TRIO Adds Three New Board Members

The TRIO Board of Directors is pleased to announce the recent appointment of three new members to its roster: James Mateiko, Lou Reardon and Merle Zuel. The induction of these new Board members brings the TRIO Board of Directors to a full contingent of members, as specified in TRIO’s ByLaws.

James Mateiko, a TRIO member-at-large from Long Island, NY, became interested in organ and tissue donor awareness after his mother died in 2005 and became a tissue donor for five individuals.

With his background in media relations, James has become a much sought-after speaker, not only for the Donor Network, but also for the American Liver Foundation and the Long Island TRIO chapter. James has also been a speaker for the Lions Club Eye Bank and at National Kidney Foundation events; and he currently serves on the Donor Family Advisory Council.

This past year he organized the first Donate Life Day at GEICO, where he works, for which the company subsequently received recognition from the US Department of Health and Human Services Transplant Division, as a work place friendly environment for promoting organ and tissue donation.

The addition of James to the TRIO Board, as a donor family member, brings a more in-depth dimension to the work that TRIO is doing.

Lou Reardon, a lifetime resident of New York and a member of the TRIO Long Island Chapter since 2008 and a volunteer with the NY Organ Donor Network, was transferred to South Carolina in 2010. Lou took a new position with his company at the Marine Corps Recruit Depot on Paris Island. Lou then joined TRIO as a member-at-large and set about finding out how he could serve TRIO from that new location. He found his new calling when he accepted an invitation to join TRIO’s Board of Directors.

Lou is currently working to develop the new member-at-large “Virtual Chapter” support group and hopes to eventually establish a sub- group focused on support for military veterans who have undergone transplant. Lou received a heart transplant at Columbia Presbyterian Hospital in New York City in December of 2007.

Merle Zuel, a heart transplant recipient of four years, lived with congestive heart failure for 11 years prior to that, so, as soon as he was back on his feet, he made a commitment to become a... continued on page 7)
"Be wise in the use of time. The question of life is not, How much time have we? The question is, What shall we do with it?"

- Anna Robertson Brown

A very special “Thank you!” to the speakers, sponsors, chapter/board leaders and members who answered that question by making time in their very busy lives to attend and contribute, each in their own way, to the recent Leadership Summit success here in Washington. I hope you will make use of your own time to “see” those exciting sessions thanks to YouTube recordings found on TRIOweb.org. With ever expanding use of technology we were able to Skype video conference with the exciting Stenzel twins as well as offer cost effective interviews with a primary care physician, Dr. Breish, and a unique video presentation by life-coach PaulaG on “Intuitive Intelligence™.” All of this and of course many “live” sessions can be seen on the web at a time of your convenience.

And speaking of technology, we are proud to announce financial sponsorship for yet a third year of our TRIO Transplant Presentation Library! With almost 30 excellent topics to choose from, every TRIO member has access to these DVDs that can be used on a home PC or TV. Contact the national office if you can’t get your selection from a TRIO chapter library. Also, check out almost daily news of medical advances on our web site such as the recently approved “in vivo” lung perfusion (see the video demo) that may over time increase and improve lung transplants to the point where the waiting list for lungs could be eliminated! Wouldn’t that be exciting? And that’s just one example of what you will find there.

With new board appointments confirmed at our May 13th meeting and featured on the front page of this issue, TRIO’s board is again at its full complement of twelve members. This is an exciting time for TRIO with new passion, energy and ideas as you see throughout this Lifelines issue and even more so as we begin planning for our 25th Anniversary celebration in 2012. Just to plant the seed, at the Summit the idea of a big conference event held in TRIO’s 1987 birth city of Pittsburgh was put forward. That’s only an idea for now, but we look for your input on how to make this past quarter century of TRIO being the “voice of the transplant community” the launching point for an even more exciting 25 years looking forward as transplantation continues to grow in numbers and ever increasing life extensions. And if you have TRIO memorabilia to share at this event, let Sylvia know so we can see how that might fit into a display or other plans for that event. Stay tuned for details as the committee develops and communicates the plan.

As you read through this Lifelines issue and see the growing outreach of support for youth, MALs, new projects and call for a network of chapter champions, challenge yourself with the question, “How am I going to use my life’s time to make a difference in service with TRIO?”

Did you know?
There are 111,632 Waiting List Candidates!
Visit www.unos.org to see TODAY’s number!
The “Affordable Care Act” and Medicare Changes in 2011

The Affordable Care Act is a federal statute that was signed into United States law by President Barack Obama on March 23, 2010. This act and the Health Care and Education Reconciliation Act of 2010 (signed into law on March 30, 2010) made up the health care reform act of 2010. The laws focus on reform of the private health insurance market, providing better coverage for those with pre-existing conditions, improving prescription drug coverage in Medicare and extending the life of the Medicare trust fund by at least 12 years.

The Affordable Care Act makes many improvements to Medicare. Moreover, it guarantees that you will continue to have your basic Medicare benefits—whether you get them through Original Medicare or a Medicare Advantage Plan. This includes transplant recipients! I would like to familiarize you with some of the changes which may be most beneficial to you.

If you have Medicare prescription drug coverage with a coverage gap (also known as the dreaded “donut hole”), the new law will reduce that gap over several years to make prescription drugs even more affordable. If you reached the coverage gap in 2010, you may qualify to get a one-time $250 rebate check. If you reach the coverage gap in 2011, you may get a 50% discount on brand-name prescription drugs when you buy them. There will be additional savings in the coverage gap each year through 2020, when the donut hole is finally closed completely. The new law also prevents Medicare Advantage Plans, or Medicare HMOs as they are sometimes called, from charging you more than Original Medicare for cancer treatment and certain other services that you might need.

An additional exciting change is if you have Original Medicare, you will now be able to get a yearly wellness exam and most preventive services for free. If you’re in a Medicare Advantage Plan, check with your plan to see if these benefits will also be free for you. Medicare covers two types of physical exams—one when you’re new to Medicare and one each year after that. The “Welcome to Medicare” physical exam is a one-time review of your health, education and counseling about preventive services, and referrals for other care if needed. Medicare will cover this exam if you get it within the first 12 months you have Part B. You pay nothing for the exam if the doctor accepts assignment. When you make your appointment, let your doctor’s office know that you would like to schedule your “Welcome to Medicare” physical exam. The second type of physical exam is a Yearly “Wellness” exam. This is for people who had Part B for longer than 12 months and it allows you to get a yearly wellness visit to develop or update a personalized prevention plan based on your current health and risk factors. You pay nothing for this exam if the doctor accepts assignment. This exam is covered once every 12 months.

The billing department of many physician offices may not yet be aware of these changes, so please check before you go to see if they have incorporated the new billing codes into their practice.

If you have questions, visit Medicare’s new and improved web site at www.medicare.gov, or call 1-800-MEDICARE (1-800-633-4227). You can also call your local State Health Insurance Assistance Program (SHIP) or area agency on aging, or visit the Administration on Aging at www.aoa.gov.

More information can be found at www.medicare.gov/publications/pubs/pdf/10050.pdf

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

TRIO Scholarship Awards
To Be Made in the Fall

The deadline for applications for 2011 TRIO scholarships was June 30. The Scholarship Committee is in the process of reviewing the applications and will notify applicants by early October. With some 40 applications for a far fewer number of $1,000 scholarship awards, the Committee is still seeking contributions from individuals and TRIO chapters. Here is a perfect opportunity to give a gift to a deserving student as a tribute to someone who has done something special for you, or as a memorial gift for someone who has passed away!

If you know someone who could benefit from an educational scholarship, but missed the deadline for this year, tell them to check the TRIO website for other scholarship opportunities. If they wish to apply for a TRIO scholarship, next year’s application form will be posted on the website in January of 2012.
Chapter presidents and members met for the 2011 TRIO Leadership Summit at the Washington Regional Transplant Community for a two-day event of sharing and education.

Transplant leaders from UNOS, OPOs and other venues shared their stories of inspiration around the summit theme of “The Power of One: Making a difference in the world, one person at a time…” Many of the sessions were recorded and can be viewed on YouTube. (See the index and description for each available on the TRIO web site home page.) As was the goal last year, a significant portion of the summit monies went back to chapters and members in the form of scholarships to help offset some of their travel and lodging costs.

Here are just some of the moments captured by TRIO photographer, Susan Pincus – see all the photos on the TRIO web page.
Summit Again in 2011
TRIO Mourns the Loss of Previous Board Member, John Harwood

TRIO lost a longtime loyal supporter when John Harwood died on May 14th. A commissioned Army officer in Vietnam, Germany and the United States during his younger years, John devoted a majority of his time following his liver transplant in 1993 to advocating for organ donation and to counseling transplant patients. John served TRIO in many capacities, including financially and as a long term member of the Board of Directors. Recently, John was a key member of a committee that is in the process of forming a ‘virtual chapter’ for TRIO members-at-large.

Despite health issues during the past several years, John continued to contribute his time and money to the causes he believed in. He also found time to relax with his wife Billie in their Colorado vacation home and to manage a family charitable foundation based in Tulsa, Oklahoma.

When news of his death reached us, those who had been working with John most recently were stunned. As was his nature, John kept his physical ailments a secret to the end so that he could continue doing things to help others less fortunate than he.

John was buried in Dallas, TX, with full military honors.

Virtual MAL Chapter Loss and Growth

It was with heavy heart that we recently received news that John Harwood, long time TRIO member, past board member and co-leader for the new “Virtual Chapter” for MALs, died suddenly at his home in Texas. John was a strong force in this new initiative and his passion and leadership will be sorely missed as we move forward with the foundation for this effort that he and the team have built.

On the other side, we have a new co-leader to pick up the reins: heart and liver recipient, Will Oler, of Alexandria, VA. Will is retired military (Marines), so brings some of John’s same discipline and interest in developing TRIO support for transplanted veterans, envisioned as a future subset of the MAL virtual chapter audience. Will joins Lou Reardon in carrying on with the development of services that will meet the needs of the TRIO members-at-large that were identified in the recent survey responses from MALs across the country. We still have room for others who may be interested in joining this leadership team, so self-nominate c/o Sylvia Leach and stay tuned for upcoming developments both in terms of leader names and initial support offerings using technology such as audio conferencing and email newsletters.

TRIO Public Policy Action Network

You can now see Troy Zimmerman’s presentation at our recent Leadership Summit on YouTube (linked from the TRIOweb.org home page). Troy, vice-president of government relations for the past 17 years with NKF, spoke on Effective Advocacy. His insights were both informative and encouraging in his testimony that individuals, especially those with a compelling story, can truly impact decision makers with their one-on-one research.

Along those same lines, TRIO is inviting each chapter to nominate a “public policy champion” who would become part of a national network of TRIO advocates responsible for communicating news and action requests from the national committee when opportunities arise back to their local chapters. Through email and public policy conference calls this action based effort would serve as spokes on a wheel of TRIO influence for legislative affairs that affect the transplant community. If that role appeals to you, talk to your chapter president and self-nominate to be that chapter champion as we develop this new network. Send your name to the national office.
Transplant Presentation Library Enters Third Year of Service

With more than 24 DVD recordings in the past two library volumes, TRIO looks forward to yet another year of great programs.

Recently released titles include: Help in Dealing with the Financial Challenges of Transplant; Getting Back to Work Post Transplant; The Yellow Brick Road of Living a Healthy Life After Transplant; Allomap Molecular Expression Testing: The Future with Non-invasive Testing for Rejection; and Latest ISHLT Guidelines for Heart Post Transplant Care.

Upcoming releases to watch for: Feet Don’t Fail Me Now: What you need to know post transplant about foot care: gout, diabetic foot and peripheral neuropathy; Intuitive Intelligence™ – Creating the Work You’re Most Meant to Do in the World Post Transplant; Skin Cancer Challenges Post Transplant; Presumed Consent: Not All It’s Cracked Up to Be – and that just takes us up to July!

One concern has been heard from chapter members, and that’s about the availability of these programs at chapter meetings. One reported asking for a program only to be told “Oh, I don’t know where we’ve put those binders, sorry!” Please be sure to make it easy for members to borrow from this extensive library. Members-at-large, all you have to do is contact Sylvia by email or phone and request any title to get it mailed to you. There is no charge for this service thanks to our sponsors’ support.

TRIO’s Transplant Presentation Library is generously funded through grants from Astellas Pharma and Genentech.

TRIO Board Members (continued from page 1)

leader in educating the community about transplant and the need for registered donors.

After joining TRIO in 2009, Merle founded a TRIO Chapter in Kansas City and currently serves as President. Merle is also the founder and producer of the MerleJam concert which raises funds for transplant families in the area.

Merle serves as a volunteer ambassador for the Midwest Transplant Network and has been featured in numerous print, radio and TV appearances. In 2010 Merle was appointed to a three-year term as the UNOS Patient Affairs Representative for Region 8.

TRIO Youth Circle Grows

TRIO’s Youth team now has a third member on its leadership team, Julie Bonn, long time liver recipient. Julie now works in the research department of the Cincinnati Children’s hospital where she was originally transplanted. You can find more of her story on the TRIO Youth Circle web pages including a unique photo from her world travels.

TRIO’s youth team has been working on a funded proposal to engage college campus groups from around the country with a cash prize supported contest focused on getting new organ donor registrations on their campus. Pending board approval, the implementation plan will target the contest for the coming 2011-2012 Fall-Spring school season.

In another initiative, the team is still looking for names of youth in the 18 to 30 age range who would be interested in attending an on-line 13-week employment workshop, so reach out to your own local network and have them register through the national office for the workshop to be scheduled on availability of those responding.

Transplant Summertime Reading

Well, it’s summertime and if you are looking for that one very special book to sit back and enjoy in the shade or on the beach, here’s my all-time favorite: When Crickets Cry by Charles Martin. This is NOT a new book, which means you can find it on Amazon for $3.02 (plus s&h in used paperback) or if you’re lucky, maybe in your local library. Be prepared, this is one of those “can’t put it down” reads, but you are going to want to savor the reading at the same time, so maybe a second read will be in order. One promise though, once you start reading it, don’t get three quarters of the way through it and stop when the emotions get too tough. You MUST read to the very end – enough said. For a review go to Book Reviews under the Communications/Resources section on the TRIO web site. There you will also find many other intriguing titles, but start with this one and write us with your own reactions to this heart rendering story by this amazing author. Oh, and did I tell you, it’s about several heart transplants?

Submit new titles for possible review by email to TRIO book reviewer Jim Gleason (email GleasonJim@aol.com.)
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: ___________________

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Name of Transplant Center(s)   City, State

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

Annual Dues: Member at Large ............... $20. Make your check payable to and mail to:

Additional Contribution ............... $ _____.

TOTAL enclosed ........ $ __________.

Thank You for your tax-deductible donation!

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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).