We are an international non-profit, founded by renowned transplant surgeon Thomas Starzl, that provides 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 for the fair allocation of donor organs and tissues.

Steve Okonek, Editor
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SF Bay Area Chapter
Transplant Recipients International Organization
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(Find TRIO online at www.trioweb.org for the national level and www.bayareatrio.org for the San Francisco Bay Area chapter)
President’s Corner

Congratulations to all who participated in the Transplant Games held in Cleveland this past June. And a special thanks to Steve Okonek who hosted a seminar about TRIO’s work in identifying specific post-transplant cancer (PTC) risks and best practices. It drew an excellent turnout due mainly to Cleveland’s TRIO chapter publicizing it at their booth. In raising awareness of PTC, he has also raised awareness of TRIO. As you know, Steve is now TRIO’s vice president at the national level and is making a difference there.

TRIO is grateful to the biotech company CareDx for its support over the years. CareDx has developed a blood test that detects rejection in heart transplant recipients (thus avoiding a biopsy), and is developing a similar blood test for kidney rejection. I also spoke at a local meeting of the Emergency Nurses Association, along with Phyllis Monroe. It’s fun to get out into the community and meet new people and show that organ donation saves lives.

We had a good turnout at our July meeting. Joel Riff came to say goodbye – he has moved to Chicago. We sure will miss you Joel. Robert Negrete and his wife Melissa came to say hello. Robert is a long-time member, but since they live in Los Banos, it’s been years since we’ve seen him. Congratulations on your liver transplant, Robert.

I went to my skin doctor last week. Do you have regular appointments set up? Six months apart would be a good idea if you take a lot of immunosuppressants, and we’ve had numerous members talking about how their dermatologists are increasing the frequency of follow-up visits for their transplant patients. While at the Kaiser-Lawrence facility, I noticed a sign for their Heart Transplant Service. This is a well-staffed clinic. They even have a psychologist and diabetes educator in the group.

At a recent visit to the Nephrology Clinic at Kaiser San Francisco, I asked to speak to the social worker and gave her a TRIO brochure and card. I asked her to refer patients to us if they needed some support. As a result, we have gotten some new members. Do you know the social worker at your transplant clinic? Let me know if you need some brochures to take to your next appointment.

On July 29th, the Okoneks and I had a good visit with Stacey Collver, who is awaiting a second lung transplant. Stacey looks great and shows a lot of spirit and humor during this waiting period. Rock climbing had been one of her passions in the past, and she was recently featured on the American Ninja Warrior Show! One of the climbers she coached, Josh Levin, was a finalist. He credits Stacey with much of his success, and Stacey says he’s become an organ donation advocate as well. At the September meeting, we’ll be showing a clip from the nationally televised competition featuring an interview with Stacey, and its great fun to watch.

Stay healthy,

Monet Thomson
http://www.bayareatrio.org/
Email: info @bayareatrio.org
TRANSPLANT NEWS OF NOTE

Is Full-Body Transplant Viable or Crazy?

Could the future of transplantation include removing two heads from two bodies, and then connecting the donor’s body to the recipient’s head? A Chinese surgeon wants to try it.

The idea belongs to orthopedic surgeon Dr. Xiaoping Ren of China’s Harbin Medical University, and before you scoff, note that he was part of the team at the University of Louisville that performed the first hand transplant in the United States. He spent 16 years practicing medicine in America before returning to his Harbin home.

The example cited in the story hopes to help a man paralyzed from the neck down in a sports accident. Dr. Ren, called “Dr. Frankenstein” by more than a few media sources, carried out a successful head transplant on a monkey earlier this year, but the chimp survived only 20 hours. Obstacles galore stand in the way, including the need for a lightning fast operation, difficulty in reconnecting spinal cords, and the unlikelihood of a solution that can store a head for a period of time similar to kidneys, livers, and hearts.

New York Times
June 12, 2016

Could Vouchers Ease Kidney Crisis?

A kidney donation incentive idea which originated at UCLA is spreading to more hospitals as the renal transplant wait list continues to soar. “Here’s how it works: If you donate a kidney now, you will receive a voucher that a loved one could use to secure a kidney in the future.” The program has just been approved by the Ethics Committee of the American Society of Transplant Surgeons, and has been sent to the group’s executive committee for formal approval. So far, ten hospitals have joined UCLA in the effort. The wait for a kidney transplant shows no signs of abating.

The wait list for kidneys alone now exceeds 100,000, and about 30-million people with chronic kidney disease may well gradually join them. About 85% of those on the kidney wait list in 2015 are still waiting.

Wall Street Journal
August 4, 2016

White House Organ Summit

President Obama and the White House Summit Actions Group hosted an Organ Summit on June 13th in Washington. In a very short 90-minutes, various speakers gave brief 5-minute oral presentations sharing the technical efforts they were involved in, followed by a three-member panel discussing research that may going to human trials within the next 18 months.

You can access both the two-hour video (TRIO President Jim Gleason suggests skipping the first 32 minutes) and/or a 16-page summary document via the TRIO website <trioweb.org>.

Cu in the Hospital

We all know that using copper for coinage makes perfect cents. But less understood are its microbial properties that make it a potential weapon for combatting the spread of infections in hospitals and public areas. The Environmental Protection Agency claims copper surfaces can destroy 99.9% of bacteria within two hours, and copper carts, sinks and doorknobs are becoming more prevalent in many hospitals. The recent drop in copper prices is a factor leading more health care professionals to consider using a copper alloy, but it remains far more expensive than stainless steel or plastic. Copper kills bacteria by draining electrons, which provide energy, and by pumping copper ions into the cell. This destroys the cell membrane, DNA and proteins, causing the cell to die.

Wall Street Journal
July 26, 2016
Team Portrait, Team NorCal

NorCal’s Jill Nolan – High Jump

Team Stenzel: L to R, Judy Nolen, Reiner, Hatsuko & Isabel Stenzel and Jill Nolan

Anna Modlin, Woman Athlete of the Games

Trailer Decorated for TGA

TRIO – Cleveland Chapter booth

TRANSPLANT GAMES 2016

Team Nor Cal medal winners in Cleveland included Jerry Benterou, Lizzy Craze, Ben Dao, Matt De Fina, Igor Gopp, Marty Holmes, Pati Hughes-Fudge, Danielle Mandella, George Minarik, Peggy Morris, Jill Nolan, Scott Pinner, Randy Stafford, Johnny Valoroso, Lacey Wood, Anna Modlin and Isa Stenzel-Byrnes. Many more images will be posted in color on the SF Bay Area TRIO website for you to browse through.
Team NorCal’s Coed Basketball Squad

Donor father/advocate Joe Chairez

Medal Awards Ceremony

Swapna Kakani with her father.

Rusty & Katie Lutz & Gelsey

Pati Hughes-Fudge with medals

Isa Stenzel-Byrnes with medals

UNOS “Art of the Scar” Exhibit
TRIO-Sponsored NorCal Team Shines in Cleveland

The Golden State Warriors didn’t quite earn a title in Cleveland this past June, but Team NorCal filled in more than admirably as the country’s Rock & Roll Capital played enthusiastic host to the 2016 Transplant Games of America (TGA) in June.

The team, sponsored by our SF Bay Area TRIO chapter, finished with 70 medals (28 gold, 30 silver and 12 bronze). And capping off the terrific showing, the team’s co-manager Anna Modlin was named Woman Athlete of the Games. The team’s other co-manager is Lacey Wood, now living in Southern California.

Modlin, who you recall had a prominent role in the movie, “The Power of Two,” took eight gold medals in Cleveland. Seven were in swimming events, long her specialty. But the eighth was in golf, which she took up just nine months ago “determined to learn a new sport!”

The Games continue to morph into a ‘something for everyone’ fest as athletic events broaden beyond the familiar track, field and swimming events into the realm of Texas Holdem poker, darts, bocce ball, bowling, volleyball, cornhole, etc., all with great live music along with ample free t-shirts, towels, stationary, and bags to stuff into your suitcase.

While many Team NorCal members are veterans of past Transplant Games, newcomers just eligible due to their recent transplants, performed exceptionally. New TRIO member Pati Hughes-Fudge, for example took bronze medals both in the 100-yard dash and 40-meter breaststroke as well as silver in the 4 x 400 yard relay. And Pati is only 8 ½ months out from a liver transplant at Stanford!

While UCSF and Stanford recipients figure prominently in the roster, the team is hardly all Bay Area. Members also hail from Murphys, Napa, Hollister, the Sierra Nevada, Watsonville, and all over the Sacramento area.

The interactions though go far beyond the tracks, pools and courts. For example, some of the remarkable individuals I was honored to meet included Swapna Kakani from Team Alabama, who attended my post-transplant cancer seminar. She asked why we had no information on intestinal transplants on our TRIO website, and shared an eye-opening account of what this surgery must be like. She has now joined our efforts. Janet Ramsey and her daughter came with Jack Eigel of Team Wisconsin. Milwaukee resident Jack carries Janet’s late son’s heart, and donor family with recipient situations like this were not at all uncommon at the games. Finally, Jess Chairez, who lost his 24-year old son, Joe Chairez, a Sacramento police officer in the line of duty in November, 2000. Jess and wife Theresa made the decision to donate their son’s organs, and Jess has been going nonstop since then carrying on his son’s legacy with organ donation awareness efforts, comforting donor families, encouraging recipients and helping those in need. An engaging conversationalist, Jess will keep you spellbound talking about how his donor awareness efforts intersected with his time helping people after catastrophes like hurricanes Katrina and Sandy. (www.joe238.com)

Team NorCal headquarters were at a nice new Hilton overlooking Lake Erie, the Cleveland Brown’s stadium, and the Rock and Roll Hall of Fame. The rust belt was apparently well hidden elsewhere. The co-manager’s mothers, Colleen Wood and Robin Modlin, opened their suites for grab and go breakfasts and lively post-event socials while relentlessly cheering the team on.

The Cleveland Clinic, one of the country’s top-ranked hospitals, was ever-present along with a number of other area transplant centers. The scrappy NorCal basketball squad improbably upset a New York City five who averaged at least a foot taller. All and all, the only things missing were Steph and LeBron!

Steve Okonek
BOOK REVIEW

“Cure”
“A Journey into the Science of Mind over Body”

By Jo Marchant

We are all familiar with the placebo effect often emerging in drug trials, which causes anything presented as medication to “work.” It is the purest example of the mind’s influence on the body. Less well known are the peculiar occurrences of patients, being fully informed that they are receiving placebos, yet still reporting improvements in their condition. What’s going on?

Emerging evidence suggests that the mere expectation of, for example, reduced pain can naturally release endorphins in the brain, making the placebo effect a physical mechanism as concrete as any drug. Did you know you can purchase placebos online? Fittingly, the bigger and more expensive the pill, the better the results!

We know that inflammation induces fatigue and depression; low blood-sugar levels make us short tempered; calming our bodies – by deep, slow breathing for example – improves our mood.

Marchant leads the reader on a whirlwind tour through real-life situations, of various mind therapies as applied to numerous maladies. Therapies include homeopathy, acupuncture as an adjunct to chemotherapy, cognitive behavioral therapy, graded exercise therapy, hypnosis, heart rate variability biofeedback and mindfulness. Chronic Fatigue Syndrome is one of many maladies cited.

The author describes a few transplant-related research efforts examining how newly identified neurotransmitters might influence immune response. The goal would be to have the mind act as a tool in enhancing immunosuppression, thus leading to using lower doses of dangerous antirejection medicines. This human-conditioned response is called Placebo Controlled Dose Reduction. (PCDR). The work described thus far is entirely outside of the United States.

The obvious rub for future research is that pharmaceutical companies, who finance 3/4s of clinical trials in this country, will not touch it. They are not in the business of promoting reduced dosages of their medicines, nor are there any obvious financial gains that would attract investors. While it might save the government billions in drug costs, the U.S. pharmaceutical lobby has effectively nixed it. Who’s going to finance a proof of concept?

The coup de grace is Marchant’s trip to Lourdes, France, where she volunteers carrying stretchers of hopelessly ill people from all over the world, to a dark grotto, home to a spring with legendary healing waters. There they are plunged into a bitterly cold pool for only seconds. She then introduces you to the Lourdes Medical Bureau, assembled by the Vatican in 1883 and sanctioned again in 1905, to assess whether the claimed miracles are truly the real deal. Its current chief is Alessandro de Francis, a former pediatrician from Naples, Italy, who has a medical degree from Harvard.

Loads of evidence points to people of faith who worship regularly being healthier and happier than those who don’t. Is this merely a kind of placebo effect? And if so, what’s wrong with feeling healthy and happy? “The United States is the richest country in the world with the most drugs prescribed,” she says, “yet our life expectancy significantly trails a country like Costa Rica.”

Marchant, an Englishwoman, writes in a genuinely bright, thought provoking, readable manner. It’s an easy book to digest and interesting in that it covers a broad swathe of areas where researchers suspect the mind may have a hand in healing. If you’re of like mind, the book provides plenty of ammunition for the cause.

Steve Okonek
Financial, Legal and Insurance Advice for Kidney Patients
BAAKP Event in Oakland

A blue-ribbon panel of experts will join us on September 11, 2016 to help you sort out your non-medical kidney problems. These problems include costs, coverage, availability and roadblocks to treatment. Specialists from the fields of dialysis, transplant, Medicare, commercial insurance and the legal world will present how they can help the kidney patient deal with these dilemmas. Be prepared and bring your questions!

Please join us on Sunday, September 11, 2016, from 1-4 pm for this FREE event. It will be held in the Fir Room (1st floor) at Alta Bates Summit Medical Center, 350 Hawthorne Avenue, Oakland, CA 94609. Reserve your seat online at http://tinyurl.com/baakp-Sept2016 or at www.baakp/events or call 650-323-2225 to register. Refreshments and door prizes too!

Donate Network West’s
Donate Life Run/Walk

The 2016 Donate Life Run/Walk sponsored by our friends at Donor Network West will be Saturday, September 10th in Walnut Creek. The event is always a hoot, with special surprises every year.

The website registration links have changed since the last TRIO newsletter, so go to Donate Network West’s “mother ship” site http://www.donornetworkwest.org and follow the links to participate in this excellent event. This year’s t-shirt is a particularly good one.

Want to Join SF Bay Area TRIO?

The upcoming year promises to be a fun one for our TRIO chapter with interesting speakers, the Transplant Games, this newsletter, and our usual great events like the picnic and holiday bash. If you want to participate, send your name, address, email address, phone, along with a tax-deductible check for $25 made to SF Bay TRIO to membership chair Tamara (Tammy) Do, 1585 Beach Street, Apt 102, San Francisco, CA 94123. If you find it financially difficult to join, we will gladly extend a full and confidential membership at no cost. Simply email Tammy at <tndinsf@gmail.com>.

Additionally, if you have member news items, send them to Lifelines Editor Steve Okonek (okoneksteve@comcast.net). We welcome story submissions.

TRANSPLANT BIRTHDAYS

Our list is now in flux due to lapsed memberships and incomplete data from new members. It should return in the next issue.

Vital Signs

Helpful Math Equivalents:

1 kilogram of falling figs = 1 Fig Newton
10 cards= 1 decacards
A half bath= 1 demijohn
1000 grams of wet socks = 1 literhosen
1000 aches = 1 megahertz
Half of a large intestine = 1 semicolon
22000 mockingbirds = 1 kilomockingbird
1 million microphones = 1 megaphone
2000 lbs of Chinese soup = Won Ton
Basic unit of laryngitis = 1 hoarsepower
1 millionth mouthwash = microscope