TRIO Leadership Summit 2012: Not Just for “Leaders”

YOU are invited! Join with TRIO members and guests Friday and Saturday, September 28-29, in Pittsburgh at the CORE offices (Western Pennsylvania’s OPO). Don’t be misled by that event title, “Leadership Summit” - this is for both TRIO leaders and members overall as a great educational opportunity combined with a celebration of TRIO’s 25 years of service as “The Voice of the Transplant Community.”

View the videos of the 2011 summit available on the TRIO website and know that the 2012 event will be even better with a broad range of topics, special speakers and panels highlighted with a 25th anniversary gala dinner event Friday night. With the $100 per person dinner included as part of the free member registration, we plan again to share anticipated grant funding support with attendees through $200 scholarships to help offset some of the travel and lodging expense for any who need it. That amount will be confirmed when grant applications are approved.

Registration is open NOW with applications available on the TRIOweb.org site or in the center of this newsletter, so please confirm that you will be with us for this only once in every 25 years very special event. Full details are available in the monthly e-News e-mails and on TRIO’s website. We expect to have every chapter represented with special awards and TRIO history highlights featured at the dinner.

Questions can be sent to info@trioweb.org. But, don’t wait: REGISTER NOW!

TRIO: Looking Beyond The First 25 Years

As we move into our next 25 years of service to the transplant community, TRIO’s strategic planning team is finalizing the plan that will support our existing unchanged Mission with a set of three goals and objectives with specific actions for their accomplishment.

There are three main goals:

- Increase human and financial resources,
- Enrich internal communications,
- Inculcate “One TRIO” culture.

The objectives supporting these broad-based goals include growing the membership base by reaching out to past members to “recover” former TRIO members into active engagement with chapter support and a special focused personal contact with the many former MALs by a central calling team. The more than 4,000 names in our historical database provide both an opportunity and a challenge, especially since so much of that data is outdated. If you would like to join a select team of outreach volunteers to call a small number of those names, inviting them to rejoin today’s TRIO, send your contact information to info@trioweb.org. Also, recruitment of new members would complement this effort to grow the membership.

Another objective is to grow the number of chapters, both new ones and hopefully, to recover some chapters that have drifted away over time, offering experienced and trained chapter leadership as mentors to help with that process. Similar objectives have been developed in support of the financial resource area: growing revenues and controlling expenditures. Expect to see objectives that improve the effectiveness of communications to all members in support of that second goal, while others will strengthen the unity of TRIO, which is goal number three:

One TRIO - across the organization through education and service development based on member survey feedback of needs.
“Create a life you can’t wait to live!”

I just finished reading a short book with that “Create a life . . .” title. Its subtitle is “ignite your passion and purpose.” I confess I love feeding my soul with powerful messages like that from inspiring speakers like Zig Zigler, author of this book. When I look back on a life extended by transplant, my own of a heart going on 18 years for example, I realize that unlike most, we have been gifted with a second chance. In visiting and mentoring waiting patients who are often bored with their lengthy hospital confinement (or even at home waiting for the call with family often away at work each day) my advice is to look on this “down time” as a sabbatical, a time off that too few ever get to sit back and reflect on their lives. This can be a time to look ahead and dream of life as it can be after a hopefully, and with today’s excellent medical care, often brief recovery to a life of “new normal” when those dreams can become your reality if planned right. First, just think of that opportunity. Even if one were to die waiting, wouldn’t that be a great way to spend those final days, dreaming of “a life you can’t wait to live?” But, as I told one very scared man waiting in hospital for a heart transplant, “they don’t lose many here, so better plan for your future years with a new heart.”

How many have the time to just sit back and do that dreaming and planning? Everyone around you, family and hospital staff, taking care of your concerns and needs, freeing you up to reflect and plan, hopefully using the “best practice” of writing down those dreams with action plans to turn them into your reality. With the inspiring example of recipients who are living life fully many, many years post-transplant, that can be a way to spend the waiting time until they too can join the family of those who, having faced the edge of life, now enjoy the gift of getting older and facing all the challenges and joys that come with advancing age.

Oh, but you say, I didn’t think of that when I was waiting and now life is too busy again to set back and dream/plan for the future. Not true, I say. Take advantage of the experience you were given going through the transplant process, realizing that life will come to an end for everyone someday, just not now, as it turns out. Look around you at the variety of post-transplant lives you see in our TRIO and other transplant networks. Do you see as I do all different ways that people are spending their gifts of life gained through transplant - some living fulfilled lives of family and purpose, in service to others with TRIO and such groups. Then there are others who see themselves as no longer normal, living a disabled life when in fact their bodies are no longer disabled, only their vision is blinded to the possibilities. Even those who in fact face other medical challenges and are truly disabled are often thankful for the lives they live, serving others when one would expect them to wait to be served, using their remaining gifts and abilities to their fullest, whatever that may be.

That is the challenge you read in these Lifelines pages, that of living your own life to its fullest, taking advantage of the many opportunities to serve and pay back for the gift of life you received through a donor’s decision to “Say YES” when their own lives were exhausted. Even in death they gave YOU life that you may “create a life you can’t wait to live.” I hope that that inspiring phrase excites you as much as it touches my own “gifted” heart, challenging us to live each day with passion and purpose, serving through TRIO to help others enjoy what we have, a life extended and fulfilled!
TRIO Transplant Presentation Library: A Major Up-grade

Have you seen the latest program titles? Six new ones were shipping to your chapter by the time you read this, along with a new tool to make them even more available to members. Feedback was that those big 3-ring binders, each holding one full year of twelve program flyers, were too clumsy to haul back and forth to meetings and thus often were not shared as intended as a loan library. A new carrying case that will hold not only the existing 36 DVDs and flyers but also many more in the years to come was sent to each chapter’s “library chapter champion” (often your president). This will make it easy to bring the full library to meetings for member use of those wonderful programs.

Look for this new carrying case at your chapter meetings:

New titles include: Men are from Mars, Women are from Venus: Even in Heart Transplant; Transplant Recovery Through Creative Endeavors; Safe Medical Practices with Medications; Health Screenings for the Healthy Lifestyle Long After Transplant; Good Nutrition Made Easy for Transplant Caregivers; 2012 Annual Update on Transplant Technology; Transplant Finances.

Members at Large should contact TRIO’s national office to request copies (email info@trioweb.org).

We are pleased to report that this program has received funding for a fourth year, so stay tuned or check out that web listing for the next 12 programs to be added over the next twelve months. The first program for our fourth year, Behavioral Patterns of Transplant Recipients, is already “in the can” for distribution later this summer. Hopefully, your chapter will record a local speaker as its contribution to this growing library. If you see such an interesting upcoming presentation, suggest that it be recorded and submitted for consideration.

TRIO Long Island Chapter Reports NY Donor Registration Law Success

For the past year TRIO Long Island Chapter members generated hundreds of calls and emails, in general made good “pests” of themselves, in a grassroots effort to help publicize and illustrate the importance of Lauren’s Law, which aims to boost organ donations throughout NY State. As of June 20, their efforts have been met with success with the bill passing in both the NY State Assembly and Senate.

The bill expands the donor options on NY driver’s license applications. The measure, which now heads to Gov. Andrew Cuomo’s desk, would require individuals who apply for a driver’s license to complete the organ donor registry section of the application by selecting either “yes” or “skip this question.” Currently, filling out the section is optional.

Lauren is a champion transplant recipient and advocate for whom this law is named. This articulate and eloquent young lady will be speaking at the annual TRIO Long Island Chapter Donor Rose Garden Ceremony on Saturday, September 22, 2012. Congratulations to this chapter for another successful public policy effort, an inspiration to all as to what a dedicated and passionate team effort can accomplish.

“Nicely done, Mike Sosna and the entire TRIO Long Island Chapter!”

TRIO Supports the Transplant Community Through Washington Roundtable Action

And the fight goes on, and on and . . . for years now: still trying to get support and funding for that Medicare prescription funding extension beyond 36 months for eligible kidney recipients. TRIO is one of more than a dozen organizational members of the Washington DC based Transplant Roundtable that meet with legislative leadership to advocate for important federal legislation that affects our cause. In a general public policy support update, see the TRIOweb.org site for an easy to use tool for expressing yourself to congressional representatives, a great resource sponsored by NKF.
Who Is Your “Chapter Champion”?  
Do you know who your chapter champions are? Maybe they haven’t been named yet and YOU could be a candidate? Local chapter members serve as the representatives for a distribution list that goes out to them with current information on specific TRIO initiatives.  
As a chapter champion you are responsible for being tuned in to the activities of that interest topic, reporting updates, following up on proposed action plans with your chapter, as well as responding with chapter support or concerns in that subject area.  
Along with public policy, chapter champions are being sought for the Primary Care Physician program, the 25th Anniversary planning and our Transplant Presentation Library. There are no committee meetings to attend, just e-mails to read and act upon, sharing news and updates with your chapter.  
Are you ready to fill any of these exciting in-the-know “chapter champion” roles? Talk to your chapter president for possible nomination. We welcome your support and getting involved with these important areas of TRIO initiatives.  
Reach out by contacting info@trioweb.org if you are interested or have questions.

Bruce Weir, Past President of TRIO Board of Directors  
The TRIO Board of Directors is sad to announce the passing of Bruce Weir on April 11, 2012. A long time survivor of a heart transplant, Bruce was well known both in the world of transplantation and in the outside world as a warm, giving person who was an inspiration to all.  
Bruce received his new heart on July 11, 1988, having been diagnosed with cardiomyopathy only a little over a month earlier. Before that, he had been a certified public accountant for many years. Even before his transplant, Bruce put much of his extra energy into community service, volunteering for the Jaycees and Band Boosters, as well as for his daughter’s political campaign, among other things. After his transplant, in appreciation of his gift, Bruce served as a long time volunteer for the Mended Hearts organization, giving hope to patients with heart disease by visiting them regularly in the Cleveland Clinic, and for Life-banc, the OPO in his area, by speaking to many civic and professional groups and organizations raising awareness for organ and tissue donation.  
Bruce was also a member of TRIO for his entire transplant life, and he served both as President of the TRIO Greater Cleveland Chapter and as President of the TRIO National Board of Directors for many years. During his tenure as TRIO’s national president, Bruce testified on several occasions before the U.S. Congress about organ allocation and other transplant related issues. He was a soft-spoken man, but when he felt strongly about something, Bruce communicated the passion he felt towards that issue.  
Bruce leaves behind his wife of 54 years, Rita, as well as two daughters and their husbands, five grandchildren and two great-grandchildren. He will also be remembered by his donor family, with whom he become acquainted shortly after his transplant.

Can You “Hear US” Now?  
With member communications a primary focus, monthly TRIO “e-blasts” go out to about 600 member email addresses, providing important updates and information complementing the quarterly Lifelines and the daily information updates that appear on the TRIOweb.org website.  
If you aren’t on that distribution list, you are missing out on an important resource! But that can be easily corrected: just send your e-mail address, chapter affiliation (or MAL) with your name to info@trioweb.org – it’s just that easy!  
These TRIO emails are short and colorful, usually with just two or three concise articles offering links to the web for things like flyers, registration forms, applications, etc. Also, if you just want to “try them out” there is a simple “Unsubscribe” option at the end of each issue which immediately takes you off the distribution.  
For those who want to keep their e-mail address private, notice of each issue is also published on the website under “News from National” with a link to view the same issue as if you had received it directly.

Just a Thought to Share  
“You give but little when you give of your possessions. It is when YOU GIVE OF YOURSELF that you truly give.” – Kahlil Gibran
TRIOweb.org – Your (Re)source for Everything Transplant

Looking to keep up with news in the world of transplant? TRIOweb.org has it with daily news feeds of what’s happening! Links to everything transplant-related: TRIOweb.org has more than 700 tested links organized by topic! Looking for connections or ideas? TRIOweb.org has the chapter contacts and event information for new ideas to adapt to your own chapter in local action. Books and movies related to transplant? TRIOweb.org has the world’s largest databases of each, many book reviews and in-depth background information on those 100+ movies, for example. Looking for member stories of transplant life or youth making a difference in this wide world? TRIOweb.org has them, too.

If you haven’t yet discovered the richness of this world-class resource, updated daily, you really owe it to yourself to visit and explore.

Did I give you that web address? It’s http://trioweb.org check it out today and consider making your own contribution of a story or ideas by contacting info@trioweb.org

Getting the Word Out: Your Meetings and Events

Transplant Living, a UNOS sponsored website, has undergone a re-design. Among other things, it’s a popular and free advertising website to post your chapter organization under organizations, and you can post your chapter meetings and special events under their calendar of events.

While many TRIO chapters are already listed, check your own, especially under the event calendar, and if you serve more than one area, list the meetings and events under each state so patients searching by state can find you. Go to http://transplantliving.org/community/

Organ Allocation Part 1: UNOS

(Part 1 of a 3-part series describing the complex process of getting a donated organ to the recipient)

Many patients get the impression that “my doctor gets me my organ.” They never fully understand the complex cooperative process by which their heart/liver/lung/kidney/etc., came to save their life in the hands of that surgeon and transplant team that are their most direct contact with the process. Over the next few issues, we will describe the typical scenario involving a donor family and hospital, UNOS, an OPO (organ procurement organization) and finally, the recipient and their transplant team.

Let’s start at the middle, with UNOS (pronounced “you nose”) which stands for “United Network for Organ Sharing” a government subcontractor based in Richmond, VA. Since its inception in 1987, UNOS has been the organization that maintains the waiting patient database of everyone “listed” for an organ transplant (114,000+ as of this writing). They also develop and update the rules by which organs are allocated. Those rules are the work of 22 committees, comprised of hundreds of volunteer medical professionals, organ procurement specialists and patient advocates—donor families, recipients, candidates and general public all of whom rotate through a 2-year term of service. Supported by UNOS staff, these committees constantly review allocation rules for fairness, changes in medical technology and run simulations to assess the effectiveness of those rules. But for our story, mainly UNOS manages the database of information about patients who have been entered (listed) in that database by transplant programs (or OPOs on their behalf). When an organ is donated, its characteristics (blood type, size, antigens, etc.) are matched against that database and a prioritized list of potential recipients is generated based on those allocation rules which are different for each organ type. Your transplant program is notified electronically of the “offer” and, based on their patient’s situation, may accept or reject that offer, a process that continues down the list until the organ is accepted. Why an organ offer might not be accepted and how that donation takes place will be the subjects of the next two parts of this series, the OPO’s role and the transplant center’s role.

Meanwhile, you can see those committees and rules at UNOS.org.
Register Now – NO REGISTRATION FEE for TRIO members!

★★★★ Please complete for EACH attendee and return this form by Sept 1st ★★★★
★★★★ Mail to TRIO c/o Sylvia Leach; 13705 Currant Loop; Gainesville, VA 20155 ★★★★
or by email to: sleach@trioweb.org

TRIO’s 2012 Leadership Summit
September 28-29: Pittsburgh, PA

Meeting Location:
CORE (Center for Organ Recovery and Education) offices
204 Sigma Drive, RIDC Park, Pittsburgh, PA 15238

Name: ________________________________________ Are YOU a:
Address: ______________________________________  ☐ Chapter Officer?
City/State/Zip: ________________________________ ☐ Local Chapter member or “MAL”? Offic:e: __________________
Personal email: _______________________________  chapter name: _________________
Phone number: (______) - ______ - ________________ ☐ non-member guest

☐ YES! I will attend the TRIO 2012 Leadership Summit  __ Fri/Sat  __ only Fri  ___only Sat
☐ YES! I will attend the 25th Anniversary Dinner on Friday Evening
  • No registration fee for 2012 dues paid members registered with TRIO national.
  • Non-member guests: $50 for two days of Summit workshops & luncheons, plus $100 for Friday evening dinner event.  (Please submit check payable to TRIO attached with this request if a non-member guest)

Scholarships may be available to help cover travel/hotel costs (pending grant approvals): Only dues paid members registered with TRIO national can apply for up to a $200 scholarship* to assist with the cost of attending the TRIO Leadership Summit. Scholarships are in the form of reimbursement upon submission of a signed Scholarship Request letter which will be distributed (signed and returned to TRIO) at the Leadership Summit.
*Exact number of scholarships for the 2012 Leadership Summit will be dependent on grant funding received.

☐ YES! I plan to apply for a reimbursement/scholarship (up to $200 to help with travel/hotel costs).

TRAVEL:
The Pittsburgh, PA, airport (code: PIT) You are responsible for booking your own flight.
  Taxi from airport to CORE offices: $75
  Shuttle service (shared) from airport: $44 (http://supershuttle.com)

HOTELS: The suggested hotel for attendees is::
  Comfort Inn, 180 Gamma DR., Pittsburgh, PA 15238 (approximately 5 minutes walk to CORE offices).
  Phone: 412-963-0600, website: http://www.comfortinn.com/hotel-pittsburgh-pennsylvania-PA669 - TRIO has blocked a limited number of rooms at the special rate of $89/night (plus tax; non-refundable; standard room, total: $101.28). You are responsible for booking your own room and must mention this TRIO meeting event to get that reduced rate (available only until Aug 28th).

SCHEDULE (Overview): The Leadership Summit begins with a luncheon at noon on Friday, and a VERY special TRIO 25th Anniversary Dinner at 7:00 p.m. Saturday’s schedule begins at 8:00 a.m. with a continental breakfast, with the Summit ending at 5 p.m. A detailed agenda will be provided on TRIO’s website, member e-blasts, and chapter presidents’ e-news. Note: Not part of the Leadership Summit but open to all, a TRIO board meeting will be held from 9 til 11:30 Friday morning.
TRIO Youth Circle’s Julie Bonn Pursues Medical Career

When you look at her, or read her bio, you would never guess that Julie Bonn’s life story includes a liver transplant when she was 12 years old. In her current life, Julie has just completed her first year of medical school at the University of Cincinnati, while working part-time in the GI department at Cincinnati’s Children’s Hospital and participating in the Pediatric Scholars Program, as a member of the medical school’s Mentor Club, and as a member of TRIO’s Youth Circle. She was also the recipient of a TRIO educational scholarship before her senior year in undergraduate school.

But her life was not always this busy and normal. Perfectly healthy until the beginning of 7th grade, Julie began feeling sick and tired and, within a few weeks, developed jaundice, but all the initial blood tests came back negative. When her hands and feet began to swell, Julie was admitted to the hospital, at which time a liver biopsy indicated that she needed a liver transplant within a week or else she would die. With a status listing of 1a, Julie’s wait for a transplant was very brief; in fact she received a new liver on October 7th, 2000 at 7pm, just one day after being listed. The diagnosis for the transplant was acute liver failure or fulminant hepatic failure with an unknown reason.

Julie’s transplant experience did not end with her transplant. During the first year post-transplant, she had several complications, rejection three times, and two cases of hepatic artery stenosis, both of which required surgery. When she was finally given the okay to return to school in January, an event she was most excited about because it signified she was finally a normal teenager, Julie was disappointed to find out that her student peers did not accept her very well in view of her 50-pound weight gain from high dose prednisone. Julie says now that, “this was the hardest part for me, dealing with superficial and shallow teenagers while I was most worried about staying out of the hospital and stable lab results.”

Over the next few years, her health stabilized, but Julie struggled with why this had happened to her. She eventually came to understand that it had happened for a reason, and she just needed to figure out that reason for herself. What Julie realized was that it is important to “live life to the fullest and be thankful for every day and experience you have, not to take things for granted (especially your health) and realize that anything can happen to anyone at anytime.” She also learned that it is important to live by the golden rule and “to treat people how you want to be treated, trying to put yourself in their shoes to see a different point of view.”

And Julie certainly has done just that. She had wanted to be a doctor (brain or heart surgeon) from the age of eight, but, after her transplant experience, due to the kindness, expertise and wonderful bedside manner of the medical staff at Cincinnati Children’s Hospital, Julie was inspired to become a pediatric gastroenterologist. Asked what are her goals for the field of transplantation, Julie replied that she has many, including doing research along with clinical medicine to “expand the current research in immunosuppression withdrawal and immune tolerance, create/improve a transitional care program bridging the gap between pediatric and adult transplant including patient education starting in the teen years and also to create/improve the social support” for transplant children, teens and young adults. We at TRIO are excited to see how our youth members will benefit in the future from Julie’s energy and focus in this area!

Hello, Members at Large!
(The below message is from Will Oler, MAL, who, along with Lou Reardon, MAL and Board member, is leading a national effort to engage MALs.)

As part of TRIO’s Strategic Plan to engage with members more often and honor their status and support to the organization, Lou Reardon and I want to begin commemorating your transplant anniversary dates. We mean to include recipients, donors and donor families.

The recognition would be in the form of a mailed anniversary card. We need to know if this is something you would be interested in. Give us some feedback at: info@trioweb.org. We also want to validate and confirm anniversary and/or donor dates to make sure we get it right. Please include this information in your feedback response.

-- Will Oler, Member at Large
Of Hope and Courage—
A Stroke Victim’s Personal Story

Like all transplant recipients, I have had many challenges— from chronic kidney rejection and liver failure to skin cancer, stress fractures in both hips, shingles, CMV, atrial fibrillation, seizures, cataracts, GI disorders, and numerous other issues. I’ve had two kidney transplants and a liver transplant, and now I’m again on dialysis awaiting my third kidney. All of these I have handled with hope and courage. But that hope and courage would be put to the test this past year.

Back in August of 2001, as I was preparing to attend the World Transplant Games in Kobe, Japan, I had my first attack of atrial fibrillation. Atrial fibrillation, or “a-fib,” is a heart condition characterized by irregular and often rapid heat beat. Since that time, I have been on virtually every medication for a-fib, all with little or no success. A few years ago my cardiologist recommended catheter ablation, a procedure performed on the heart to correct a-fib. I had four such procedures between 2007 and 2010; none of them proved to be successful long-term. Out of options, I remained hopeful that one day the procedure would work.

Early in the morning on September 12 of last year, I went to have my fifth ablation procedure. Having had the procedure performed four times previously, I knew what to expect: I’d go into pre-op, get prepped, be out for a few hours, wake up in the hospital, have some dinner, get some sleep and go home the next day. That was the plan. But that evening following the procedure, as I awoke from the anesthesia, I became aware that I was unable move my left arm or leg. Within hours I had a CT scan and an MRI, both confirming that I had suffered a stroke during or immediately following the procedure. The next day I was transported to a local rehab hospital where I spent more than three weeks in intense physical and occupational therapy, literally retraining my brain to control my left arm and leg. I had to relearn how to stand and walk, how to eat and get dressed, how to do all the things I used to do with such ease. In total, I was in therapy for more than five months. I won’t lie: it was tough. There were and still are times when I get angry and frustrated.

Yet in many ways, I feel lucky. Strokes typically affect the facial muscles, causing appearance changes and difficulties speaking. They also frequently cause personality changes, lessening of cognitive or decision-making skills, and complications with chewing and swallowing. I have had none of that.

Now, ten months after the stroke, my recovery continues, but in many ways, my abilities have plateaued. Walking, showering, fixing meals, and daily household chores are all still difficult. I’ve learned to adapt and do what I can, how I can.

As the effects of the stroke linger and I await transplant, hope and courage remain strong in me, but not without help. Family and friends have been so loving and supportive. Three very dear friends have offered their kidney to me and been tested for possible donation. Though not a match, they each have agreed to become part of the Paired Kidney Exchange. Their courage has given me courage to stand up to the challenges that face me and hope that better days lie ahead. But with hope (seeing the light through the dark) and courage (the desire to keep moving forward), I know that life has a lot yet to offer, and I have a lot to offer life.

-- Steve Binder, Member, TRIO Northeast Florida Chapter

A stroke occurs when the blood supply to part of your brain is interrupted or severely reduced, depriving brain tissue of oxygen and food. Within minutes, brain cells can begin to die. The warning signs of a stroke include:

- Sudden numbness or weakness of arm or leg
- Sudden confusion or trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden dizziness, trouble walking, or loss of balance or coordination
- Sudden severe headache with no known cause

If you notice any of these, call 911 immediately. The effects of a stroke can often be lessened with prompt medical attention.

Aside from atrial fibrillation, the main risk factors for stroke are: high blood pressure, diabetes, smoking, high cholesterol, being overweight, inactive lifestyle, age 55 or older, history of heart disease, family history of stroke, heart attack or TIA (often called mini-stroke).

To learn more, visit www.mayoclinic.com, click on “Health Information”, then ‘stroke’. Also, see the National Stroke Association’s website www.stroke.org
Looking for that “Summer Read”?  
Well, it is summertime and the reading is lazy and fun. Allow me to recommend the best transplant novel I have ever read, “When Crickets Cry” by Charles Martin. While this isn’t a new book (actually, it came out back in 2006), it remains the most engaging read you can find. Without giving away anything, let me just say it’s a human interest type story of a heart transplant surgeon and involves three heart transplants before you get to that final page.

Charles Martin lives in TRIO’s Jacksonville Florida chapter area and has been a much-enjoyed speaker at chapter meetings there. As a fan of his many books, I “attended” that meeting via cell phone. The author put the cell phone in his pocket so I could both hear him well and ask questions when they got to the Q&A.

One caution though, when your emotions get to a fever pitch and you are tempted to put the book down because you can’t handle them anymore, promise me that you will keep on reading through the final chapters—you won’t regret it!

In the “real world” there is a book, “Your Medical Mind: How to decide what is right for you” by authors Groopman and Hartzband, that really hits home in our world of facing daily medical challenges. While making the right medical choice is harder than ever, this book aims to provide “the essential tools for making our own best medical decision, cutting through the confusion caused by the health care system, the media, and gaps in our own reasoning.”

With more than 80 pages of supporting notes, bibliography and appendices, the reading can lead you into any depth of interest you may wish to pursue. Great read, great insights into how we make those life-altering decisions every day and how to be more effective in dealing with those up-coming issues.

And don’t forget to check out reviews for both of these books and many more (100+) under “Resources” on TRIOweb.org.

TRIO Quarterly BoD Meeting Report

Your TRIO board held its quarterly meeting May 12 by phone to review and discuss many projects and issues, including a draft of the Strategic Plan that was still under development.

Financially, TRIO remains solid, on track within budget for another good year (dependent, of course, on critical grant support for the big Summit/Anniversary event in September).

With grant approval for a fourth year of the Transplant Presentation Library now in hand and reduced but still generous support by the DeVos Foundation along with membership dues slowly coming in, we are working hard to both control expenses and continue healthy revenue growth to support member services in the months and years ahead.

Our next meeting, always open to members, will be held Friday morning from 9:00 to 11:30 immediately before the opening luncheon of the September 28 Leadership Summit in Pittsburgh at the offices of CORE. If you are coming to the summit and can attend, you would be most welcome. Note: the Leadership Summit starts at noon. The following quarterly board meeting is Saturday, November 17, from 2:00 to 4:00 p.m. via conference call, so put that on your calendar if you wish to sit in.

TRIO PCP Program: Looking for Chapter Champions

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 to address 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.

There will be a special nation-wide formal launch of this PCP program at the September Leadership Summit.

Ventura County West Valley and the Philadelphia chapters have named chapter champions for this special initiative and agreed to test market the approach. All chapters are invited to name their PCP chapter champions to carry the message and process to local members as this develops and takes on momentum. Are you that person? Talk to your chapter president to offer your service to this important new initiative.

MALs: stay tuned for your role in this activity.
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):

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