



Lifelines

April 2013



Transplant Recipients International Organization, Inc.

2100 M St., NW, #170-353; Washington, DC 20037-1233

www.trioweb.org • info@trioweb.org • 1-800-TRIO-386

Harvey Mysel Joins TRIO Board of Directors

Harvey Mysel, founder of Living Kidney Donors Network, brings another personal experience of a transplant recipient to TRIO's Board of Directors.

The Living Kidney Donors Network was established after his first kidney transplant in 2007. His wife was his donor.

He later developed a rare virus that attacked his transplanted kidney and in 2012, he needed another kidney transplant.



Harvey says "It was ironic, that five years after starting LKDN, I needed to take my own advice and start a campaign to find a kidney donor." And through that effort, Harvey met a living donor who was not compatible with him, but was involved in a 3-way kidney paired donation, also known as paired exchanges or swaps.

One of Harvey's goals, as a member of TRIO's Board, is to develop more programs to reach and help those who need an organ transplant.

In addition to the work he does at LKDN, Harvey is a tri-athlete, competing in a triathlon five months after his transplant. He is a Gold Medal winner in the 2008 Transplant Olympics and was awarded two Gold Medals and a Silver Medal in the 2010 Transplant Games. Harvey is an avid bicycle rider, tennis player, bowler, hiker and rock climber.

To learn more about Harvey's passion for the Living Kidney Donors Network, see page 11 of this issue.

To learn more about the LKDN, go to:

www.LKDN.org or email Harvey at Harvey@LKDN.org

TRIO's Strategic Plan Sets Action Items for 2013 Growth

Over the past year and more, it seems like every organization has been creating or updating their strategic plan, often a daunting task but a sign of a forward-looking leadership team. Once such a plan has been created and approved, too often that's where it stops: a good looking document sitting on the shelves (or stored in some computer folder) when in fact, that's where the real challenge begins. The follow-up on the action plan, with committed discipline to carry out that plan, is both the key to long-term success and is the most difficult part of the process.

TRIO's officers and board are committed to regular review of our recently developed action plan to insure its success. The final "Goal 4" of that strategic plan calls for us to "make the plan real and 'living' for the long term" in three phases. First, by MSD and president monthly reviewing progress of actions vs. plan. Second, quarterly the Strategic Plan team will review and produce a formal progress report for the board meeting. Finally, an annual report and updated plan is to be presented for board discussion and approval.

(continued on page 6)

Marty Maren Named TRIO Chapter Council Chair

Marty Maren, President of the TRIO Maryland Chapter, has accepted the challenge of guiding the TRIO Chapter Council. Marty, and his wife Michele, recently founded the Maryland Chapter. Marty says, "I offer my drive and passion to find positive and supportive ways to contribute. I also bring a 'newbie' enthusiasm and perspective to the position."

As Chapter Council Chair, Marty assumes a place on TRIO's Board of Directors. He will work with existing chapters to enhance their efforts and to give support.

President's Message



Jim Gleason

"I can't control what life does to me – but I can control how I react to what life does!"

Lewis Timberlake

Hey, Spring is almost back again! Isn't this an amazing time of renewed hope for each of us? Yes, I am going to get out from this office and start a daily exercise walk again, a reminder to us all of how important to our post-transplant lives daily exercise really is. Reflecting on the recent passing of two special TRIO leader friends, I was always inspired by JT's facing his own medical challenges (see the power of words and attitude in another article) with his racing in bicycle competitions at the world transplant games. Both he and Alex showed how to control and react to what life deals us. And, along with the great organization they both helped build and support for many years, that inspiration is part of the legacy they leave with us. Whether it was Alex and Pat losing their son or JT squinting to see the printed word (what a challenge for JT's life as a CPA), nobody ever heard either of them complain, controlling how they reacted to each thing life threw at them. I know I speak for all of us when I say they will be missed and "Thank you, for all you gave!"

Thoughts of their loss came back to me as I was surprised by my wife, Pam's, throwing me a surprise 70th birthday party last week. Just a small gathering of very close friends and family who came together to share in that joyful event, even if I still can't believe I'm really SEVENTY! It seems like only yesterday that the doctors said: **"Mr. Gleason you have just two years to live,"** when, in fact, that was almost 19 years ago. That wasn't scary at all as I had accepted that from the day we are born, we are guaranteed to die, someday, hopefully not soon, but some day. Every time we gather for a loved one's funeral, we seem to hear those words of regret: **"Too bad he/she isn't with us now to hear these nice words."** I'm sure that was said at JT's and Alex's funerals. Well, I was blessed with these 19 years of life extension and to hear those wonderful words from friends gathered, not for my funeral, but for the birthday party, made possible because a young man of 38, in death, offered life to this dying man. Roberto Cuebas of Brooklyn lives on with his heart beating even now. How does one say thanks for that anonymous gift? I found it easy to express my thanks to his family, but that is not everyone's

experience. Read the article about why many find it so hard to write that special note of thanks for their life's gift in transplant, and let's see if that doesn't help those who haven't yet to finally find it in their heart to send a note of thanks to their OPO to pass along to that donor family. **"Just do it!"**

Some would say ". . . **well, Jim, it's been easy for you to have that outlook given the quality of life you've enjoyed with that heart transplant these many years.**" Let me share that it's been prostate cancer, skin cancers (just got a 'nose job' here a few weeks back to remove cancer on the nose that took 106 stitches), and then there was that partial kidney removal last January to take care of a tumor on the kidney--all good and totally curative. Just a week ago I was sharing my life experience with nurses on the cardiac floor and the head of the transplant program asked **"So Jim, looking back over those years since '94, what would you like to have changed?"** I thought hard before responding and then gave my answer, **"Absolutely nothing!"** I have lived long enough to face those challenges that come with 70 years of living and my reaction is and continues to be, **"Wow, above ground another day! This is going to be a good one!"** That is the reaction I choose even as I go off to see that Moh's surgeon tomorrow morning for whatever he has to do next to keep me living another day to serve you in my life with TRIO. I hope you choose to do that also, today and each day of a gifted life you are given.

Sincerely, *Jim Gleason*
President, TRIO Board

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UNOS Resources

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888-894-6361

TRIO Board Holds Quarterly Meeting

The most recent Board meeting was held via teleconference on Saturday, February 2, 2013. Many topics were discussed and several key proposals were voted on.

The Board continues to review our progress on our strategic plan. [See article on page 1 for more detail.] One of the key areas of the plan deals with chapter development and the Board voted to offer additional incentives to chartering chapters – namely, contributing \$500 from TRIO (as assistance with start-up funding) and giving them a TRIO banner as well. In addition, the Board discussed and approved moving ahead with a TRIO website re-design.

Other topics covered included the identification of new Board prospects, fundraising and grant writing. The 2013 Leadership Summit, which the Board voted to rename the “Leadership and Education Summit”, is scheduled for September 20-21. The location is yet to be determined, but mark your calendars for the dates! You are also invited to attend the Board meeting, which will precede the Summit.

The next Board meeting is scheduled for Saturday, May 18 from 2-4 p.m., by teleconference. If you would like to listen in, notify info@trioweb.org.

Other Board reports from the February meeting are covered in articles elsewhere in this issue.

TRIO Scholarships Available

The TRIO Scholarship application has been posted on the TRIO website since mid-January. Applications will be accepted until the deadline of June 30, 2013. Remember: the \$1,000 scholarships are for TRIO members, who are recipients, donors or family members.

A 2013 Board of Directors Scholarship has been named in honor of Alex Boyer and J.T. Rhodes, two recently deceased Board members. All contributions received in memorium to Alex and J.T. will be used to fund that scholarship.

Each year, we have many more worthy applicants than we can fund. TRIO needs your financial support of the scholarship program.

We are looking for individuals, chapters and others to help fund these scholarships – if you have any ideas on sources of funding, please let Sylvia know (email info@trioweb.org).

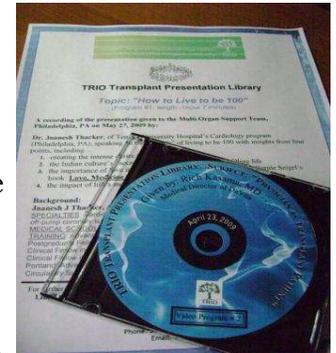
TRIO Presentation Library Grows in Use

After posting eight new titles on the trioweb.org site under Communications/Resources in our last issue (DVD's to be distributed to chapters bi-monthly through August), we now have two more exciting titles in hand with still more scheduled for recording in the coming months. All these DVD's are in stock now, so members at large can contact the national office to receive any title.

Don't forget: you can read the full informational flyer just by clicking on its title on the web listing.

New programs are:

- **Pgm 51: "Heart Health Factors: Facts and Figures" (86 min) by Dr. Mariell Jessup (Sept 2013)**
- **Pgm 52: "Shift Your Fate: Life-changing Wisdom On How to Live Your Best Life Possible" (76 min) by Risa Simon ((Oct 2013) based on dialysis vs. kidney transplant life experience**
- **Pgm 53 (recording in April): "Re-conceiving Transplantation As The First Step Towards Long-term Health and Wellness" by Dr. Alden Doyle (Nov 2013)**



From chapter newsletters and activity reports, we see many interesting presentations taking place across the country. If you see such an interesting upcoming presentation, suggest that it be recorded and submitted for consideration.

More chapters are reporting increased use of these programs with the ease of carrying the library in those new cases to chapter meetings.

Also, there have even been requests outside of TRIO for some company education program use of our titles, an exciting outreach that we are happy to support if you send such requests to the national office at info@trioweb.org.

To review all four volumes of the Presentation Library, go to www.trioweb.org and under “Resources,” click on “Transplant Presentation Library (DVD) Program.”

Phasing In of New Healthcare Benefits *(How has it affected you so far?)*

With the Supreme Court upholding the often controversial “Affordable Care Act” (commonly called the “ACA” or “Obama Care”) and the 2012 election confirming the plan with the president’s re-election, we are now seeing more and more changes in our healthcare insurance coverage. While some elements wouldn’t go into effect until 2014 and beyond, there are already benefits that have been put in place along a timeline from 2010 through today. Maybe, for example, you received that \$250 check in 2010 if you had “hit the donut hole” of Medicare Part D coverage? That was offered as an interim step towards the total elimination of that gap with phased-in discounts each year until 2020 when the gap is eliminated altogether. But that’s just one example out of many that play into our often complex and costly transplant life challenges.

While we certainly don’t have room to detail and explain all of them here (as Liz Shore did in the January issue. You can see her expanded article on the TRIO web site where she did a great job listing such detail), you can go to the web and see a really easy-to-use tool that shows by year each benefit and when it becomes effective. Click on the short benefit description to get more details for that item, including when it becomes effective. That tool can be found at <http://www.healthcare.gov/law/timeline/index.html> and you will be pleasantly surprised at the clarity of information provided in a nice graphical format.

If you have seen changes in your life already from the ACA, drop us a note to info@trioweb.org so we can add on-going educational and personal experience about this changing environment in future issues of *Lifelines*.

For full information about ACA, go to <http://www.healthcare.gov/law/> and be sure to scroll down to see video stories about individual patient experiences. Sure, this site is a promo for the program overall, but it is very well done and specific to your care, so stay informed and get your well-deserved benefits.

TRIOweb.org: A World-Class Web Resource

It’s that time of year again: Looking for a scholarship targeted for transplant youth? Check out the TRIO scholarship page (under Communications/Resources) for a current listing of [twenty scholarship opportunities](#), including TRIO’s own scholarship program. Some of these programs offer up to \$5,000 to the selected youth or adult professional.

That’s just one of many resources to be found on our web site, updated daily with news (hundreds archived), links (over 700 validated regularly), databases of transplant books (150+) and movies (120+), surveys (Sex Post Transplant), newsletters (Lifelines and E-News), youth forums and stories, support group and chapter leadership contact information.

The site will be re-designed in the next few months for a new look and feel, to be more people-focused, easier to navigate and find what you may be looking for, highlighted with TRIO chapter and member photos. To support that, and as part of the re-design, we need your help in sending us TRIO related photos to info@trioweb.org today so we can consider them.

TRIO’s Primary Care Physician Program At Work

Calling all those who made commitments at last fall’s Leadership Summit to speak with their primary care doctors: *how are you doing with that commitment?*

I recently visited my internist, and was pleasantly surprised to see that the form I had to fill out had the question: Have you signed up to be an organ donor? When I went in for my exam I told the doctor how pleased I was to see that question. Then I engaged in a conversation with her about the subject. As it turned out, she had trained in Boston under a transplant surgeon, and had considered becoming one. I am sure she could have been a good transplant surgeon, and I know I will benefit from her knowledge and experience in the field of transplantation.

Before I left the office, I asked the doctor whether she would like me to bring her some additional information regarding organ and tissue donation.

It was an easy conversation to have with my doctor, and it took only a few minutes.

-- Elizabeth Rubin
Vice President,

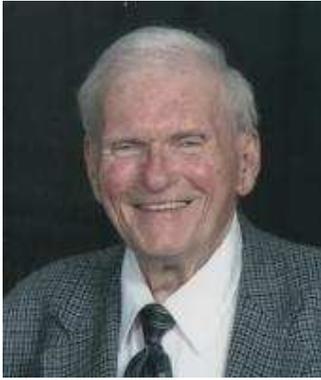
TRIO Board of Directors

HealthCare.gov
Take health care into your own hands

Find Insurance Options Now

Prepare for the Health Insurance Marketplace

TRIO's Loss: Two Great Supporters, Board Members and Friends



Alex Boyer (1937-2013)

Alex served TRIO as a member of the Board of Directors, Chapter Council Chair, and as President of the TRIO Pittsburgh Chapter for many years. He and his wife Pat were always willing to take on a challenge.

Pat recalls that the winter of 1993-94 was a bitterly cold season during which Alex was hospitalized for three months at the University of Pittsburgh Medical Center, first waiting for a liver transplant and then beginning the slow recovery post-transplant. One day during Alex's recovery, Pat read about TRIO in a newspaper. When Alex was healthy enough, they both got involved and became very active TRIO members.

Alex enjoyed visiting new transplant patients and allaying their fears about the procedure.

Alex's skillful guidance at TRIO was an extension of many years' experience as a guidance counselor. A lifelong educator, his longest tenure was at Avella High School, where he shaped students' lives and careers for 31 years.

Alex was devoted to his job and his students, but he also had a vital life outside of work. He was an active member of the Church of the Covenant, where his son Randy was minister. He enjoyed musicals, the theater, the cinema. And then there were the nearly annual trips to Gettysburg and other Civil War battlefields, often taken with extended family.

Alex and Pat took their final battlefield trip together last summer, during which they rode an old-fashioned excursion train on the Strasburg Rail Road. What Pat remembers most about the ride is just how much she and Alex enjoyed each other's company, completely relaxed and in the spirit of the ride, chatting and laughing.

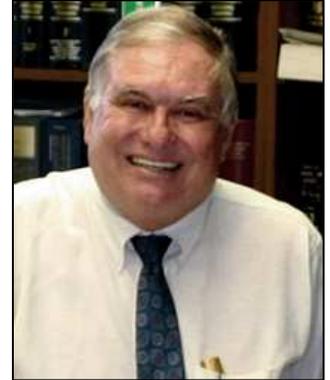
Alex was preceded in death by his son Randy, who died of cancer in February of 2012.

Alex's wife of 50 years continues her involvement in TRIO, participating in the Pittsburgh Chapter activities and in developing a Caregiver Committee at the national level.

--The above is based on an article written by Jane Liaw (jane.liaw@stanfordalumni.org). Jane's full article can be viewed at www.trioweb.org click on "Members" then on "Stories".

J.T. Rhodes (1948-2013)

A CPA in private practice, J.T. was instrumental in founding the TRIO Northeast Florida Chapter, where he served as President of both the chapter and TRIO's Board of Directors. He also served as Chapter Council Chair of TRIO.



J.T. not only loved his Florida Gator football team, he was also an avid participant in the World and U.S. Transplant Games since participating in Manchester, England, in 1995. In 1997 he rode his bicycle from Atlanta to Jacksonville and then, on to Gainesville, FL. As he rode over 450 miles in five days, he promoted organ donation at various events during the ride. He was selected as the Elite Athlete from Florida to represent Team USA in Thailand in 2007.

J.T.'s good friend and fellow chapter member and transplant recipient, Steven Binder, says: "As I look back on the past 18 years, I see J.T. as a beacon of hope. He stood strong, often in the face of adversity, for transplant recipients. He fought tirelessly to help patients get desperately needed organs and to help recipients live longer, healthier lives. His compassion and conviction in serving his fellow recipients were unyielding. I admire and stand in awe of all that he accomplished. I think if he could say one last thing to us, it would be: 'Enjoy life, don't take a single day for granted, and use your blessings in the service of others.'"

J.T.'s family was deeply touched by the need for organ transplantation. Polycystic Kidney Disease (PKD) caused liver and kidney failure in his family. JT, a kidney recipient, is survived by his five sisters: Mary Rhodes, Patricia Robinson, Jeanne Prince, Louise Wright, and Catherine Kasriel. Of his five sisters, two have received kidney transplants and one a liver transplant. One of his sisters donated a kidney to another sister.

-- The above is based on an article written by Steve Binder, a member of the TRIO Northeast Florida Chapter.

To read Steve's full article, and see great photos of J.T. and his experiences during the Transplant Games, go to www.trioweb.org and click on "Members" then on "Stories".

Leadership and Educational Summit Expands in 2013

Note the renaming of this annual event. It was felt that some were not taking advantage of this series of excellent workshops due to the “**Leadership**” title focus, so the “**Educational**” focus was added. This event is *NOT just for TRIO leaders* (although that may have been its initial intent). The event certainly has grown well beyond that with the workshop subjects so varied. With the most recent fall timeframe fitting most attendee schedules, we are planning for another fall event tentatively set for September 20-21. Several options for a location are still under consideration, such as San Francisco or Kansas City. With ITNS meeting the same dates in Washington, DC, and the history of a great joint conference with ITNS in St. Louis, that option is also being explored.

We really would like to move west this time since the past three have all been east coast locations (Philadelphia, Northern VA, and last year, Pittsburgh). Prime consideration factors are attendee cost for travel and lodging, support for facilities (usually a local OPO donates excellent meeting space) and local sponsorship which provides for free registration and often scholarships to help attendees with their expenses.

You can review the last two summits in full workshop videos on the TRIO website as a way of helping to decide the value to you based on typical topics and seeing the engagement of attendees. For now, just put it on your calendar and stay tuned for location decisions that will be coming out in the months ahead.

Hope you can make it (again?) this year!

Strategic Plan (continued from page 1)

The first report was presented in a new, easy-to-understand format of action versus plan progress (or lack thereof) at the February 2 Board meeting, resulting in board overview and acceptance. These three steps are critical in meeting Goal 4 and insuring that our new Strategic Plan will live on for years to come, supporting a growing and vital TRIO organization for our next 25 years. But only with YOUR help!

In subsequent issues of *Lifelines* we will report on progress against individual plan goals. The key to the success of that plan is the reporting process being shared with the membership. To review the plan, go to www.trioweb.org and under “About” click on “Strategic Plan.”

Are YOU Reading This???

As part of a readership survey to help reduce unnecessary expenses by finding out who is actually reading *Lifelines* and possibly reducing this costly mailing only to those who wish to receive it, we ask that you e-mail info@trioweb.org or call 1-800-TRIO-386 with your name to confirm that you wish to continue receiving this hardcopy *Lifelines* or would opt for an e-mailed color version.

If you do not respond, that will be considered an answer of: “**I no longer wish to receive Lifelines**”.

Note: Past *Lifelines* issues are archived on the TRIO website and are available on our website, in full color, about a week before the hardcopy is mailed.

Email delivery of *Lifelines* will begin soon. So, if you haven't already responded with your preference, please do so NOW.

Recommended Reading

For this month's featured book, we recommend your reading a beautiful book of poetry by Joe Kralicek, a liver transplant recipient of 19+ years. The following tribute to his donor is one gift of inspiring poetry included in his book (available on Amazon.Com): *The Courage of One: The Inspirational Poetry of a Transplant Recipient*.

Thanks To You

I saw the sun rise in all its glory this morning,
Thanks To You.

I smelled the sweet scent of a spring flower,
Thanks To You.

I ran through the ocean's racing tide as it
caressed the sand,
Thanks to you.

I held the hand of my loved one and professed
my undying love,
Thanks to you.

I held my children close, shedding a tear of joy,
Thanks to you.

I saw the stars, bright in the sky, for the first
time,
Thanks to you.

I tasted the sweet nectar of life like never
before,
Thanks to you.

I stopped to live my life rather than run
through it,
Thanks to you.

I see more, experience more, and appreciate
more,
Thanks to you.

I am alive, Thanks to you.

Of all the debts in my life, I will spend the rest of my
life repaying a debt of gratitude for all you gave.

I am alive, Thanks to you.

Is This Going To Be the Year?

For too many years now legislation to extend Medicare coverage of kidney transplant medications beyond the current 36-month limit has been introduced to the Congress, only to die in committee and never brought to a vote.

The **Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act** was re-introduced in the US Senate with the bi-partisan support of Senators Richard Durbin (D-IL) and Thad Cochran (R-Miss). This legislation (S.323), which TRIO, AST and a long list of Transplant Roundtable organizations have been fighting to pass for years, will finally eliminate the current arbitrary 36-month limit on immunosuppressive drug coverage imposed on Medicare end stage renal disease beneficiaries.

A TRIO Membership “Call to Action!”

TRIO members, families and patients everywhere need your help! Now is the time for action! Call your Senator's office today and let them know how strongly you feel. The number for the Senate switchboard is (202) 224-3121. When you call, ask to speak with the Legislative Assistant for Healthcare.

Here is what you can say:

- Currently, Medicare Part B coverage of immunosuppressive drugs ends 36 months after the patient receives their transplant, but patients are required to take these drugs indefinitely in order to preserve their gift of life.

- Patients often find themselves unable to afford their medications once Medicare drug coverage lapses and they are often forced to begin reducing their medications or forego them altogether, eventually resulting in a completely unnecessary failure of the transplanted kidney.

- If the transplant fails, patients return to dialysis or are re-transplanted. Medicare spends more than \$86,000 per year on a dialysis patient and these patients are eligible for Medicare indefinitely. However, the average annual Medicare expenditure for a kidney transplant recipient after the year of transplant is \$24,000!

- Not only does removal of the arbitrary time limit on immunosuppressive drug coverage make financial sense, the unnecessary human toll as a result of the current policy is tragic and unconscionable.

- The Durbin-Cochran legislation recently introduced only grants a beneficiary access to the Medicare Part B immunosuppressive drug cover-

age benefit (not to other Medicare services), and provides that these individuals are responsible for only that portion of the Part B premium which covers the immunosuppressive benefit.

- Consequently, patients will only choose this option as a last resort. This legislation has always been seen as a “coverage backstop” to provide immunosuppressive drug coverage only when a patient has no other form of coverage.

- It is not sound public policy or cost effective for Medicare to cover a kidney transplant and then stop immunosuppressive coverage after 36 months—which can lead to someone rejecting the transplanted organ.

This is your moment. We've all worked hard to get here and this is the year we will finally pass this vital legislation.

Call your Senator's office today! Or, you can **write** to your Senator with sample text and contact information as provided at:

<https://secure2.convio.net/nkf/site/Advocacy?cmd+display@page=UserAction&id=115>

(Note: At press time, a companion bill is still pending introduction in the House. We'll give you that House bill number when it happens.)

TRIO Youth Circle to Rise Again

We have new Youth Circle leadership: two young men who are developing plans to reach out and support transplant youth (between the ages of approximately 18-30.)

Muran Veniszee, a heart and liver recipient of three years, lives in New Jersey. Muran is an energy-filled 32-year-old who wants to give back by developing resources to help those who follow in his footsteps. He sees TRIO as the organization to help make that happen.

Josh Morrison is a 28-year-old lawyer working for a Boston-based corporate law firm. Josh responded to the growing need of kidneys for transplant by altruistically offering one of his own to an unknown recipient in December 2011.

Together, these young men are creating a plan of action to identify support needs of transplant youth and create TRIO services to address those needs. See the TRIO Youth Circle web pages to learn more.

Other news to report: **Mary Wu**, a member of the TRIO Youth Circle, has just had her book “**Confessions of a Kidney Transplant Recipient**” published on Amazon. Go to:

<http://www.amazon.com/dp/1480259748>

Life Change Through Empowering Language

(Science tells us that our mind really can't distinguish between the real world and what we imagine. Think about that dream that woke you up in the middle of the night in panic and sweat, feeling that what you were dreaming was so very real. We can put that knowledge to good use once we understand it. In this issue we will discuss the power of language to help or hinder. In the next issue of Lifelines, Elizabeth Rubin will expand this concept into a full "mind over matter" topic.)

There are two key areas that we can tap into that will help us deal with our everyday life experience, both very powerful in facing life leading up to and after transplant surgery, but don't limit their application to that narrow part of life. The first is the power of **self-talk**, and the second is the **language** (i.e. **words**) we use. Both are deeply rooted in our life habits that can be forceful tools but sometimes difficult to change when change is needed.

Let's look at everyday language. When we ask, "*How are you today?*" isn't the typical response "Not bad"? Imagine that, a simple greeting draws out two negative words, "not" and "bad" - words that cause an emotional "downer" even though there really isn't anything meant by that. Wouldn't the same meaning be conveyed if we were to respond with the more positive and uplifting (both for the speaker and the listener) words "*I'm good!*" After all, doesn't "not bad" mean "good"? Then there's the word "problem" as in "*I'm facing a problem.*" Problems are associated with frustration and roadblocks which our minds accept as defeatist and "can't be done." What if, instead of the word "*problem*" we substituted "*challenge*"? Challenges can be fun, challenges imply a solution is possible if we apply enough resource to it. Say it aloud to yourself now, "*I'm facing a challenge...*" Doesn't that carry a different connotation in your mental reaction to it?

Another classic word that can be replaced in most sentences is the word "*try*". In most sentences you can just drop that word out altogether and immediately the implication is that this will take place. "*Want to have dinner some day?*" A response of "*Sure, I'll try to make it*" is typical and our minds interpret that as having a very low probability of happening. Both parties will go away from that "try" exchange not expect-



ing it to happen. If, on the other hand, the response leaves out the "try", in most cases a date is set and the dinner happens. In business I have converted a technical team from the habit of using "try" by getting them to notice when they use it (to interrupt that habit, any team member who said "try" had to climb up on a chair and "cluck like a chicken" in front of the team - yes, it really did work and had a profound positive effect on our everyday discussions and actions).

Our minds really do tune in to our language and the outcome changes according to how our mind thinks we feel about that subject at hand, our choice of words conveying the hidden message.

When it comes to the power of language, our self-talk (words seldom spoken out loud) is even more impactful, either positively or negatively. Reflect on your own self-talk (and don't tell me you don't talk to yourself, because even as you may have reacted "I don't" to that statement, you were talking to yourself; we all do it, constantly, unconsciously). As a child, we accepted input from our parents without challenging their message. As we grew up, we learned to filter input, often making judgment based on the source of the message. In many cases, even as an adult, feedback from a parent still is accepted without weighing the validity of the comment. In the case of a negative parenting environment, we have all seen how that can impact development, often causing serious long-term damage to one's personality or how we face or deal with the world around us, well beyond those early formative years. But, of more importance, is the fact that we totally "trust" what we hear from ourselves; that self-talk comes right through without being filtered with judgment as to message validity or how it will impact one's self. Listen to yourself over time. Sometimes we talk to ourselves in a way that we would never allow another to talk to us. If we stopped to consider the message (as we do with emotional maturity in listening to others) we would see it as invalid or damaging, thus allowing for the option of rejecting or blocking it from becoming part of our thinking or belief. Again, this is a habit that can be changed once we recognize the challenge of negative self-talk.

Both these insights can lead to powerful tools that will help us not only in our medical environments but include our everyday dealings, not just doctor or hospital situations. For now, just work on recognizing your vocabulary in the use of empowering words,

(continued on page 10)

Why Didn't They Write?



In my favorite transplant love story movie, *Return to Me*, there is a touching scene dealing with the difficulty many transplant recipients experience in writing that “thank you” note to their donor family.

In this scene, Grace, the heart recipient (played so perfectly by Minnie Driver), is still torturing herself about actually mailing the letter she has written and been carrying around with her since receiving her new heart a year ago. Her sister (with five small kids in tow) offers her the encouragement she finally needs to so tentatively drop that letter into the nearby mailbox at the zoo (where, coincidentally, her donor’s spouse, played by David Duchovny, is working and they come into contact for the first time). While this may be just a movie story, it does accurately capture the difficulty many recipients find in expressing themselves after a life-saving organ transplant.

Reaching out to a large random sample of recipients, I asked for insights as to why patients hadn’t written to their donors, at least to express a simple thank you. The response was not overwhelming, hopefully indicating that most actually do write, but enough replies came back to provide a realistic insight into that lack of communication. But let’s be reminded up front that both sides of this gifting process understand that neither is under any obligation to communicate, accepting and respecting each other’s rights in that it is an anonymous giving and accepting process. That said, human nature being what it is, there is often an expectation by donors of some acknowledgement and a corresponding interest by some recipients in knowing something about the donor. But given the process, neither side knows enough about the other to be able to understand what to expect or what is acceptable. There-in lies some of the basis for the insights shared in this too brief article, reasons which are as varied as the parties involved in the issue overall.

Reason #1: Perfection/Inadequacy - Most write, but either rip it up as not being good enough, wanting it to be perfect, not being able to find the “right words.” Tony shares: “I haven’t written to my donor family ’cause I just don’t know what to say. Words cannot describe how

thankful I am to them for giving me a second chance at life! That was a miracle itself! It is overwhelming to me at times ‘cause I wouldn’t have my daughter either! There are no words that could express my feelings for saving my life and giving me the child I have always wanted! I am forever grateful.” I can hear you thinking as you read this, “But she just did say it!” Or, as Ken, a liver recipient one year out, put it simply when he finally did write: “You never received any of the other letters I previously wrote, because I was left feeling none of them were good enough to express my feelings reasonably well. This attempt may not be as good as I would wish, but I feel ashamed that so much time has gone by without a word of acknowledgment or thanks from me. If I continue to keep striving for perfection it will delay the message to you even longer.” So, while an often-cited professional or friendly advice “to just write it from your heart” empowers some to overcome this “never perfect enough” concern, saying that isn’t the same as actually doing it, which leads to the second most common response.

Reason #2: Fear – Even once written, actually mailing it (as in the movie) is still a big challenge for many, mostly out of fear of causing pain to someone they feel so grateful to for this ultimate life saving gift offered at a time of extreme tragedy for the donors, and it is recognized that that donor is often the living person who said yes to the donation request, the one who will be reading the letter. Here is where that fear of the unknown comes to play, not knowing the family situation of the donor family, are they ready to hear about where their loved one’s gifts went? Will such a note bring back all the pain and grief felt at the time of donation? And then we have the choice of words, not just the “perfect” words, but the expression of that gratitude, reason #3.

Reason #3: Grief vs. Celebration of Life – As Pat wrote: “...there wasn’t any way to say how grateful I felt to have gotten this chance at a normal life with my big, ever-so delighted family without feeling that hearing all our good news would cause sadness and hurt to the donor’s family.” This was repeated in many variations as Sandy affirms: “As the years rolled on, I found it much harder to write, because now I didn’t know what to say. I was still equally excited, but felt as if I was saying look at me, I am doing great, while your loved one is no longer here.”

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Reason #4: Privacy – John is one who did write shortly after his transplant, and received a loving response, would like to write again but hasn't since out of respect for the donor family's privacy, not wanting to intrude further on their lives.

As many shared, Richard too wrote, but tore it up many times, even though wanting desperately to hear from the donor family. Instead, he keeps the thanks in his daily thoughts and prayers for the donor and their family, never actually finishing that note out of respect for their privacy.

Reason #5: Ignorance – Not as common with today's education and support for writing, but cited by some long term transplant survivors such as Eddie, who got kidney transplants in 1971 and in 1980, such communications were not encouraged and he got little if any knowledge of a process by which such a note could even be given. Eventually such patients acknowledge feeling it is too late and reason #2 comes back into play, not wanting, as Joan, a long term liver recipient said, to "reopen wounds" for the donor's loved ones, not knowing if that is a widowed spouse, child's mother, loving sibling or whom-ever.

Reason #6 – Protective Oversight – From a "new heart family" we see another roadblock when "...in 1985, I wrote a heart-felt note to my donor family. Many years later I discovered that the letters are screened by the hospital staff and they can decide not to send it without letting the letter writer know." This can also be well-intentioned OPO staff making protective judgments based on their direct contact with the donor or patient family. I have also known donor families who have hidden recipient letters from a loving mother out of protective concern, only to find that "discovering" one such letter years later, she was open and thankful for that message, eventually asking for a meeting with the recipient.

Maybe the best advice for patients in overcoming such reasons can be found in the following insightful sharings from Steven and Robert (among others), heart recipients, who wrote similar words (merged together here...): My Coordinators told me to just be myself and write from the Heart (pun intended). I wasn't sure how to do that, but after more false starts, I finally sat down one afternoon to write the note and I told myself that no matter how it came out, I would send it. I decided to write it with pen instead of

typing as I thought this more personal. I did mail the letter and have never heard back from them.

After many, many false starts we hear another's variation on this: ...but the thought that came to me was "Just write it from your donor's heart." The letter that I eventually sent took me twenty minutes to write from start to finish. You would think that deciding to write a letter would be an easy task compared to the decision facing the donor family and at the worst time of their lives. Sometimes we need to look at the big picture. Fortunately, we as transplant recipients get a second chance to do just that.

But then, maybe things haven't really changed much in 2,000 years when we recall how in the bible story about Jesus healing the ten, only one comes back to say thanks. But my experience tells me that our numbers today are at least better than that 10% and are getting better with each passing year. From this grateful fourteen-year-out heart transplant correspondent, let me say on behalf of recipients everywhere who still wrestle with the issues above, our love and thanks go out to donors everywhere, if not in letters still locked in our hearts, at least in daily thought and prayers for you and your loved one.

And one last thought, as eight-year-out heart patient Gene acknowledges, "...I know the above feelings are just excuses and I hope to someday be able to write a letter."

-- Jim Gleason, President,
TRIO Board of Directors

(For an expanded discussion on this topic, read the on-line chapter on patients communicating with donor families: <http://www.rjwitte.com/changeofheart/GiftFromTheHeart/Section2/CHP-31-DONOR-COMMUNICATIONS.pdf>)

Life Change Through Empowering Language *(continued from page 8)*

substituting "challenge" or eliminating "try," for example. Secondly, listen carefully to what you are saying to yourself and if that is undermining your self-image or your outlook in daily living, interrupt yourself and, instead, substitute a better message each time. It does take time, but once you recognize it, change is possible and your life will be better for it.

(In the next installment, Elizabeth Rubin will discuss using mind over matter, another application of this power of the mind concept that can change your life dramatically for the better.)

Harvey Myself's Passion for the Living Kidney Donors Network

The Living Kidney Donors Network (LKDN) was established after my first kidney transplant in 2007. I was very fortunate that my wife was my donor. The LKDN primary Mission is to educate those in need of a kidney transplant about the living donation option and to help them develop a communications plan to let their family members and friends know about their situation. The LKDN offers workshops, webinars and personal support to those in need and individuals interested in being a kidney donor.

I developed a rare virus that attacked my transplanted kidney and in 2012 I needed another kidney transplant. It was ironic, that 5 years after starting the LKDN I needed to take my own advice and start a campaign to find a kidney donor. A mutual friend introduced me to Stephen Liegghio. Stephen was not compatible with me and we were involved in a 3-way kidney paired donation, also called paired exchanges or swaps.

This sequence of events may sound like one in a million, but kidney paired donations are becoming very common and they have the potential of adding thousands of additional kidney transplants every year.

Most people know about registering with their Department of Motor Vehicles to be an organ and tissue donor, but the general public knows very little about living kidney donations and the impact that living donors have on saving lives. Most people think that "matching" is a very complicated and a difficult process, but as a result of new anti-rejection drugs it has become much easier for non-blood relatives to donate. Ten years ago over 70% of the living donors were blood relatives, now it is closer to 50% because of these new drugs. To read more about the



matching process go to:

http://www.lkdn.org/LKDN_Matching.pdf

There's a growing trend of people who learn about the long waiting list for a deceased donor kidney and decide to donate a kidney even though they don't know someone in need. This type of donor is referred to as a non-directed donor. (NDD) Medical technology and kidney paired donations can result in NDD's being able to save the lives of not just one person but many. These transplants are called "domino paired exchanges" or "ongoing paired exchanges." To read more about kidney paired donations go to: http://lkdn.org/LKDN_Paired_Exchanges.pdf

In a study from 2008 – 2012 the research found that each NDD resulted in 4.8 kidney transplants. For each NDD that was blood type O there were 6 kidney transplants for each NDD. Blood type O is the universal donor, they could donate to any other blood type. About ½ the population is blood type O. However, when someone in need is a blood type O they can ONLY receive a kidney from another blood type O, making it more difficult for these individuals. Another benefit that resulted from these NDD is that more blood type O recipients were transplanted.

-- Harvey Myself, Member

TRIO Board of Directors

TRIO Fills Last Open Board Position



As we 'go to press,' TRIO is very pleased to announce the appointment of Rodger Goodacre to TRIO's Board of Directors. This action completes TRIO's Board with a full 13-member roster, as prescribed by TRIO's ByLaws.

Rodger, a member of the TRIO Maryland Chapter, brings a wealth of experience to the TRIO board. From 1978 to 2012, he held various administrative positions for federal health care with the U.S. Centers for Medicare & Medicaid Services (CMS) Headquarters in Baltimore, MD.

Rodger is a member of the Maryland bar, having graduated with a J.D. degree from the University of Maryland. We look forward to sharing Rodger's full story in our next issue of *Lifelines*.

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!

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