TRIO Leadership Summit 2012 – Another BIG Success!

More than 60 TRIO members and guests joined Friday and Saturday, September 28, 29 in Pittsburgh at CORE (Center for Organ Recovery & Education, western Pennsylvania’s OPO) offices with an opening lunch welcome by Susan Stuart, CORE CEO. That was followed by sixteen educational workshops with topics ranging from an emotional “Finding Meaning in Death: Life as an Organ Donor Specialist” to a humorous and passionate panel-led open discussion on “Post Transplant Intimacy.” This “sex session,” with TRIO’s recent 110-response survey results presented by ITNS nurse facilitator, Chris Shay-Downer, was expanded by popular demand from its scheduled 30 minutes to a full hour with requests to even offer a full day on this important and engaging topic. Survey results are posted on the TRIO web site. Videos from these sessions are also available on the TRIO web site, along with many photos (several featured in the center fold of this issue) taken by TRIO’s “national photographer” and TRIO Secretary of the Board of Directors, Susan Pincus.

The highlight of the weekend was the 25th anniversary gala dinner event Friday night. Special guests, Dr. Tom Starzl of UPMC, and Walter Graham, UNOS CEO, received “TRIO Lifetime Achievement” awards. Awards for long term service went to Yushi Nomura, TRIO Japan’s president, and 25 years of TRIO service recognition for Pat Folk, transplant coordinator nurse.

The recognition caught Pat totally by surprise, receiving her award with tears, sharing with all a very emotional moment. Along with a passionate call for raising organ donor awareness worldwide, Yushi offered special sweet Japanese treats as gifts from his 200 member chapter in Japan. In his keynote dinner address, Walter Graham provided an inside view of the new UNOS strategic plan that is setting the path for their work in the coming years. He also urged members to educate the public about the recently released new kidney allocation proposal, asking each and every TRIO member to express their comments on the UNOS.org website.

Historical videos of the 1991 and 1992 TRIO conventions held in Pittsburgh and Las Vegas were shown and are now available on YouTube for your home viewing. Check the TRIO web site (trioweb.org) for links to everything related to this very exciting meeting and dinner event.

Dr. Thomas Starzl (left) and Yushi Nomura, TRIO Japan
President’s Message

Jim Gleason

“TRIO Looking Back and Moving Forward!”

This was our theme for the exciting 25th anniversary gala and Leadership Summit. As you read in our cover story, those who were able to attend certainly had a great time together and saw the launch of our new TRIO Strategic Plan that supports that “Moving Forward” goal (see separate article).

At the dinner, I shared my personal excitement and repeat it here to the full membership audience, hoping you too will feel that emotion as you read of our growing success and aims for the years to come:

September 28, 2012
Dear TRIO member, family, friends, and distinguished guests:

We join here in Pittsburg, the birth city of TRIO, to celebrate 25 years of TRIO. Tonight we enjoy a life filled with joy, passion for our cause, and excitement of our 25th anniversary gala. We are joined by world change leaders; Dr. Thomas Starzl, pioneer of liver transplantation, Walter Graham, UNOS longtime leader, and Yushi Nomura, TRIO Japan’s leader and advocate for new laws and transformation of public attitude towards organ donation and transplant in Japan.

Each of us is here tonight because of the gift of life saving organ donation, most anonymously but some through the unselfish gift of living donation. We offer our gratitude for what God, through our donors, gifted medical teams, and caring families have done in our lives.

As TRIO’s president, it is my privilege and honor to serve, giving back for the life-saving gift of a heart. Roberto never knew me, but I know him well, and while he died 18 years ago, amazingly his heart still beats strong.

Tonight we express our gratitude to JT Rhodes and Elizabeth Rubin, both past TRIO presidents, who through their many years of leadership, kept TRIO afloat during several difficult years. "Thank you for having the faith and vision that keeps you so committed and keeps TRIO alive!"

Looking back this quarter century, TRIO is indebted to you, those unable to join us, and those who dedicated themselves to our TRIO mission that have passed on. I am grateful and indebted to pay forward those gifts that led to the TRIO we celebrate this evening.

It is an exciting time for our organization, poised to continue growing in support of our vision and mission through our partnership with UNOS, our local OPOs and related organizations. As local chapters and members-at-large, we are building a greater united "ONE TRIO,” a stronger voice for organ donation and transplantation.

Allow me to highlight a few reasons for that excitement: a dedicated full 12-member Board of Directors, a new strategic plan, 14 active chapters, 2 newly incorporated not yet chartered chapters, inaugural medical advisory board, solvent financial position, today’s USA Today national ad for TRIO’s PCP program, and your joining us for this Gala and Leadership Summit.

Feel that excitement and share it when you return home.

Thank you for all you do, for being here with us on this very special occasion of "Looking back 25 years, and moving forward . . ."

Sincerely,
Jim Gleason
TRIO President

PS: Contrary to my remarks above, our past president, JT Rhodes, was not able to travel to the gala but was certainly with us in spirit from his hospital bed where he was undergoing tests. I am happy to report, as we go to print, JT is back home and working hard to regain his usual active life.


Lifelines is published by the Newsletter Sub-committee of the Communications Committee. The Newsletter Subcommittee consists of Pat Beeman, Jim Gleason, J. T. Rhodes, Elizabeth Rubin, and Dr. Tom Peters, Advisor. Editor: Sylvia Leach.

Disclaimer: All contents of Lifelines, including text, graphics, images, information obtained from other sources and contributors and any other material, are for informational purposes only and not intended to be a substitute for medical advice, diagnosis or treatment. Neither Lifelines nor TRIO recommends or endorses any specific tests, physicians, products, procedures, opinions or other information in this publication.

Did you know?

There are 115,909 waiting list candidates!

Visit www.unos.org to see TODAY’s number!

UNOS Resources
UNOS welcomes your questions, requests, comments and suggestions: 888-894-6361
(Monday-Friday, 8:30 am – 5:00 pm; Eastern Time)
TRIO Strategic Plan Approved
By Board of Directors

At the September 28 national board meeting, TRIO’s strategic plan was approved. That plan is both challenging and broad in scope, the first new plan in well over a decade, supporting our existing unchanged Vision and Mission with three key goals, measurable sub-objectives and specific actions for their accomplishment years ahead. There are three main focused goal areas with their sub-objectives:

1. **Increase Human and Financial Capital Resources**
   - Grow membership base
     - Reach out to recover inactive names as members
     - Grow the number of TRIO chapters
     - Grow the number of new members
   - Improve financial position and stability
     - Increase overall “net income” annually by 10%
     - Control operating expenses

2. **Enrich Internal Communications**
   - Support the other goals/objectives with effective internal communications to all members

3. **Instill “One TRIO” Culture**
   - Make “A TRIO member is a TRIO member” a cultural reality throughout the TRIO organization
   - Increase membership engagement in using TRIO services

See the full, approved plan on our web site under “National News.” The plan is being distributed to chapters encouraging all to become engaged for a strong TRIO future as our transplant community continues to grow with more families facing organ transplant and longer lives post-transplant in need of TRIO support. Each chapter and MAL is encouraged to find ways they can support the success of this plan. Finally, this plan and its time-bound action list will be reviewed in detail annually at the board level with reviews by board leadership monthly and the strategic planning committee quarterly to insure its success long term.

---

TRIO Fall Board of Directors Meeting Hosted at CORE Headquarters in Pittsburgh

Your TRIO board held the quarterly board meeting on September 28, immediately preceding the Leadership Summit at CORE, the Pittsburgh OPO host for the weekend events. With several member guests from chapters as far away as Japan, it was a very special opportunity for them to see and participate in our discussions. A very special guest, Yushi Nomura, TRIO Japan’s president, flew in for the Summit and was able to join the meeting in progress.

Among the many business issues on a busy agenda, TRIO elected Steve Okonek, former president of TRIO San Francisco Bay, to the board. Steve is replacing Tom Peters, MD, who is moving over to lead TRIO’s newly created Medical Advisory Board. The TRIO Strategic Plan was adopted and presented later in a Leadership Summit workshop. Treasurer James Mateiko gave a very positive financial report showing continued strong growth without details from the Leadership Summit and Gala Dinner Event (not available at time of the meeting). As an update to that, net proceeds have since been reported as another very successful project resulting in positive cash flow to the treasury with a majority of the cash out-flow going directly to members in scholarships and free registrations and meals.

With two new potential chapters in Seattle and Baltimore (recently incorporated but pending chartering) and all fourteen current chapters’ dues paid, the future looks brighter still. The board voted to honor four special guests with Lifetime Achievement and other special awards, as described in related articles in this issue.

TRIO’s next Board of Directors meeting will be held by teleconference on Saturday, November 17, from 2 to 4pm. Contact the national office (email: sleach@trioweb.org or call 1-800-TRIO-386) if you would like to join that meeting by phone.
UNOS Calls for Public Comment on Kidney Allocation

On Friday 9/21, UNOS released the long anticipated new proposal for changing the kidney allocation rules for public comment. In a last minute addition to our Leadership Summit agenda, Ron Taubman, a TRIO chapter president serving on the UNOS kidney committee, Jim Gleason serving on both the UNOS national board and Patient Affairs committee, and our keynote speaker for the dinner, Walter Graham, UNOS CEO, explained how you can get educated on the topic and express your own thoughts/opinions/support/concerns to that UNOS kidney committee.

The public comment period is open now and extends to Dec 14th, after which the committee will digest the comments with the UNOS board expected to act on their final proposal at a June 2013 board meeting.

Link to the OPTN.org web site to read the proposal (39 pages, but this is complex and important, so stick to it for the whole document). On that site is a summary news release about the proposal:
and a link to a document addressing frequently asked questions:
http://optn.transplant.hrsa.gov/ContentDocuments/Kidney_Proposal_FAQ.pdf

TRIO encourages all chapters and members to engage in open discussion based on those resources and to express their individual feedback in response to this invitation from UNOS and the kidney committee.

(Note: this information is also available on the TRIO website where you can just click on those links for easy access.)

Monthly Member E-News Blast Meets Strategic Plan Goal to “Enrich Member Communications”

With TRIO’s new strategic plan calling for “enriching member communications,” the monthly E-news is an important and timely bridge between the quarterly hard copy Lifelines newsletter you hold in your hands and the daily updated TRIOweb.org on-line web site resource. Each plays an important and different role in keeping members aware and tuned into news of transplant and opportunities to engage in TRIO activities, both local and national.

While most are now being served with this email-based, colorful and concise messaging tool, if you have email and are not already receiving your own copy, just send that e-mail address to info@trioweb.org to be included. Already getting too much email you say, well, welcome to the club! If you add your name and find this isn’t right for you, it’s so simple to unsubscribe. That option is at the bottom of every issue. Click on the ‘unsubscribe’ option and “It’s done”—you are automatically off the list. So why not give us a try and see if you find it as engaging as 600 of your fellow members have already.

Finally, for those who want to keep their email address private (we do NOT share them with anyone!), notice of each issue is also published on the web site with a link to view the same issue as if you had received it directly, except that version isn’t personalized with your name. Check out the October issue on the web site under News from National. We hope with what you see there, you will want your own copy delivered directly to your “electronic front door.”

TRIO Needs Your Frequent Flyer Miles!!!

TRIO is fortunate to partner with United Airlines in the UAL Charity Miles Program, through which tickets are provided to those who may not be able to afford to fly for pre- and post-transplant medical visit. If you have frequent flyer miles with United or Continental, please go to www.united.com and donate those miles by selecting “Frequent Flyer Miles,” “Donate,” and “TRIO.”
TRIO Transplant Presentation
Library Enters Fourth Year of New Releases

By now you should be seeing that new library carrying case at your local chapter meetings. It is filled with three (going on four) years of DVD program releases. Be sure to check the complete library listings on the TRIOweb.org site under “Communications/Resources,” where five more titles are “in release” and more in the “Coming Attractions” list for the months ahead:

- Pgm 38: “Everything you wanted to know about how (emergency room) physicians think” (Aug)
- Pgm 39 "Healthy Transplant Vegan Eating" (Sept)
- Pgm 40: "Writing to Your Donor Family" (Oct)
- Pgm 41: "Heart Transplant Research: Why It Matters and How You Can Help" (Nov)
- Pgm 42: "The Role of Hypnotherapy in the transplant patient" (Dec)
- Stay tuned for many more to come . . .

Hopefully, your chapter will record a local speaker as its contribution to this growing library of DVDs. If you see an interesting upcoming presentation, suggest that it be recorded and submitted for consideration.

TRIOweb.org: “The Power of Two”

TRIO members (our famous twins) Isa and Ana, released their movie on September 25 for general use. We’ve seen it in special theater showings around the country, at the Transplant Games of America (where it brought their audience to tears!) and now out in DVD for home use. Check the link on our web site to Amazon.com where you can buy your own copy for $19.99.

This is one very special show. You wouldn’t want to miss seeing it and sharing with family and friends, both for entertainment and for carrying out TRIO’s mission of raising donor awareness and the success of transplant through that sharing experience.

If you haven’t yet discovered the richness of TRIO’s world-class web resource for news and many resources, updated daily, you really owe it to yourself to visit and explore. Don’t forget that web address: http://trioweb.org - check it out today - and consider making your own contribution of a story or ideas c/o info@trioweb.org

Fall Is a Time for Reading/Viewing

Imagine yourself in your early 20s, it’s 1992 and, recently married, you discover you have a kidney disease that will be dormant for about 20 years before becoming a threat to your life!

Well that’s the beginning of Troy Lewis’ story. His is an inspiring life built on a foundation of faith in God’s plan for his life that becomes a roller coaster ride. That ride leads to questioning what God’s plan really is when the obvious path becomes a detour rather than the one Troy envisioned. Read about Troy’s path in his book: “Another Second Chance: God’s Story.”

Troy and his lovely wife have been doing a great job promoting his book, even hosting a table at the recent Transplant Games of America (TGA). Having reviewed Troy’s book years ago, it was a special pleasure to greet them both in person at the games. You can buy the book on Amazon and I promise you a great inspiring real-life story for your fall reading season.

TRIO President, Jim Gleason, greeting author, Troy Lewis, at the 2012 transplant games in Grand Rapids.

Youth Circle Leaders Address Challenges at Leadership Summit

At the Leadership Summit, youth leaders Mary Wu and Allie Weese shared their life transplant experiences as the opening to a lively discussion with chapter leaders on how TRIO chapters can develop support for youth in their local areas. This action would serve not only the youth, but also address the long-term concern for getting younger members involved with chapters, filling in for many who are moving on in age and crying out for new energy and creative ideas.

The video recording of this workshop can be found on www.TRIOweb.org. View it and raise the conversation in your local chapter and networks about engaging transplant youth, both in support while also connecting with this very important organ donor registration audience as they sign up for driver licenses and answer the DMV question: “Do you want to sign up as an organ donor?” now part of that life milestone.
“TRIO Looking Back . . .

With this annual two day educational and sharing summit event dating back only three years, TRIO Leadership Summits have been held in Philadelphia (2010), Washington (2011) and now in 2012 in our founding city of Pittsburgh on the occasion of our 25th anniversary - how very fitting. I can hear some of you saying: “Why always the East coast?” Well let’s see what 2013 brings.

Sixty-eight members, speakers and special honored guests all celebrated TRIOs 25th year with smiles and open sharing over dinner, lunches and sixteen workshops. Thanks to CORE’s generous hospitality, the venue was perfect allowing TRIO to be their first user of the brand new auditorium, a major expansion to this two decades old growing OPO facility. As has been our practice, many of the sessions were recorded and can be viewed on YouTube with links from trioweb.org. (See the index and description for each available on the TRIO web site home page.) As was the goal last year, most of the summit monies went back to chapters and members in the form of scholarships and meals to help offset some of their travel and lodging costs.

Here are just some of the moments captured by TRIO photographer, Susan Pincus – see more photos on the TRIO web site.
...TRIO Moving Forward"
The Miracle of Lon Bullman

If a man who’s had three heart attacks, fought several bouts with cancer and overcome other serious illnesses tells you his life is a miracle, you pretty much take him at his word.

Lon Bullman is a miracle man and a fighter—after getting knocked down by so many health challenges, he keeps getting back up again. He’s also a lucky man, and he knows it. If not for the blessing of receiving a donor heart in 1997, he would not be here to tell us the tale of his wondrous life.

Growing up in rural Montana and working at a sawmill, Lon felt good. He didn’t yet know he’d inherited a heart condition that would eventually kill his father and all four of his father’s brothers.

Lon’s first serious health problem was a mild stroke in 1983, then the next year he suffered his first heart attack and underwent a triple bypass. Soon after, he had a malignant bladder tumor removed and subsequently, in two-year intervals, he had angioplasty in both legs, a second heart attack, and a third attack followed by double bypass surgery.

Finally, in 1992, he was diagnosed with congestive heart failure. The doctor who diagnosed him gave him one year to live. Lon’s wife Maudie remembers that terrible time. “It’s the most terrifying news anyone can receive,” she says.

Lon had met Maudie when they both worked in St. Regis’ Atlanta office. Lon had transferred into the sales department by then and had relocated several times around the country in that position. When Maudie met him, she was attracted by his “terrific sense of humor. He always had a positive outlook,” she says. “And he’s a salesman,” Maudie laughs!

After Lon received his dire prognosis in 1992, he sought a second opinion, and this cardiologist gave them better news: Lon was still young and a perfect candidate for a heart transplant. He was put on both the transplant list and a daily regimen of pills to keep his condition in check. Then there was nothing to do but wait. Believing their time together might be short, Lon and Maudie set out to see more of the world, including cruises in the Caribbean and Alaska.

One year of waiting, living and traveling turned into two, and eventually into five. By 1997, Lon’s heart had weakened considerably and during his third hospital stay of the year in September, he was told it was time. He moved immediately from the bottom of the transplant wait-list to the top. His doctors advised Lon to stay in the hospital until a heart became available, a wait that could be as long as three months; Lon didn’t want to, and with his salesmanship skills, persuaded them to let him go home for a few days. He promised he’d be back on October 6.

Lon spent the next few days packing and relaxing. On October 3, he went out on his boat to enjoy some peace and quiet with the morning paper.

The silence on the creek was broken by his beeper. Maudie was trying to contact him: there was a heart waiting for him at the hospital in Gainesville—if he could make it there in three hours!

Lon made it back home in record time, got his bag and his wife, and while Maudie put the pedal to the metal, Lon called ahead to the police department of each town they would be passing to warn them they’d be flying down their roads. No one stopped them.

A little over two hours after he’d been beeped on the creek, they pulled into the hospital parking lot, and Lon was on his way to receiving a new heart.

When Lon awoke that evening, he felt confused. “I knew the surgery had been done, yet I felt no different,” he says. But Maudie was holding his right hand and his son was holding his left hand, and they assured him he had a new heart. “I was filled with a great sense of relief,” Lon says. “It was an unbelievable feeling of happiness for me and sadness for the donor family.”

The morning after his transplant surgery, Lon says, he knew he’d “made it up the mountain and was at its very peak. I still have not come down.”

Since the transplant, Lon’s health has not been perfect: among other things, the immunosuppressant drugs have led to multiple incidents of skin cancer, including one time the cancer metastasized and Lon had to endure chemotherapy treatments. Lon and Maudie don’t dwell on the negatives of their situation, though. They use the word “miracle” often.

“It’s truly a miracle what the transplant has done for our family,” Maudie says. Lon has been around to see five grandchildren born in the 15 years since his transplant.

Lon wrote letters to his donor’s family but never heard back. He doesn’t know anything about the person who gave him his new heart, yet he often thinks about the family of that person. “To realize that someone lost a loved one, and that loss in turn let me live, is rather hard to comprehend,” Lon says. “I shall be forever grateful that I was allowed the opportunity to receive this miracle, and my prayers shall always include the family from which it came.”

(Editors Note: This story was written by Jane Liaw, a professional writer and TRIO Member-at-Large. Her full story as the wife of a transplant candidate can be read on www.TRIOweb.org, where you can also read Lon’s full story in his own words.)
Organ Allocation: the OPO Role

(This is part 2 of a 3-part series describing the complex process of getting the donor’s organ gift to the waiting recipient. Part 1 appeared in July Lifelines, describing the UNOS part of the process.)

Both at the beginning and in the middle, the Organ Procurement Organization (the “OPO”) plays a critical role in the process whereby you receive that long awaited gift of a donated organ. So what is an “OPO”? The government, through their contractor, UNOS, regulates the donation process with rules that divide the country into 58 regions, each with an assigned organization called an “OPO” that carries out several important roles in the process. Primary in those roles is coordinating the allocation of a donated organ (“the gift”) from a donor family.

The OPO coordinates between UNOS, the “list,” the donor recovery hospital, and the recipient organ transplant program where a listed patient is waiting. The “transplant coordinator,” a member of the OPO staff, provides family support in carrying out end-of-life decisions made by the deceased donor as a registered organ donor or, in absence of a prior decision, helping the family understand death and the options that remain in offering their loved ones’ organs to save lives through organ donation. Before talking with the family, the OPO transplant coordinator reviews the donor’s medical records as a suitable candidate for donation. This timing prevents disappointment if (in offering an option to donate) that might not be possible should the conditions of death prevent organ recovery. The transplant coordinator then works with the UNOS database to generate the ordered “list” of recipient candidates for each organ being offered. That list is prioritized based on a complex but public list of UNOS allocation rules with offers sent out electronically to each candidate’s medical team for consideration for their patient. There are many reasons why a program might “pass” over an offer, such as their patient being too sick to undergo surgery or a patient not being available, etc.

Eventually a recipient down the list accepts the offer and now the OPO’s transplant coordinator coordinates the recovery surgical teams. That effort often involves several teams coming from distant transplant centers to “recover the gifts” at a time when a surgical suite is available.

The OPO also has many other roles, such as donor family grief counseling, hosting events and providing resources to educate the public on the need for organ donors and the process for registering an individual’s decision, through a state registry or DMV, as an example. They maintain a 24/7, 365 days a year, phone referral service for hospitals to call when someone is approaching end of life, a call that is mandated by federal law for all hospitals. The OPO often works to create and support local legislation affecting the organ donation process, including laws to provide education for students as they approach an age of decision on being an organ donor (when they get their driver’s licenses).

You can see how critical this OPO team is to your getting “the call” as a waiting patient. Also, most OPOs offer active volunteer programs to train recipient and donor family speakers and coordinate volunteer efforts. You can find your local OPO on the UNOS.org web site and call to offer your service to help in many ways. Check the TRIO Transplant Presentation library for talks by OPO staff sharing their daily life in carrying out the process described above.

(In our next issue, part 3 of this series will describe the transplant center’s role in the organ allocation process, from listing a patient for transplant to the transplant surgery.)

TRIO Elects New Board Member

At the TRIO Board of Directors meeting on September 28, the board affirmed the election of Steve Okonek. Steve, a long-time TRIO member, has served as the Treasurer (1985-2002) and President (2003-2011) of the TRIO San Francisco Bay Area Chapter. He also currently serves as a Volunteer Ambassador for the California Transplant Donor Network. He continues to serve his chapter as the editor of the chapter newsletter.

Steve brings to the board a strong background in research and consulting. For 25 years he worked for The Electric Power Research Institute and continues to consult for EPRI and other organizations.

He is a two-time liver transplant recipient (1993 and 2001). Steve and his wife Bonnie live in Half Moon Bay, CA.

The board looks forward to Steve’s strong and well-thought-out input in many areas.

Steve Okonek
Facing Re-transplantation: Personal, Medical and Ethical Considerations

When an individual is faced with the prospect of needing an organ transplant they can be thrust into a world of uncertainty, dependence upon family and friends, and an instant and dramatic change in the roles they held previously. Getting through the wait for transplant and reconstituting family dynamics is no small feat and, once accomplished, can be a great relief and source of pride. There is a tremendous amount of literature tracking the medical and personal journeys upon which families embark when they face transplantation. Imagine then being told that you, your family, and your transplant team must confront this again?

There are many reasons primary transplants fail at points along the post-transplant continuum. Sometimes the need is immediate but more often, many healthy years can pass until the possibility is raised. Regardless of the time interval, the shock of the possibility is uniformly felt by patients and families. The idea of having to mobilize resources, face a long wait, re-apply for disability, and possibly be separated from family is indescribably daunting. And what of the new medical risks associated with re-transplant which was not a factor before? This article seeks to examine some of the guiding principles which help patients, families, and health care teams decide if re-transplant is the best option.

Because of organ scarcity, health care professionals and patients must not only consider survival rates in re-transplantation but also the ethical considerations when dealing with resource-limited organs. The data available on re-transplantation is significantly less than data on primary transplant, and is somewhat limited in scope, thereby making an informed decision that much more difficult. Although each situation must be individualized, consideration of burden versus benefit must be examined when making such a complex choice. It can be helpful to reflect on principles usually found in the field of ethics: “Nonmaleficence” which implies that harm is not performed, “Beneficence” which implies ensuring that good is done and finally, “Distributional Justice” which implies that resources will be shared equally by those in need.

Both the notions of nonmaleficence and beneficence are seemingly medically based and your transplant team has likely taken these concepts into consideration when posing the question of re-transplantation. It can be helpful to ask how the team has weighed the information in the context of such unknowns. Although patients want to live, most also want a related improvement in quality of life; focusing solely on survival rates does not help transplant teams and patients truly make informed decisions.

Distributional justice is in many ways a far more personal pain for the patient and family who may already be struggling with survivor guilt or who may know another patient who is waiting for their first transplant; re-transplantation disturbs the notion of distributional justice. Each individual must take into consideration their own mortality coupled with the burden of knowing another’s shall be affected much as they did at the time of initial transplant. In facing re-transplantation, this burden is in effect doubled. Much the same can be said for the health care team’s deliberations as well.

As long as organ scarcity remains so prevalent, both transplant and re-transplant bring up the issues of nonmaleficence, beneficence, and distributional justice. The improvement in safety of live donation for some organs has helped assuage some of the concerns regarding distributional justice. Advances in the management of end stage organ failure have extended length and quality of life for other patients. Yet more work needs to be done to increase organ donation awareness and in the progress of new technologies designed specifically for the failure of primary transplants. Ultimately, facing re-transplantation can be an overwhelming prospect. Patients, families, and health care teams should seek out resources to help them with this difficult decision including but not limited to medical data, ethics committees, counseling, and spiritual guidance.

—Elizabeth Shore, MSW, CSW
Member, TRIO Board of Directors

1 Andrews, Tracy (2009). Restarting the Clock...Again. Dimensions in Critical Care Nursing, 28 (3)
2 ibid
3 ibid
The TRIO PCP Process Defined: “A Grassroots Approach”

Every TRIO member (and their family members) can carry out this short and easy process to engage family physicians (Primary Care Physicians or PCPs) in promoting organ donation with their patients.

The TRIO PCP process is very simple. Other groups have tried much more complex approaches, but all have failed.

On your scheduled family doctor (i.e. "primary care physician" or PCP) visit
1. casually remind him/her of your connection to organ donation/transplantation
2. Ask if they ever talk to their patients about being an organ donor
3. Depending on their response . . .
   a. If they say yes, they do, thank them and ask if they would like supporting brochures for their office or if they need any additional information for their own education and use
   b. If they say no, point out that according to studies most physicians both support organ donation and see it as part of their patient responsibility to bring up that topic - ask if they need information to help them in talking about the subject - offer to have them sent a doctor's fact sheet about organ donation and ask if you can have brochures sent for their office waiting area
4. Follow up your visit with a call or e-mail to Sylvia in the TRIO national office with the results of your visit and she will arrange to have the materials sent to your doctor’s office (have their name and address handy, of course)
5. Sylvia can be reached via email at info@trioweb.org or by phone by calling 1-800-TRIO-386 or (202) 293-0980

The TRIO PCP (Primary Care Physician) process is a way to use your personal transplant success as supporting evidence for a powerful conversation that will encourage your own family physician in addressing organ donation with their patients. With a TRIO physician’s brochure and Donate Life America informational pamphlets, you will have the resources to make it easy for them to cooperate. That is our goal. The simplicity of this one-on-one “grass roots” approach should succeed where others have failed, but that will be up to your participation as a TRIO member. Check out the Summit’s videos for more with our special presentation on this PCP program.

UNOS Patient Services Line Goes Global

The toll-free UNOS patient services line offers interpreters in more than 170 languages for limited-English proficient callers who have questions about transplantation.

UNOS’ toll-free patient services line, 1-888-894-6361, is available Monday through Friday, 8:30 a.m. to 5 p.m. (ET) to answer general questions about the transplant process. After work hours and on weekends, the caller can leave a message, and UNOS staff will return the call the next business day.

The patient services line is one of a number of educational resources UNOS has available for transplant candidates, recipients, and caregivers. UNOS also offers a patient website: transplantliving.org (for Spanish speakers: transplantesyvida.org), and a number of brochures and fact sheets in both English and Spanish, many of which can be downloaded free of charge at www.UNOS.org.

TRIO Announces 2012 Scholarship Awards

Each year TRIO awards several $1,000 scholarships to TRIO members or immediate family members. These scholarships are made possible by generous funding from TRIO chapters. In 2012, four TRIO chapters funded scholarship awards: TRIO Greater Cleveland, TRIO Northeast Florida, TRIO Philadelphia and TRIO San Francisco Bay chapters.

Awardee selection is based on a set of criteria which can be found on TRIO’s website. The Scholarship Committee is composed of Elizabeth Rubin, TRIO Board, Chair; Steve Binder, NEFla; Dorene Kray, Greater Cleveland; Sylvia Leach, TRIO MSD; and Susan Pincus, Philadelphia.

This year’s awardees are Jacob Carroll (Akron, OH); Katherine Janzen (Fresno, CA); Marissa Salgado (Forest Grove, OR); and MacKenzie Tannhauser (Crystal Lake, IL).
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): _______________________________________

<table>
<thead>
<tr>
<th>Type of Transplant</th>
<th># of Transplants</th>
<th>Date(s) of Transplant(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Transplant Center(s)</td>
<td>City, State</td>
<td>Time Waited</td>
</tr>
</tbody>
</table>

Donor Profile (Optional): _______________________________________

<table>
<thead>
<tr>
<th>Type of Donation</th>
<th># of Donation(s)</th>
<th>Date(s) of Donation(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Transplant Center(s)</td>
<td>City, State</td>
<td>TRIO Committee. Please contact me.</td>
</tr>
</tbody>
</table>

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

Annual Dues: Member at Large ............ $20.
Additional Contribution ............ $ _____.
TOTAL enclosed .... $ ______.

Thank You for your tax-deductible donation!

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

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).