



Lifelines

Summer 2014



Transplant Recipients International Organization, Inc.

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“California, Here We Come!” TRIO’s 2014 Leadership and Educational Summit

Excitement is building as presenters and sponsors are finalizing details for TRIO’s fourth Summit, designed not just for TRIO leaders, but expanded to include educational opportunities for everyone. This year the Summit, with strong support from the local TRIO Ventura County/West Valley Chapter, moves to Los Angeles, CA, after three prior events on the east coast, thus affording easier access for our central and western membership.

What can you expect? Beginning on Friday, September 19, prior to the Summit, there is a national TRIO board meeting at the offices of One Legacy in downtown L.A. from 9:00 to 11:00 a.m., open to all. The Summit opens at noon with a welcome box luncheon followed by seven TRIO topic- centered panels and workshops from 1:00 to 5:00 p.m. Friday evening features a dinner and awards event sponsored by the University Kidney Research Organization (UKRO). The dinner event will be held at the L.A. Hyatt hotel, across the street from One Legacy. Our keynote speaker for the dinner is the new UNOS CEO, Brian Shepard, along with speaker, Lorrie Hartwell, founder and president of the Renal Support Network (RSN).

Saturday is filled with world-class medical professionals presenting on many transplant related topics and is expected to draw many from the local medical community in addition to our TRIO members.

How much and how to register? A registration fee of \$50 for dues-paid TRIO members covers all workshops, presentations, two lunches, refreshment breaks and the Friday awards banquet. (Non-TRIO attendees pay \$75.) The L.A. Hyatt is the event site and special TRIO room rates for the first 25 registrants are available for \$149 (+ taxes) per night. Depending on pending grant applications, there may be scholar-ships available (in the past these have

been up to \$200) for TRIO members who need help with their travel and lodging expenses.

Plans are for more than 150 attendees. We hope that YOU and your family will be among them.

Click on or go to <http://trioweb.org> for further details and registration information.

TRIO Welcomes New Chapter in Texas

TRIO is pleased to announce the formation of the TRIO Central Texas Chapter. The chapter, headquartered in Temple, TX, serves the north-central Texas region including Temple, Killeen, Waco, Hillsboro, and Dallas.

Early in 2014, Amanda Raye Jones, LMSW, set out to form a TRIO chapter. Raye is a Cardiothoracic Transplant Social Worker with Baylor Scott & White. She was diligent in her tasks and by May, the Central Texas Chapter was formed with 22 members. Raye says: “We are trying to reach 100 members by the end of the year.”

Raye serves as President of the new chapter. Other officers are: David Morgan, Vice President; and Hector Flores, Treasurer.

Visit the chapter’s website at:
www.triocentraltexaschapter.yalosite.com

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Plus many interesting and exciting articles you shouldn’t miss. Please let us know what you think! (see page 12)

President's Message



“The longer I live, the more I realize the impact of attitude on life. Attitude, to me, is more important than the facts.”

-Charles Swindoll

Each morning, when I awake, my first thoughts are this daily mantra:

“Wow, above ground another day – This is going to be a great one!”

• Jim Gleason

No matter what happened the day before, this day is another opportunity and we have a choice to make of our attitude in facing that day. Attitude became an underlying theme for this issue and I hope you, too, can find your opening daily mantra to set the stage for your own ‘great day’ fueled by that positive outlook, a gift possible by your life-extending organ transplant.

Let me open with a special welcome to our third new chapter: the TRIO Central Texas Chapter joins TRIO Pacific Northwest and TRIO Maryland in a growing TRIO network of chapters serving their local communities.

Where is our next chapter going to serve? Only time will tell as some of our many listed support groups may develop into fully chartered chapters in the months ahead. Nice work, Sylvia, in supporting them in that chartering process that often takes many months. Check out that newest Texas contact information on the web site and send them a welcoming note of support yourself.

I feel proud to see this Summer *Lifelines* issue featuring more than 20 educational and action-challenging articles contributed by seven authors (thanks to Steve, Rodger, Harvey, Pat, Marty, Erin, and, of course, Sylvia) making this one of our broadest and most exciting *Lifelines* yet. With colorful photos, graphics, and live links throughout to make it easier to move beyond just the reader's page, we're adding another dimension to this TRIO communication resource with those technology enhancements. I hope you are taking advantage of them by clicking through and enjoying each issue more and more.

Of course, that is only possible for those who are opening and linking to this on-line

document, so see what you can do to help improve our readership in the **“Are you reading this?”** article challenge. (PS: a special thanks to those who have already given feedback in response to that invitation recently; we read and take your input seriously).

You will also notice our growing focus on TRIO's **BIG ‘C’** challenges of **post-transplant ‘C’ancer** and **effective ‘C’ommunications** that will gain on-going attention in the months and years ahead. As one who has so far faced and survived prostate cancer (2001), kidney cancer (2012) and many skin cancers in my 20 years since heart transplant in 1994, I am passionate in joining Steve Okonek and others in bringing the power of an engaged TRIO to bear in support of our transplant community living with higher risk for cancers. This is one of the biggest challenges TRIO has ever undertaken and we hope that you and everyone will come together to support and benefit from this work which will span years of development but even more years of long term life benefit for our members and the whole transplant community. Stay tuned for special initiatives with opportunities for you to help.

But don't just read the articles, see if there is some action you can take away from each. That's where the real power will come from: your personal action follow-up. As you read about the upcoming Leadership and Educational Summit, for example, is there any way you can join us in L.A.? Or maybe your chapter can sponsor a representative to come, either yourself or someone else who may not be able to afford it on their own but would be willing to give the time if they were sponsored?

And in a final note, check out the UNOS opportunities to learn more about the upcoming new kidney allocation process going into effect this fall, or about the status of research on changing the liver allocation by districts to improve waiting time and survivals of those facing a liver transplant. There are so many exciting things going on every week to check out on our active TRIOweb.org web site to stay informed and inspire that daily attitude choice we all have.

As for me, **“Wow!, above ground another day...”**

--Sincerely, **Jim Gleason**, TRIO President
(celebrating my 20th year post heart transplant)

And Speaking of 'Attitude' . . .



Check out program #61 as July's [TRIO Transplant Presentation Library](#) offering a growing collection of now 63 titles. In this very special sharing by caregiver, mother and author, MaryAnn Raccosta, titled "[The Survivor, The Hero, The](#)

[Angel: A Mother's Story - One Decade](#)" (<-click to see full flyer), you will be moved at how her inspiring attitude survives the daily health and transplant challenges of not one, but two, very handicapped boys (and a daughter) for over ten years to date. I promise you that your own life will be changed in the viewing. The TRIO Philadelphia Chapter hosted this author and the attendees were blown away by her faith, family dedication, and energy in dealing with the everyday, never simple tasks that you and I take for granted each day in our own lives.

This is just one of many great free programs available for members-at-large (by calling the national office for a copy) or in your local chapter library. Also recently added and scheduled for distribution (click titles for program flyer) this summer are **Pgm 62: "Transplant Life Experience from Two Sides"** (90 min) by George Alburger, MSN, RN, and lung recipient (Release date: August '14) and **Pgm 63: "Returning to a Life's Dream"** (59 min) by Lynne Samson, Esq., Retiring CEO HelpHOPELive (Release date: September '14).

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Chapter Council Challenges

Chapter Council Chair, Marty Maren, continues to reach out to chapter presidents across the country: welcoming the new Temple, TX, chapter president, Amanda Raye Jones; discussing best practices and recent chapter events with Tina Marie Sammon of TRIO Manhattan; working with other chapters sharing their own local challenges, some in common, some unique to that local situation, as just some examples of his contacts. As another example, check out TRIO Maryland chapter's website at http://www.triomaryland.org/calendar_2014 to see how very active that young chapter is.

At the September Leadership and Educational Summit, a panel of chapter leaders representing the stages of chapter life (i.e., new, developing, mature, dormant and recovery under the workshop title: **The Spark, Flame and Re-ignition**) will share their experiences with the challenges and best practices for each life phase.

We look forward to the next Chapter Council meeting now scheduled for **Monday evening, 8:00 p.m. Eastern Daylight time, July 21**. If your local chapter president can't make that schedule, hopefully another representative of the chapter can attend. Marty will be reaching out to chapter leaders before that call to suggest a discussion topic that will go beyond the traditional reporting of chapter events, making that call even more valuable for participants. We hope to see your chapter represented both on that call and at the fall Summit in L.A.



Marty Maren (left) Chapter Council Chair, Rodger Goodacre (center) Member of TRIO Board of Directors, and Jim Gleason (right) President of TRIO Board of Directors discuss chapter challenges.



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Post-Transplant Cancer Risk

Jim Gleason and I have been pleased at the response from various TRIO members concerning an evolving initiative on cancer in the post-transplant community. In all cases, these individuals had battled various forms of the disease after transplant and knew the issue well. The challenge to TRIO and the transplant community is making every recipient more familiar with the nature of the risks.

I've been blessed with 21 years post two liver transplants, dealing with occasional skin cancers but getting them removed by a dermatologist who knows the red flag we immune-suppressed recipients fly. Skin cancers are the biggest risk, and it isn't only melanoma. We have lost a TRIO member due to squamous cell cancer. If you aren't regularly using sunscreen and seeing a dermatologist every six months, it's time to start.

Losing several of our SF Bay Area chapter members, most of them young, to other kinds of cancers and watching other members battling the disease has shaken me, particularly as I hear them say their physicians pointedly told them that the immune-suppressants were a big part of the problem. Every human faces cancer (the second largest cause of death in the U.S.), so we are hardly the only passengers in the rowboat. But I'm learning how significantly greater the risk is to particular recipients (sometimes 50x) and those on particular immune-suppressants. As an active patient, you need to be aware, as well.

We have been fortunate to meet with researchers who specialize in the transplant cancers riddle and continue to make connections for the most typical organ transplants. We've seen a number of papers from premier hospitals, such as Johns Hopkins, as well as NKF and the NIH. However, these date back nearly a decade and clearly involve data that is sometimes strictly qualitative and may no longer be as relevant to the issue. And, it is emphatically clear that some transplant centers are slower than others in integrating this risk into overall transplant care.

At our own chapter's recent meetings, we heard from Bay Area biotech researchers explaining the lengthy cycles to identify therapeutic targets that regulate growth, proliferation, and cancer cell survival. And that's before any animal or clinical trials get underway. I struggle to keep my right and left brains from wagering what will come first: cancer cures or new kidneys in a test tube!

I strongly urge you to come to Los Angeles this September for the Leadership and Educational Summit, where this post-transplant cancer issue (and determining how TRIO will address it) will be key topics. We can't start the next chapters of our lives by continually re-reading the last one.

Let's go and take charge of our health!

-Steve Okonek

Secretary, TRIO Board of Directors,
and Past President,
TRIO San Francisco Bay Area Chapter

Annual ITNS Symposium: "One World of Caring"

The annual ITNS Symposium will be held September 27-29, 2014, at the JW Marriott in Houston, TX. The [Annual ITNS Symposium](#) is the premier professional development event for transplant nurses and professionals. ITNS' focus on specialty transplant nursing education and research sets our symposium apart from other educational events. [Come to Houston, Texas](#) to hear from our nursing experts on nursing care of transplant patients, families, and communities during or after transplant. ITNS is committed to the transplant nurse. View the [symposium brochure](#) and [full schedule agenda](#) for more information! The [23rd Annual Symposium](#) includes a wealth of benefits:

- Best practices for the management and education of our transplant patients and their families
- World-class insights shared by the International Panel
- A robust exhibit hall where you can view products and experience new technologies
- Inspiring [concurrent sessions](#) and fun [social events](#)
- Networking with hundreds of transplant professionals from around the world
- **Register by 19 August and save BIG!**

Do YOU have a story to share?

Lifelines welcomes your article contributions for consideration by the editorial board. Suggestions for an article, either one you write or a topic you would like to see authored by someone else, should be submitted to info@trioweb.org in summary form.

The editors will respond and, if accepted, you would then write the full article for use in an upcoming issue.

**Become a part of the action!
Offer your ideas today!**

TRIO Board Focuses on Exciting Challenges Ahead

On May 7, your TRIO Board of Directors held its quarterly meeting face-to-face (vs. the usual teleconference). The meeting was hosted by the TRIO Maryland Chapter at the Living Legacy (OPO) offices in Baltimore. With most of that chapter's board in attendance, it was a fully engaged and well received event both reporting on the activities of the national organization, but more importantly, sharing a focus on the three major challenges in the days ahead:



First: The up-coming Leadership and Educational Summit,

Second: The challenge of effective communications and engagement with our growing chapters and membership, and

Third: A new initiative developing something TRIO can do about the high cancer risk in our post-transplant population.

In summary, the board reviewed the results of a survey of member interest in the Summit and, based on that positive feedback of interest, gave final approval to move ahead with that event. Analytics of our current TRIO communications outreach were presented, resulting in a challenge issued to expand our communications committee membership. That team was asked to come together and devise approaches to further improve readership and action-based responses to those resources (ie. quarterly *Lifelines*, monthly E-News, daily web site updates and our social media).

The biggest reaction came when the subject of post-transplant cancer was brought up. With initial research identifying at least three possible initiatives in this area, both the board and chapter attendees responded overwhelmingly with an excited "Why haven't we done this before!" While this may seem overwhelming in scope, the meeting closed on that high note with work assignments enough for everyone. Clearly the board is listening to and taking positive challenging action in these areas based on your input to our surveys, e-mails and phone conversations. Keep it up and stay tuned as updates and opportunities continue to be shared in upcoming communications (as seen elsewhere in this *Lifelines*) and through your local chapter champions!

A very special thank you to the TRIO members in Baltimore for a great meeting facility, a unique (ie. Maryland crab soup, etc.) and delicious lunch and enthusiastic support and participation in discussions. We wish every chapter might have the opportunity to support and participate as you did.

The next Board of Directors meeting will be held on September 19 in Los Angeles, prior to the Leadership and Educational Summit.

TRIO Congratulates Board Member Merle Zuel

Board of Directors member Merle Zuel is congratulated on the completion of his RN degree. Merle completed his Registered Nurse's training at Kansas City Kansas Community College and received a license issued by the State of Kansas. Merle said: "I really just wanted to reclaim my professional life and get involved in healthcare."

When asked to comment on the challenges he faced in returning for his degree, he said: "The main challenges were dealing with the time commitment of school and clinical hours and the risk of exposure to infection." Merle received a heart transplant seven years ago.

Merle and his wife Kim were the founders of the TRIO Kansas City Chapter and Merle now serves as president of the chapter. He is also the force behind an annual fund raiser concert, MerleJam, with proceeds going to Saint Luke's Foundation-MerleJam Transplant Fund.

Congratulations, Merle!



TRIO's Public Policy Initiatives

TRIO is actively re-invigorating its outreach activities toward lawmakers and policymakers. These public policy activities promote knowledge and increased understanding about how they can help the transplant community in general and transplant recipients in particular. Since its founding, TRIO has maintained this long-standing role in public policy. TRIO currently participates in four policy forums:

The Transplant Roundtable TRIO, as an active member of the Washington, DC, based Transplant Roundtable (a coalition of organ transplant patients, professionals, and related organizations) is asking Congress for an increase in the budget for organ donation and transplantation programs operated by the Division of Transplantation (DoT) within the Health Resources and Services Administration (HRSA). TRIO strongly supports the work of the DoT as being essential, providing oversight and funding for the nation's organ procurement, allocation, and transplantation system. You should also be aware that the DoT provides funding for travel and living expenses of living donors whose income level may otherwise prohibit them from donating an organ.

The Transplant Roundtable will also be taking up the issue of proposed Medicare changes to payment for re-admissions. TRIO will work to make sure that transplant patients are provided special considerations, given the possibility for frequent medically necessary re-admissions both pre- and post-transplant.

Partnership for Part D Access The Centers for Medicare and Medicaid Services (CMS) issued a proposed rule last January, which included provisions to possibly remove the protected class status of certain groups of medications as part of a broader review of Medicare prescription coverage. TRIO, along with the other transplant professional and patient advocate organizations in the Partnership, responded to the proposed rule and asked CMS to keep the current status of these medications for the continued health and survival of transplant recipients. Because of this vigorous response and advocacy, CMS recently announced that it would retain the existing "protected class" status for immuno-suppressant medications available as a benefit under Medicare Part D coverage. This action will allow transplant recipients covered by Medicare to continue to receive these medications without having to either pay substantially more for them or possibly forego taking them because they are

unaffordable. Although we were successful, we need to remain vigilant about this issue because new efforts may be undertaken in the future to remove the protected class status.

Chicago Transplant Ethics Consortium This group focuses on the question of should payment be considered for organ donors. Since 2006, TRIO has supported payment as a general concept and there is a broad array of policy options for financial incentives in transplantation. These options range from removal of financial costs borne by organ donors up to a full-fledged open market payment for organs. Each option would have associated costs and benefits along with distributional and ethical consequences. TRIO is working with the group to collect current data and formulate policy options for consideration in the future.

UNOS The United Network for Organ Sharing (UNOS) is the principal organization charged with development and execution of policy on organ procurement and allocation. TRIO participates actively on numerous UNOS subcommittees. UNOS has recently announced new policies on kidney allocation that will take effect in December. To review these new policies, go to: http://www.unos.org/docs/Kidney_Brochure.pdf Currently under consideration are new policies on liver allocation designed to achieve a more just allocation of organs. The proposal currently under consideration would reduce the donor service allocation areas from eleven to four. To review the current options paper on the issue, go to http://optn.transplant.Hrsa.gov/Content/Documents/Liver_Concepts_2014.pdf. UNOS is accepting comments through July 11.

How you can help: Each TRIO chapter should consider identifying a member or members who have an interest in public policy. Those individuals can help review national issues and monitor state and local activities that affect the transplant community. TRIO needs input from all chapters to formulate any national position our organization might take. Each chapter is also more familiar with and better positioned to understand what is happening at the individual state legislative level. As these members are identified, we will establish a national mechanism to obtain and share your input and about state level initiatives and to work with chapters on any national positions TRIO may wish to consider. For more background, contact Rodger Goodacre at rodger.goodacre@gmail.com.

--Rodger Goodacre, Member, TRIO Board of Directors;
Chair, Public Policy Committee

Mark Jackson, TRIO Board Member, Receives Honor from Japan's Consul General

Mark Jackson, who has served on TRIO's Board of Directors since April of 2009, has been appointed by the Japanese government as Honorary Consul General of Japan in the state of Alabama. In this position, Mark is responsible for representing Japan in all diplomatic and business matters of interest to Japan within the state of Alabama.

Mark is the President and CEO of Moreson Conferencing and provides conference services at no cost for TRIO's Board of Director activities.

Mark lives in Birmingham, AL, with his wife, Allison, and two teen-aged sons.

Mark's Dad, his life-long hero, died earlier this year at the age of 87. Mark said: "I wish Daddy had been here for the announcement. He was very proud to know that I was being considered for the appointment. He mentioned how great it was that he had fought the Japanese in WWII and his son might now be their top Diplomat in Alabama. I am very honored to serve in this capacity."



(Left to right) Elmer Harris, previous Honorary Consul General; Kazuo Sunaga, Japan Consul General; Mark Jackson, newly appointed Honorary Consul General.

TRIO to Award Scholarships

The deadline for TRIO 2014 scholarship applications closed on June 30. As it does every year, TRIO will award as many scholarships as possible, depending on contributions from individuals and TRIO chapters. Awards will be announced in late summer. Please provide your donation to this worthy cause. If you have questions, please contact info@trioweb.org

Personal Reflections of a Transplant Coordinator

I'm sitting here trying to concentrate on writing something profound for the TRIO newsletter but my mind is far away with a dear friend and fellow transplant coordinator who is critically ill in the ICU. It makes me stop to think about how precious life is and how life, as we know it, can change in the blink of an eye. I've been a nurse and transplant coordinator for a very long time. I've seen life-death-pain-suffering-and yes, even a few miracles. I understand the medical science side of it all. I've attended numerous courses on dealing with death and grief, care giver support, and compassion fatigue; and I've dealt with the long illness, debilitation, and eventual death of my parents. But nothing has truly prepared me for this critical illness of a close friend. Maybe it's the fact that I (yes... ME, MYSELF) am getting older and dealing with life changes like retirement, physical limitations, and coming to terms with my own mortality that is making this so difficult.

Transplant recipients and their families are forced to deal with these issues and not just at age 60+ but often as young children and often over and over again. I've always been amazed at the courage and perseverance they demonstrated and often wonder if I could do the same. I don't think I could. You are my HEROES !!!

Many years ago, when I was having a minor out-patient surgical procedure done, a wise "old" doctor said to me ... "I think all doctors and nurses should be required to undergo some medical procedures yearly so they don't forget what it's like to be a patient". I've shared his words with numerous medical professionals over the years, especially at times when we found ourselves being less than compassionate.

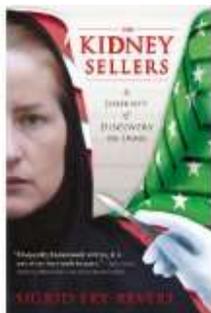
These words have hit home again with the illness of my friend and having recently undergone surgery myself for the repair of a torn rotator cuff. Every time I struggle in physical therapy, complain of pain, or start to feel sorry for myself I think of what transplant recipients go through and how lucky I really am.



-Pat Folk, RN, MSN, MBA, CPTC
Member, TRIO Board of Directors

“The Kidney Sellers” A Journey of Discovery in Iran - By Sigrid Fry-Revere

Imagine a country where the supply of kidneys is ample enough that virtually every resident needing one gets transplanted. Even more astonishing is that there is a waiting list of people willing to donate!



Sound absurd? This situation describes Iran, where compensation to living kidney donors has seemingly solved the chronic supply deficit for kidney donations, the most demanded organ worldwide.

Sigrid Fry-Revere, an American lawyer and medical ethicist, is intrigued by this confounding situation. She has family and friends suffering from kidney disease, and like so many, is perplexed by the perils of long-term dialysis and soaring wait list times in the U.S. Despite gentle misgivings from her family and colleagues – “Are you crazy?” – she sets out for the country once termed by former President George W. Bush, part of the “Axis of Evil.”

While she suggests that Iran’s health care system is the best in the Middle East, it is a far cry from that found in Europe or the U.S. Yet without the money, technology, or inclination to set up a Western-style system of cadaver organ procurement, Iran began condoning, regulating and even encouraging compensated living kidney donation.

She finds an Iranian nephrologist, who teaches at the medical school at St. Louis University, to accompany her on the journey. His knowledge of transplantation in Iran and many contacts allow her access to various transplant wards. Also, he arranges interviews with the *Anjomans*, the government-approved non-profit organizations that arrange living donor kidney matches and ensure the smooth functioning of the payments system.

One of the jobs done by the *Anjomans* is to negotiate a fair price, considering the donor’s needs and recipients’ ability to pay. The average compensation for a kidney is 4-5-million tonans coupled with at least 1-million tonans coming from the government. In US dollars, that comes to about \$5,000 (in a country where the average annual individual income is just over \$3,000).

Fry-Revere makes clear that the program is hardly a panacea. On the positive side, she

believes that the Iranian system has strong laws in place that protect the basic rights of compensated donors. For example, Iranian kidney sellers are guaranteed some informed consent, and mechanisms are in place to help ensure that donors receive the amount of money they are promised. This is not the black market for organs found elsewhere in the world. Donors are entitled to medical care long after their donation, something the United States sadly fails to insure.

But her donor interviews show a good deal of seller’s remorse, “I should have held out for more money.” Most decided to donate with some level of altruism, but getting out of debt, sending the kids to college, and starting a new business predominated. The *Anjomans* have apparently backed off from allowing donors to support drug addictions through kidney donation, an earlier problem.

One of the reasons I liked Fry-Revere’s book so much is that she hardly limits herself to the issues of transplantation. She describes the journey of a woman into a country where females sometimes meet horrific ends, or at least a flogging in the local square. She shares the delights of Mid East travel – sampling Kalepache, a traditional soup made of sheep’s heads, the typical toilets being tiled holes in the floor with footrests and a hose for flushing, taxi drivers missing exits and then backing up on busy freeways in order to get back to them. It’s right out of “Indiana Jones.”

But this spa lifestyle has its limitations. Despite the often-scorching temperatures, sandals are taboo for women, as bare feet are a sign of debauchery.

She even touches on the country’s Islamic traditions and explains how the Ayatollah Khomeini and Ayatollah Khamenei are two different guys and not simply a spelling mistake.

The author’s relentless research, coupled with fair and thoughtful analysis, makes this a very worthwhile read. She argues that such a system in the United States would certainly cut government health costs, where the average Medicare cost for dialysis for a single patient on average was \$77,156 in 2010. And, of course, we know that the vast majority of people on dialysis, who would benefit from a kidney transplant, never get one.

-Steve Okonek, Secretary, TRIO Board of Directors,
Past President, TRIO San Francisco Bay Area Chapter

Benefits of a Living Donor Versus a Deceased Donor

Kidney transplants save and improve the lives of people with kidney failure. Over 5,000 people on the kidney transplant waiting list die every year hoping for a kidney transplant.

Living kidney donation has revolutionized kidney transplantation. Kidneys from living donors last on average twice as long as ones from deceased donors. Other benefits of having a transplant from a living donor are:

- Recipients don't need to wait for a transplant. The wait is about 5 years for a deceased donor, for some 10 years.
- About one-third of deceased donor kidneys don't function immediately. That almost never happens with a living donor. Recipients need to return to dialysis and outcomes are impacted.
- Shortens the waiting time for others on the waiting list.
- An individual's health often deteriorates the longer they are on dialysis
- A living kidney transplant doubles the life expectancy of the patient, compared to being on dialysis.
- Kidney dialysis is very expensive. The payback for the initial cost for a transplant is about 14 months, even after taking into effect the ongoing cost of anti-rejection drugs.
- Waiting for a deceased donor can be very stressful.

Perhaps the most important aspect of living donation is the psychological benefit. The recipient can experience positive feelings knowing that the gift came from a loved one or someone who cares for you and that no one died so you could live a better life. The donor experiences the satisfaction of knowing that he or she has contributed to the improved health of the recipient.

-Harvey Mysel, Member, TRIO Board of Directors

Harvey Mysel is a two-time kidney transplant recipient and founder of the Living Kidney Donors Network, a non-profit organization offering FREE workshops, webinars and private consultation to educate people in need of a kidney transplant about living kidney donation and helps prepare them to effectively communicate their need to family members and friends. The LKDN assists those who are interested in being a living donor through the transplant process. Harvey is also a member of the TRIO Board of Directors. The LKDN website is: www.LKDN.org and Harvey can be reached at: harvey@LKDN.org.

To learn more about living kidney transplants, go to: www.LKDN.org

TRIO Youth Circle in Action

Don't you wish you had the youthful energy and many years ahead of you that our Youth Circle members do with their own life-extended transplant lives? How are you and your TRIO chapter reaching out to find and engage the younger generation who may take on the reins of future leadership for your group? By way of example, come and see Josh Morrison, altruistic kidney donor/lawyer and Mary Wu, donor advocate and author, when they share their stories and careers in their September Youth Circle Summit workshop. Both have been leaders for that TRIO youth group and busy with lives that are dedicated toward advancing our cause in many ways. Josh is currently working with heart recipient, Melissa Speck, to re-design and implement TRIO's social media and web page changes to make them more youth-attractive. To add perspective to that, understand that Josh, a Harvard graduate, is a young lawyer working for the [Alliance for Paired Donation](#). As an altruistic kidney donor himself, can you image a better place for him to work?

Check out our TRIO Youth Circle pages for inspiring stories of these and other young people like liver recipient, Emmalyn Brown, transplanted seven years ago at Cincinnati Children's Hospital, who writes in her on-line YC story:

"I'm a teenager who can do what everyone else can, except clean out my cat's litter box or eat grapefruit. And, to be honest, I don't have a problem with that. I know that I'm lucky and blessed. Now that I am older I can truly appreciate the gift I have been given and my friends are much more understanding and supportive. Over the past several years, I have become a proud organ recipient and advocate, volunteering across the state. I have participated in the U.S. Transplant Games every year since the transplant, and I rode the Donate Life float in the Rose Bowl parade. I dance at my local studio and go to high school. I do things that without my transplant, I wouldn't have been able to do, and it's my goal to make sure that other future recipients can as well."



Awareness: Fraternal Organizations



Whether it's the web site of the [Connecticut Freemasons](#) (←click to view) or this example of a state President's appeal to his New Mexico Elks:

“Let's not forget during this season of giving that we as individuals can give life by becoming an organ donor. It's easy and simple. Just check your driver's license. If you have a little red heart on your licenses, you don't have to do anything else.

If you don't have a red heart on your licenses, you can sign up to be an organ donor by going to <http://donatelifenm.org> or www.donatelifenm.org or www.nmdonorm.org. Invite your family members (mothers, fathers, brothers, sisters, aunts, uncles, cousins, nieces, nephews, friends, co-worker, etc.) to sign up. Each individual can save or improve up to 50 individual lives. Just think, this doesn't cost you a dime.”

It's a good bet that such outreaches are a direct result of the passionate work by Richard Denno and his committee members working to spread awareness of the need for organ donors countrywide in the community of Masonic brothers, but also his outreach to other fraternal organizations such as the Elks.

Motivated by his beloved wife's transplant experience, Richard has taken it upon himself to attend and get appointed to Donate Life America's committee work. He has been reaching out to TRIO chapter leaders to personally connect them with local Masonic and Elk leaders, creating opportunities for TRIO members to share their stories at weekly meetings, gaining support for their own TRIO chapter local efforts. Engaging fraternal groups can be very effective

and rewarding but often a challenge due to their unique structure and rotating leadership. Richard's long-time experience in that world can make that partnership easier and stronger. He invites TRIO chapters to contact him at toursone@comcast.net to explore the possibilities of more effectively carrying out their own donor awareness mission by working with the very powerful network of fraternal organizations.

Special note: TRIO's national board member, Harvey Mysel, has created a unique donor awareness slide set for use in presenting to fraternal organizations. Contact him at harvey@lkdn.org for this excellent PowerPoint resource.

A Call for Action from UNOS:

Input sought on concept document for liver distribution



The OPTN/UNOS Liver and Intestinal Organ Transplantation Committee requests feedback from the transplant community, other stakeholders and the public regarding next steps to consider as it seeks to increase equity in access to liver transplantation.

The committee has prepared [a paper](#) summarizing challenges in fair access to liver transplants posed by geographic disparity, concepts under current consideration, and alternative approaches investigated.

The concept document also includes a link to a questionnaire. Feedback from the questionnaire will be used to develop a national public forum for participants to be held in September 2014 in Chicago to further discuss the concepts in the paper, seek additional input from interested stakeholders, and recommend ways to address current inequities in access to liver transplantation.

TRIO members are encouraged to take this opportunity to learn more and take ACTION by reading the concept document and responding to the questionnaire by July 11, 2014.

Help Get the Word Out!

Do you know someone who isn't seeing Lifelines on the TRIOweb.org website? Help us share the message by forwarding this downloaded .pdf document to them. Or, if they don't have web access, maybe print out a copy and give it to them so they, too, can be as engaged as you are.

Of course, they can send us their email address and be added to the distribution list!

A Breath of Fresh Air

"To know even one life has breathed easier because you have lived. This is to have succeeded."

-Ralph Waldo Emerson

People often ask, "Why would you leave the busiest pediatric lung transplant program in the world to recreate the wheel somewhere else?" The answer is a simple one that we quote to all of our patients and families contemplating lung transplant: 5 year, 50%. Based on registry information from the International Society of Heart and Lung Transplant (ISHLT), the current 5-year survival for lung transplant patients is 50%. Survival for lung transplant has come a long way in the past 2 decades; however, this still lags behind other solid organ transplants. There are only five other true pediatric lung transplant programs in the United States, performing the majority of pediatric lung transplants worldwide. Our goal in starting a program at Cincinnati Children's Hospital was to de-construct and evaluate the process from referral to transition, looking for ways we could improve and eventually change these outcomes.

Over the past 11 years, I have been privileged and blessed to work at several outstanding children's hospitals across the country. I have worked on amazing multidisciplinary healthcare teams from coast to coast. Growing up in south Louisiana, I was raised with very deep roots. I would have been a frontrunner had there been a "most likely to never leave the state" award when I graduated high school. Life has a funny way of closing doors and opening windows. I have always felt that I was where I needed to be personally and professionally at any given moment in time. The one constant for me has always been the inspiration I draw from my patients and their families. I am humbled by their grace, strength and courage displayed in the face of repeated challenges. Our transplant patients and their families are no exception.

While lung transplant is new to Cincinnati Children's, our core medical and surgical teams bring a wealth of experience and passion from our previous pediatric center. We have worked to build a talented and dedicated multidisciplinary team whose focus is providing individualized, compassionate, high quality care for every patient and family who comes through the program. Our research team is focused on identifying new therapies and care protocols for pediatric lung transplant recipients.

*-Erin Wells, RN, BSN, CPN
Cincinnati Children's Hospital
Lung Transplant Program*



(For more information on the Lung Transplant Program at Cincinnati Children's Hospital, call 513-803-7009 or visit our website: <http://www.cincinnatichildrens.org/service/lung-transplant/default/>)

USA Today Publishes Transplant Information Issue Insert

USA Today has published an insert dealing with transplant issues. The insert was distributed in NY, Houston, Chicago, LA and Cincinnati. You can review the full insert by going to: <http://www.transplantation.com/>

There you can read articles, just to name a few:

- By Brian Shepard, CEO of UNOS: ***New Kidney Donor Matching System Promises Efficiency and Fairness*** (Organ Donation-Tens of Thousands of people in the United States get successful Kidney Transplants each Year)
- ***Multiple Listing to Reduce Wait Times for Transplant Patients*** (Being an Organ Recipient). MediaPlanet sat down with Dr. Sridhar Tayur, owner of OrganJet, to learn how to list smartly.
- ***Transplant Triumph: One Patient's Unlikely Happily Ever After*** (Being an Organ Recipient)
- ***The Next Generation of Transplants: Do You Believe in Miracles?*** (Industry News). Article by Dr. Daniel R. Salomon, M.D.; President, American Society of Transplantation

UNOS/OPTN Publish Latest Data

Following is data on the number of patients waiting for a transplant, as of June 27, 2014.

	<u>Active</u>	<u>Total</u>
Waiting for Kidney	61,783	100,889
Waiting for Liver	12,956	15,757
Waiting for Pancreas	330	1,181
Waiting for Pancreas islet cell	18	186
Waiting for Kidney-Pancreas	984	2,053
Waiting for Intestine	185	256
Waiting for Heart	3,017	3,999
Waiting for Heart-Lung	34	54
Waiting for Lung	1,332	1,638
TOTAL:	78,916	123,088

Visit www.unos.org to see TODAY's numbers

UNOS Resources: 888-894-6361

Donor Designation 2014 Report Card

June saw the release of the latest National Donor Designation Report Card. Each year, this shows state by state the number of registered organ donors with comparison by year since 2010.

It is exciting to see that there are more than 117 million registered donors, 48 percent of the US adult population. Thanks to people like you sharing a very personal transplant life story, the appeal for registering as an organ donor is having its effect across the country, in some states more so than in others. Keep up the good work as we are getting close to Donate Life America's national goal of 50 percent.

To download the full report (a .pdf file), click on the cover image at Right or here: [2014 Report Card](#).



Are You Reading This?

Obviously YOU are, so this message isn't directly getting out to the intended audience of those who are not opening the e-mail, or not reading the overall message in that email or not linking to this electronic issue of the Summer Lifelines, or once there, not reading it. But **YOU are** doing all those steps - YOU are one of a special minority and we thank you. You are the audience we reach and thus ask this question: "Why?"

Why are we asking?

Our communications committee is working on improving the effectiveness of our communications. Understanding why you are a reader can provide insights that will help expand readership so important TRIO information and education gets to all TRIO members. Only **IF** those members get the information can they become aware and able to support with their action important campaigns such as the recent protected class HRSA issue, the upcoming Educational Summit or TRIO cancer initiatives.

You can help with your action . . .

Share your answer to the question: "**Why did you read our Summer Lifelines and this article in particular?**"

Click [here for a one item survey](#) (the shortest you've ever taken  - if reading this in hard copy, go on-line to:

<http://survey.constantcontact.com/survey/a07e9gtyzs8hwnlftoz/start>). Alternatively, send your response to info@trioweb.org or you can contact TRIO president, Jim Gleason, at GleasonJim@aol.com or (609) 877-4493 to share your insights as to why you read this, and if you have any thoughts about why others do not.

Did you know?

Industry reports less than 10% respond to surveys, and only about 33% even open email messaging. While TRIO is seeing better results (thanks to YOU), this is far from our goal of reaching 100% of membership with our communications.

Thanks for reading and helping with this **big "C"** concern: **Communications Effectiveness**.

Five “Mind Hacks” to Better Manage Your Attitude

Let’s face it, dealing with disease, waiting on ‘the list’, the organ transplant surgery and recovery process, not to mention living a long life with a transplant can be very challenging, but many would argue that attitude plays a big part in how we survive that experience. Our reality is what it is; it does not change. But it’s how we choose to see the world that leads us to act differently. Here are five ways to stay in control, using the power of your mind and personal choice - in psychology, it’s called framing - to create a positive attitude in facing life’s reality.



Vee Sophon, a management consultant and writer, offers the following tips:

- 1. Cultivating gratitude.** Count your blessings. Since I learned the importance of appreciating little things, I no longer pursue happiness. I now know that happiness is a byproduct of gratitude.
- 2. Remembering what's important.** Tough circumstances have a way of distracting us from the things that matter most. During such moments, it is crucial to remember your deeper purpose. What meaning did you want to give to your life? Figure out what's important then build your life around it.
- 3. Using adversity to build resilience.** It is tough for the world to break the person who easily adapts to his or her shifting environment. Adaptability increases resilience. Resilience is your inoculation against the hard times.
- 4. Staying hopeful in hopeless situations.** Hope is a thing worth protecting. Without it, it's easy to fall into despair. When you can visualize the future you want, hope feeds your dream.
- 5. Honing a positive outlook under negative circumstances.** Know that circumstances will always be temporary but your spirit is a permanent force to be reckoned with.

To easily remember the mindhacks, use the acronym, C.R.U.S.H. Now go and crush it!

Read more in Vee Sophon’s full Huffingtonpost article click on

http://www.huffingtonpost.com/vee-sophon/positive-attitude_b_5126837.html

TRIOweb.org: “Speaking of Attitude”

Every day at least four or five transplant related news stories appear on the TRIO web site home page News section. As one who reviews and posts each one, I am amazed at the activity and great news of medical advancements and inspiring stories that enrich my knowledge that in turn allows me to help so many others facing the challenges of transplant. Take *attitude*, for example, sort of a theme in this issue.

Got five minutes? Watch Chris, the farmer, and how he deals with his personal challenges with a ‘can-do’ attitude that can be an inspiration to you and I as we sometimes feel overwhelmed in our transplant life in this web video recently added under General News on our website (click on photo).



Membership – NEW or Renewal: **TRIO membership is renewable as of January 1 each year.**
Please support TRIO and its important work on behalf of transplant recipients, donors, candidates and their families by joining us in this important endeavor. Thank you for your support of TRIO!

Name of Member: _____

Names of other family members: _____

Address: _____

City: _____ ST: _____ ZIP: _____

Phone: _____ Fax: _____ email: _____

Member is: ___ Recipient; ___ Donor; ___ Candidate; ___ Family Member; ___ Other: _____

Recipient Profile (Optional): _____

Type of Transplant	# of Transplants	Date(s) of Transplant(s)
Name of Transplant Center(s)	City, State	Time Waited

Donor Profile (Optional): _____

Type of Donation	# of Donation(s)	Date(s) of Donation(s)
Name of Transplant Center(s)	City, State	

I would like to participate on the _____ TRIO Committee. Please contact me.

Annual Dues: Member at Large \$20.

Additional Contribution \$ _____.

TOTAL enclosed \$ _____.

**Make your check payable to and mail to:
Transplant Recipients International Organization, Inc.
2100 M St., NW, #170-353
Washington, DC 20037-1233**

Thank You for your tax-deductible donation!

PLEASE NOTE: If you are a member of a TRIO chapter, please pay dues to your local chapter instead of submitting this form. If you are not a member of a TRIO chapter, please consider joining a local chapter to receive the many benefits of chapter affiliation. TRIO national strongly supports local chapter membership. A list of chapters is available on our website www.trioweb.org. OR: consider starting a transplant support group or TRIO chapter in your area (contact info@trioweb.org).

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