior Thalassemia Outreach Coordinator Laurice Levine, MA, CCLS, at UCSF Benioff Children's Hospital 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.