

**Transplant Recipients International Organization**

**L  feBr  dge**

**San Francisco Bay Area Chapter  
Newsletter**

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An international non-profit group providing emotional support to transplant recipients and candidates, organ and tissue donors, and their families. TRIO also promotes public awareness of organ and tissue donation, and advocates the fair allocation of donor organs and tissues.

**Steve Okonek, Interim Editor  
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## **President's Corner**

### **My August Notes**

Hello TRIO members,

As transplant recipients and candidates, we certainly understand life's ebbs and flows. And after 28 years together, our chapter is bound to experience losses. It's easy to be happy when life is flowing along. The challenge is to maintain this balance when you're not feeling well or facing possible death. Steve Hummer, who passed away in June, met every setback and challenge of his long wait for a second liver transplant with calm good humor. In life, there are obvious heroes who are strong and brave. And there are quiet ones who courageously soldier on. Steve was one of those heroes. We miss him.

How has your summer been going? I hope you Had some new experiences, whether they were

### **NEXT MEETING**

**Join us Thursday, September 12 at El Camino Hospital in Mountain View when we welcome Dr. Kathy Tang from UC-Davis, who will talk about her research in heart transplant at UCSF.**

stay at home, or traveling. It was certainly a new experience for me to participate in the July 4<sup>th</sup> parade in Redwood City that saw us spreading the word the "Organ Donation Saves Lives!" We enjoyed lots of cheers as we walked with our big banner, and a convertible comfortably driven at very low speeds by our Bob Moss. Thanks especially to Ana Stenzel for making it happen.

Another fun activity, as always, was our August 10 picnic. Thanks to Paul Yang and all you good chefs. Next up, is our September 12 meeting, featuring Dr. Kathy Tang (See above), and lastly, don't forget about the CTDN Donate Life Run/Walk on September 21<sup>st</sup>, this time at Santa Clara's Great America.

Do you know about the new UNOS policy on kidney transplants announced June 25? Here is a summary of the policy, which goes into effect in 2014. As you know, TRIO is well represented on UNOS.

- Existing definitions of "standard" and "extended" criteria donors will be replaced with the Kidney Donor Profile Index, (KDPI), a clinical formula that classifies donor kidneys based on how long they will likely function once transplanted.

- The policy will also include a clinical formula that estimates the number of years each specific candidate on the waiting list would be likely to benefit from a kidney transplant. This score is called the Estimated Post-Transplant Survival formula (EPTS).

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# Steve Hummer

## Missed, Remembered

Our chapter lost one of its most integral and longest-serving members with the passing of Steve Hummer on June 14, 2013, in Cleveland, Ohio. He was 64 years old.

Steve served as the chapter's able and cordial treasurer for many years, but his influence on the group extended well beyond this role. Steve touched TRIO with his wit, insight and empathy for people struggling with the myriad of issues surrounding organ transplant.

The vagaries of the Model for End Stage Liver Disease (MELD) scoring system for liver allocation baffled many of us as Steve regularly attended meetings clearly in a state of physical decline. Yet the three scores that make up the MELD were not "bad enough" for him to move up the list here in California.

More than a year ago, Steve told us of his intention to seek an out-of-state transplant center, which potentially offered better organ availability and transplant at a lower MELD score. This was hardly unique as we now meet many Bay Area individuals who went elsewhere to receive their transplants. His choice was the Cleveland Clinic, a very well known and admired transplant center. He wrote in an issue of Life Bridge earlier this year about the many factors that went into his decision. He promised regular reports on his adventure, and we thought of how difficult the transplant process was with a center close by, let alone several thousand miles away.

Steve and his wife Alice, a frequent participant at TRIO events, had been married for 38 years. Their children are son Michael (Abigail) of Porter, Texas, daughters Stephanie (Sergio) of Okinawa, Japan and Alison (Joshua) of Morgan Hill, California and six grandchildren. Also surviving are Steve's mother Margaret, brother Greg (Sydney) and sister Martha (Gary) both from the East Bay.



On Sunday, July 14, a large turnout gathered at a San Jose club for a celebration of Steve's life. Many TRIO members were present at the event. We heard his children, friends, and relatives share memories of how Steve touched their lives.

Paul Yang, another long-time liver recipient, reflected on our loss saying, "Every time I saw Steve at meetings, I saw myself 25 years ago – very fragile. I so wish he could have pulled through all the difficulties he was facing, and he fought with all the strength he had. In the end, it was too much for his physical condition, and I am missing a big brother." Steve touched all of us in TRIO. We all deeply sympathize on this loss with Alice, their children and grandchildren and join them in remembering a loving and energetic man.

*Steve Okonek*

## Infectious Disease Expert Addresses TRIO Members



**Dr. Dora Ho**

Dora Ho does not subscribe to the “take a couple aspirin and call me Monday morning” school where transplant patients are concerned. Infections present considerably more challenging moments in this population, making procrastination ill advised.

Dr. Ho, Clinical Chief of Stanford’s Division of Infectious Diseases and Geographic Medicine, emphasized this point and many more in her June 13 presentation at our monthly chapter meeting. “Understand who you are. The expression ‘wait and see’ doesn’t apply to you as it would the general population.”

She described the four kinds of infection sources – bacteria, virus, fungi and parasites – and noted the common medications prescribed for each type. (Parasitical infection is very rare in the U.S., but may present risks when traveling overseas.) The common thread spanning all four is that immune-compromised individuals are more likely to get them, get them more severely, and present them in an atypical way. Dr. Ho distinguished the infection dangers presented at the time of transplant vs. those in

everyday life long after. Organs vary in susceptibility with hearts and lungs being the most vulnerable while kidneys are the least. One getting a lung due to cystic fibrosis is far more likely to face infection problems compared to a recipient due to COPD. And a liver recipient who suffered from Hepatitis C will be far more vulnerable than one who was transplanted following liver failure due to poisonous mushrooms.

“If you and your spouse go to the movies, sit together, and are equally exposed to something infectious.” she notes, “the transplant recipient in this couple will always wind up with the infection and generally a worse one.”

Discussion covered a wide variety of specific risks – tattoos, sushi, acupuncture, Jamba Juice, and home gardening. Dr. Ho emphasized paying immediate attention to cuts and deep scrapes. Clean up the wound immediately with soap and water, and then apply Neosporin or hydrogen peroxide. Certain foods presented similar risks, and she strongly discouraged recipients from eating products made from unpasteurized milk.

A perennial problem Dr. Ho cited in treating transplant patients is that they frequently don’t remember what medications they take. Coming to a clinic with a full-blown infection is an even bigger challenge, and she urges, “Write down every pill you take and the time you took it. When you are ill, I guarantee you won’t remember exactly what you had put in your mouth.”

She emphasized being the squeaky wheel, both at home and at the clinic. “Having support was critical in your being transplanted,” she said. “Someone living under a bridge isn’t going to get a transplant. If the clinic doesn’t call you back, keep calling and calling.”

She shared strange cases that reflected the detective nature of her job: The strict Jewish family that contracted a pork-borne bacteria and the man whose pet dog faithfully licked the wounds on his legs.

But it all boils down to transplant patients needing to “lower their threshold for seeking medical attention or asking for medical advice.”

*Steve Okonek*



*A first for the SF Bay TRIO chapter! We march in the July 4<sup>th</sup> Parade in Redwood City, the largest such parade in the entire Bay Area. The crowd size was estimated to be more than 25,000, and we had an excellent reception throughout our walk. We shouted “Donate Life” and Transplant Saves Lives” until we were hoarse as well as tired. Thanks so much to Ana Stenzel for her work in planning this event!*

## **SF Bay TRIO Marches for Life on July 4!**

Photos by Gary Garchar and Steve Okonek

## TRANSPLANT NEWS OF NOTE

### *The Poop on Stool Transplants, or FMT*

The story “Why I Donated My Stool” describes a patient with ulcerative colitis, “a colon riddled with bleeding ulcers.” Facing either a large regimen of immunosuppressant therapy or a total colectomy (removal of the colon), he started reading about a procedure called fecal microbiota transplant, or F.M.T.

While transplanting the stool from one person into the digestive tract of another seems repulsive, it also makes sense. Roughly 60 percent of the matter in stool is bacteria, dead and alive, but mostly alive. While they can make us sick, they also serve many positive functions including aiding metabolism, hormone regulation, and the immune system.

“The microbiome of the digestive system is particularly important. At least a thousand strains of bacteria coexist in a healthy human bowel, and beneficial bacteria are involved in vitamin production, digesting and keeping ‘bad’ bacteria in check. Thus, changes to the gut microbiome can precipitate disease. For instance, taking an antibiotic wipes out both the good and bad gut flora, which can lead to opportunistic bacteria taking over and causing infection. The idea behind fecal transplants is that restoring colonies of healthy bacteria can either dilute or crowd out the harmful strains.”

While controversial, fecal transplants are hardly new. A variation was used for digestive problems during the Ming Dynasty, and they have long been used on sick horses in the U.S. But it is no longer just for Mr. Ed, as testing on humans is gaining ground. The New England Journal of Medicine reported that the first randomized trial of fecal transplants for *Clostridium difficile* had been halted because the treatment worked so well that it was unethical to withhold it from the control group. Nonetheless, there are only 16 centers in the country that offer the treatment.

*New York Times, July 6, 2013*

### *Organ Transplant Observation Program Prompts Second Thoughts*

Harvard Medical School student Nathaniel Morris writes a compelling and emotional essay, “Beautiful Pathologies” in the New York Times Op/Ed section. He notes how popular the organ transplant observation program is in his class, allowing students to shadow doctors performing transplants. “It’s pretty great. When it’s your turn, you might go to a nearby hospital and watch surgeons put in a heart or hop on a private plane, bound for another state, to recover a kidney. Over half of my class signed up the day the forms went online.”

When a beeper went off loudly in the lecture hall during a pathology class, “the entire class erupted in applause and started cheering the lucky student whose name had come up to observe the surgery. This reaction did not sit well with the professor, who solemnly told the class he often cared for transplant patients. “And he reminded us of what we had forgotten: that someone had probably just died. The room fell quiet. We shifted uncomfortably in our seats. Dozens of Type-A medical students, we were ashamed of what we had just done.”

This is a superb essay on a future doctor’s stark emotional dilemma as the beauty of science runs headlong into the face of life’s end.

*New York Times, August 19, 2013*

### *Transplants for Children Spark Controversy over Listing Criteria*

The mother of a 10-year old Pennsylvania girl recovering from two lung transplants said she had been taken off oxygen and was doing well. Janet Murnaghan said Sarah has started to walk around the hospital with the aid of a walker, and has even gone outside briefly. The Newton Square girl with end-stage cystic fibrosis received the transplants after a federal judge intervened in her parents’ lawsuit challenging

national transplant rules. Sarah's first set of adult lungs had failed.

(Note: My UNOS sources say this will be a sensitive but important issue in the future, as management of transplant waiting lists by the judiciary presents unforeseen levels of complexity to an already challenging allocation system.)

*San Francisco Chronicle, August 26, 201*

## TRANSPLANT BIRTHDAYS

Paul Yang	8/20/1988	Liver
Nancy Hacker	8/21/1992	Liver
Robert Siirila	8/21/2004	Liver
Ruth Harrell	8/15/1989	Liver
Marjorie Beckman	9/11/1994	Liver
Kate Lutz	9/21/2011	Kidney
Rodney Keck	10/4/1988	Liver
Steve Hummer (RIP)	10/22/1994	Liver
Gloria Ramos	10/11/2000	Kidney
Linda Smith	10/30/2008	Heart

## ***BAAKP Event***

On Sunday, September 22, BAAKP features two experts speaking about early intervention and sources of ongoing support following a chronic kidney disease (CKD) diagnosis.

Dr. Glen Chertow, Chief of the Nephrology Department at Stanford Hospital will discuss "Stages of CKD: What do they mean, and what should we do?" Dr. Nancy Powers, a psychologist, will then talk about emotions associated with a CKD diagnosis, and a panel will share their stories.

The free event starts at 1:00 pm at the Palo Alto Medical Foundation, 795 El Camino Real, 3<sup>rd</sup> floor conference room. In addition to social interaction and patient support, there will be refreshments and door prizes.

**To reserve a seat, go to [www.baakp.org](http://www.baakp.org) or call 650-323-2225.**

## ***Monet's Notes. (continued from Page 2)***

- A limited number of kidneys expected to function the very longest will be considered first for candidates expected to need them for the longest time. I read this as "the best kidneys go to the youngest recipients." ISSUE: Is it harder for older candidates to receive transplants? Or, to get "good" kidneys? Or, to get second transplants?

- The 15 percent of kidney offers estimated to have the shortest potential length of function based on KDPI score will be offered on a wider geographic basis. ISSUE: Will these go only to older patients? Will hospitals be reluctant to use these kidneys because the percentage of failures?

- Transplant centers no longer owe "payback" kidney debts when they accept a well-matched kidney from a different organ procurement organization (OPO).

- The waiting time calculation is as the current allocation system: the longer a candidate has waited for a transplant, the more priority he/she will have compared to others who have not waited as long.

- The current national default policy assigns wait time when the candidate is listed with the program, even if he or she had begun dialysis or met other criteria for end-stage renal failure before being listed. Under the amended policy, the wait time of a person accepted as a transplant candidate would be calculated first from when he/she had a GFR score  $\leq 20$  ml/minute, or when the candidate began dialysis or other renal replacement therapy, even if that date preceded the transplant listing.

Monet Thomson  
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**MEMBER NEWS:** **Ana Stenzel** is resting at home after treatment at the Mayo Clinic earlier this month. She has good days and bad, and sleeps a lot. Isa writes that although Ana is not able to respond to phone calls and emails, she appreciates our cards and expressions of care. Our chapter sends our heartfelt love and best wishes to you both, Ana and Isa.

Your interim editor is completely responsible for the lateness of your August newsletter. **Steve Okonek** is recovering after 17 days at UCSF following a hematoma apparently caused by an overdose of LovenoX prior to a hip replacement surgery that had been set for July 30. The faulty hip stays until several months after the hematoma disappears. While painless, the immense hematoma, covering the right side of his chest is disappearing extremely slowly.



**Pictures from 2013 TRIO picnic, August 11. Top picture is by Yi-her-Jou. Lower picture, by Gary Garchar, shows picnic organizer and egg roll king Paul Yang.**