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Lifelines

January 2011



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

Catherine Paykin Joins TRIO Board of Directors



TRIO's Board of Directors is pleased to announce the appointment of Catherine Paykin to the Board.

Catherine comes to TRIO's Board with a distinguished background of service to the transplant community. She began her career as a Clinical Social Worker at New York-Presbyterian in

1985. She worked in the heart, lung and liver transplant programs.

Many know her for the recent twelve years she was the Transplant Services Program Director of the National Kidney Foundation in NYC with many assignments including responsibility for their TransAction Council and transplant web site content.

When Katrina devastated the southern region, she worked on-site to get dialysis and transplanted patients relocated and in the aftermath, provided emotional support to those who remained.

Catherine has been in most transplant programs around the country at some point during the last 25 years. She recalls when the idea of TRIO was born in Pittsburgh in the late 1980s and was at one of the very first Long Island TRIO Chapter meetings and attended their first Rose Garden planting.

Presently, Catherine is the Community Outreach and Volunteer Manager with the second largest organ procurement organization in the country: New York Organ Donor Network in New York City. In addition to managing volunteer recruitment, training and deployment, she oversees the HHS, HRSA Work Place Partnership Program and supervises the college and service learning outreach.

(... continued on page 4)

TRIO Issues Press Release of Public Policy Statement on Arizona Budget Decision

In a December 18 email newsletter blast to members and chapter presidents, TRIO's President Jim Gleason alerted members to the very serious situation facing transplant recipients in the state of Arizona.

Jim asked: *Have you been following the Arizona Medicaid cutback issue?*

He went on to state: "You should, since it has set a precedent that could cascade to other states if left unchecked. In summary, to help balance their state budget, Arizona eliminated state Medicaid funding for certain types of organ transplants, affecting about 100 patients already listed and waiting for their life-saving transplants."

On TRIO's website (www.trioweb.org) you can read all the facts and some very interesting documents issued in protest and concern about this issue by United Network for Organ Sharing (UNOS), the American Society of Transplantation (AST) and the American Society of Transplant Surgeons (ASTS) and the Washington Transplant Roundtable, of which TRIO is a member. These organizations, along with TRIO, are trying to get the Arizona legislature to reverse that misguided budget cut when they return to session in January. TRIO's Press Release, drafted by TRIO Public Policy Committee Chair, Mike Sosna (TRIO Long Island Chapter) and approved by the TRIO Board of Directors, can be read in full on TRIO's website.

(... continued on page 6)

Inside this Issue:

2011 Leadership Summit Set: page 3

UNOS Kidney Exchange Pilot Program: page 3

TRIO Board Elects New Officers: page 5

TRIO Hosts Virtual Town Meeting: page 5

Eight Scholarships Awarded: page 7

2011 Membership Renewal Due: page 8

President's Message



Jim Gleason

Another year has just flown by, and it was both exciting and life changing for so many of our TRIO members. I hope that you enjoyed life this holiday season and are now ready to live it to the fullest again in 2011, sharing in service some of that energy through TRIO. Now going on 17 years with this “new” heart, I know how important giving back with all we have been given through transplant makes that life so worth living. Hopefully this holiday season you took time to remember your donor and if so moved, wrote them a note of ongoing thanks for their gift. It’s not too late if you haven’t.

As the incoming TRIO president I offer a special thanks to our outgoing president, J.T. Rhodes, for his leadership these past five years in bringing our organization to where it is today, growing and financially on solid ground. My goal is to continue that growth and progress of service delivery to our membership and the transplant community through new and creative service offerings. This is only possible if we fully engage both our national board members and the TRIO membership countrywide. Whether it’s TRIO’s committees or our network of local chapter champions with their focus on public policy or other individual programs, there are many opportunities to utilize *your* individual skills and resources to make a difference in the world today.

Speaking of making a difference, I hope you can join us for the **TRIO 2011 Leadership Summit** in Washington DC., May 13 and 14. There will be a limited number of scholarships to help cover travel and lodging for this leadership development event which was so well received in the spring of 2010. See the accompanying article in this issue for more detail. I look forward to meeting you in person there.

Another goal is to keep our eyes on the four areas of Mission in all that we do: SUPPORT, ADVOCACY, EDUCATION and DONOR AWARENESS. In this issue you see a major focus on **ADVOCACY** with that national news Arizona issue and other Medicaid cutback events, along with important federal legislation extending funding for UNOS and drug coverage extension. We all need to be informed on those issues, helping to spread the word of support in

getting them to reverse some very critical actions that affect everyone in our transplant world, actions which threaten to cascade through other states in the months to come if we don’t raise the voice of protest.

While we feature articles in all four areas of our Mission in every issue, there will be a different area of focus in each issue, four areas, four issues of Lifelines a year. It is important that we understand and retain a balance of action in all four areas. When you visit our trioweb.org web site, you will again see our Mission focused balance. That broad Mission is what makes TRIO the unique organization it is, striving to truly be “Your voice of the transplant community.” Together, with your help, we can raise that voice to be heard loud and clear throughout the land (and world)!

Serving and making that voice heard through service will also be featured in each issue. See how Faith Carlin is doing that with her unique personal life experience in such an article in this issue. If you know of another, or if you yourself have a similar story of personal inspiration, please share it with our editor for a future issue, yet another way of making a difference, through example and sharing.

I had just such an opportunity recently at a UNOS Regional meeting where, on behalf of TRIO members everywhere, I offered our thanks to this large gathering of medical professionals, OPO and UNOS leaders for their work which makes it possible for each of us to live the lives we do every day. They were touched by the message from patients amidst this busy business meeting, our “voice” heard again within the transplant community.

So, after reading the articles in this *Lifelines*, I leave you with a personal challenge, **“How are YOU going to make a difference in this world through your service with TRIO?”**

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Did you know?

**There are
110, 252
Waiting List Candidates!**

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

TRIO to Host 2011 Leadership Summit

Building on the success of the Spring 2010 first TRIO Leadership Summit, where attendees strongly recommended that this event be repeated next year, we can now confirm that the 2011 Leadership Summit will be held in Washington, DC, on May 13 and 14. Using donated facilities of the Washington Regional Transplant Community (WRTC), the OPO for the metropolitan DC area, this year's leadership development theme will be **"The Power of One: Making a World of Difference One Person at a Time."**

Friday morning will again be the open TRIO national board meeting followed by the Leadership Summit's noontime luncheon kickoff with a keynote speaker not yet announced. The Summit will consist of guest speakers and associated workshops building off each speaker's presentation on a topic designed to enhance and develop leadership skills of chapter attendees. This year there will be expanded times allocated to open sharing of best practices from chapter leadership, a key request from those who attended last year's event in Philadelphia. Workshops and breakout sessions will continue through Saturday with the event scheduled to close by 5 p.m.

Depending upon grant support, there will again be a limited number of scholarships to help support attendees expenses for travel and lodging. Last year such scholarships were \$300 each with a target of two per chapter. Additional chapter scholarships may be available depending upon registrations and funding. Write or call the national TRIO office to register and obtain nearby lodging information and special rates. A detailed agenda will be available on the TRIO website in late January.



TRIO's Next Board Meeting

The addition of Catherine Paykin fills TRIO's Board of Directors to the number of positions specified in the Bylaws. TRIO will hold its next quarterly meeting on Saturday, January 22, at 2:00 p.m., via teleconference. If any TRIO member is interested in attending, please contact TRIO's Managing Services Director, Sylvia Leach, at sleach@trioweb.org.

TRIO Transplant Presentation Library – Have you seen one yet?

There are now 24 programs "in the can" with 18 already released to your local chapter for viewing. The remaining ship bi-monthly, two at a time. Members at large can request any released program by contacting the national office. Local chapters are encouraged to record and submit programs for possible inclusion in the library.

Recently released titles include: **Transplant Tourism** (Aug), **Liver & Kidney Transplantation, Allocation, Policies and Controversies** (3 talks in Sept), **Doing a Liver Transplant in 10 Easy Steps** (Oct), **How to Do a Heart Transplant** (Nov) and **Medicare for Baby Boomers and Beyond** (Dec).

The TRIOweb.org site lists all released and scheduled listings under the Communications section.

New UNOS National Kidney Exchange Pilot Program Has First Success

UNOS started a pilot program in October to facilitate "kidney paired donation," where someone donates a kidney to a stranger so their friend or loved one can receive a compatible organ in return.

The prototype project's first transplants were performed December 7 at Dartmouth-Hitchcock Medical Center in Lebanon, NH, and Barnes-Jewish Medical Center in St. Louis. Volunteer pilots met in Pittsburgh and exchanged containers carrying the kidneys.

Fewer than 17,000 kidney transplants are performed in the US each year, and just over a third are from living donors - relatives or friends who happen to be biologically compatible. About 760 of those in the last three years were kidney paired donations through regional alliances among transplant centers, but specialists predict that number could increase to 2,000 to 3,000 more transplants a year. Under the new project, 77 transplant centers submit information about patients and their would-be donors to the database, which periodically alerts centers to potential matches with people from other parts of the country, supplementing the existing local programs.

Transplantation Pregnancy Registry

As a Research Coordinator with the National Transplantation Pregnancy Registry, it is my great pleasure to speak with transplant recipients who are currently pregnant, have had a pregnancy or are thinking about pregnancy after transplant. This also includes male recipients who have fathered a pregnancy. Our registry includes the grandchildren of transplant recipients. As of October 2010, the NTPR has 1,985 transplant recipients enrolled!

As a double transplant recipient of almost 20 years, I have truly been given and I am thankful for “a second chance at life”. Meeting my donor’s family and then having a family of my own years after transplant were both unexpected and amazing experiences.

Many may be surprised to know that it is possible to have healthy children after an organ transplant and also remain healthy yourself. My daughter Elizabeth was born 8 years after my kidney and pancreas transplant, and Erin followed her 2 ½ years later.

Most transplant centers recommend waiting at least 1 year after transplant to become pregnant, however I had waited even longer as I met my husband 6 years post-transplant.

Shortly after we were married, Alex and I met with Dr. Vincent Armenti, Principal Investigator of the National Transplantation Pregnancy Registry, at Thomas Jefferson University to discuss our questions about the safety of having a child. We considered the fact that my transplanted organs and immuno-suppression regimen were stable, as was my blood pressure. Dr. Armenti also showed us the data collected by the NTPR since 1991 about outcomes of pregnancies in women on the same medications I took. It was surprisingly encouraging to us. Based on the information from Dr. Armenti and the National Transplantation Pregnancy Registry, we were satisfied to move on and meet with a high-risk obstetrician. The obstetrician worked closely with my transplant center. Dr. Shuin Yang, transplant surgeon, witnessed the cesarean birth of Elizabeth. He whispered to Alex and me that our baby was beautiful and my kidney was looking good too.

If you are interested in learning more about pregnancy after transplant, please contact the National Transplantation Pregnancy Registry. You can even ask to speak with Faith if you’d like! Toll-Free: 877-955-6877; direct: 215 955-4820; website: www.jefferson.edu/ntpr



Faith Carlin explaining the Transplantation Pregnancy Registry at the 2010 Transplant Games in Madison, WI.

-- Article and photo submitted by Faith Carlin, Secretary, TRIO Philadelphia Chapter

Catherine Paykin *(... continued from page 1)*

Upon joining TRIO’s Board, Catherine stated that she is looking forward to being a true “working board member,” supporting TRIO’s mission. She further stated that she is “dedicated to helping recipients stay healthy and working to assure there are organs available when people need them.” She brings extensive experience and skills from many decades of working in the world of transplantation and donation.

UNOS RESOURCES

UNOS welcomes your questions, requests, comments and suggestions:

888-894-6361

The UNOS patient services staff is available to help you Monday – Friday, 8:30 a.m. – 5:00 p.m. (Eastern Time)

To read UNOS new “Patient Information Letter” go to:

http://optn.transplant.hrsa.gov/Shared Content Documents/UNOS_Patient_Info_Ltr_11-2010.pdf

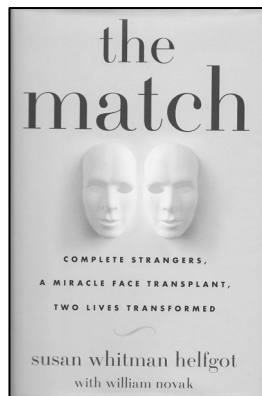
How Can TRIO and It’s Partnership With United Airlines Help You?

TRIO is most fortunate to be one of only 30 organizations partnering with United Airlines to allow frequent flyer seats for pre- or post- transplant-related travel AT NO COST. To take advantage of this wonderful program, generously provided through United Airlines, call 1-800-TRIO, go to the TRIO website (www.trioweb.org) or email us at info@trioweb.org.

To donate your United Airlines frequent flyer miles to TRIO, call 1-800-421-4655.

Transplant Book Review

“**The Match**” is a newly released book about a very different kind of transplant, a face transplant. This true story by author, Susan Whitman Helfgot (with William Novak, co-author of the famous **A Change of Heart** from back in the mid-nineties), makes for riveting and emotional reading, capturing the donation process accurately. The full review is available on the TRIO web site, along with a listing of almost a hundred other transplant books, many with complete reviews. Go to **Book Reviews** under the **Communications** section (i.e., <http://trioweb.org/communications/bookreviewshome.shtml>).



If you know of any other transplant related books not listed, we welcome titles for possible review and addition to this list. Please email that information to our resident book reviewer, GleasonJim@aol.com.

TRIO Elects New Board Officers

With a unanimous vote, the TRIO Board of Directors elected Officers from currently serving Board members, as specified by TRIO Bylaws.

President: Jim Gleason. Jim, a 17-year heart recipient, has served on TRIO’s Board in various capacities since 2005, most recently serving as Treasurer since 2007. Jim is also President of the TRIO Philadelphia Chapter and serves as a representative to the United Network for Organ Sharing (UNOS). Jim and his wife, Pam, are active in numerous transplant awareness organizations in the Philadelphia area and serve in several leadership capacities in their church. Jim and Pam live in Beverly, NJ.

Vice President: Elizabeth M.P. Rubin. Elizabeth, an 18-year liver recipient, is a Past President of the TRIO Board of Directors, having served on the Board for more than 13 years. Currently, Elizabeth serves as Chair of the Scholarship Sub-committee. Elizabeth is actively engaged in various non-profits in the Philadelphia area. Elizabeth and husband Bruce live in Swarthmore, PA, and have two daughters.

Secretary: Susan Pincus. Susan, a kidney/pancreas recipient, joined TRIO’s Board of Directors in 2009 and immediately became involved by serving as Secretary. Among other

(... continued next column)

TRIO Hosts First “Virtual” Town Meeting

The **TRIO National Services Survey** analysis was the main agenda item in the first two recent chapter meetings, one presented in person (Philadelphia chapter) while the second was the long anticipated “virtual town meeting” format (Akron/Canton chapter). The technology of Skype video conferencing went well, allowing for both presenter and chapter meeting attendees to see each other in the Q&A part of the meeting. Compliments to the local chapter “technical support” who were both familiar with Skype use and had the right equipment to make this projected presentation and sound work well. The key outcome of the survey was a very positive view of service value given the fourteen TRIO National services that were reviewed. Chapter members at both meetings were able to add their personal comments as further feedback to the National Board, one of the major goals of these “town meetings.”

An open invitation has been extended to all chapter presidents to host this presentation at their local meetings in the months to come, in person where possible, virtually for others where travel is impractical. For more details be sure to come to your chapter meeting when the full presentation will be offered and your additional ideas solicited even if you missed the survey opportunity itself. After all such meetings are completed, there will be a special audio conference to share the results with members-at-large and anyone who couldn’t make it to a chapter meeting presentation. Hope to see YOU when the town meeting comes to your local chapter.

Board Officers

(... continued from previous column)

non-profit activities, Susan has a long history of participation in the US Transplant Games. Susan is a member of the Philadelphia Chapter. She is owner and manager of a family business, Carbonator Rental Service in Philadelphia.

Treasurer: Mark Jackson. Mark, who joined TRIO’s Board of Directors in 2009, is CEO and President of Moreson Conferencing and is very generous in providing TRIO conferencing services. Mark participates in many non-profit organizations, including the American Lung Association and March of Dimes Alabama Chapters. He sits on several volunteer boards, and serves on the University of AL Birmingham Business School Advisory Board. Mark and wife Allison live in Birmingham, AL, with their two sons.

TRIO Ventura County/West Valley Chapter “Seizes the Day”

The TRIO Ventura County/West Valley Chapter is a long-term participant in decorating a float for the annual Rose Bowl Parade, held on New Year’s Day. This year the Chapter designation was raised by One Legacy OPO from a "Participating Partner" to a "Floragraph Participant".

George Miller, a long-time member of the Ventura County/West Valley Chapter, was selected to honor his donor family on the parade float.

Here is a photo of chapter members “seizing the day.”

TRIO Ventura County/West Valley Chapter members preparing to decorating the Rose Bowl Parade float.



Loss of Previous TRIO Board Member, Richard Valli

TRIO is saddened to share the news of the death of Richard Valli, who served TRIO for many years as a Board of Director member.

Richard, a 16-year liver transplant recipient, joined TRIO in the mid-1990s and immediately became very active. He was a founding member of the TRIO San Francisco City Chapter.

Richard and his wife of 52 years, Lillian, were both very active in representing and supporting TRIO at the national and local levels.

Not only was he active in TRIO, Richard served in many capacities, representing his interest in serving others. He was a Commander in the Military and Hospitaller Order of St. Lazarus of Jerusalem, Past Grand President and life member of the Italian Catholic Federation, and a charter member of Branch 258 Italian Catholic Federation.

Bruce Weir, previous president of the TRIO Board of Directors, said: “I’ve known Richard since the late 90s when we both served on the national TRIO Board. We hit it off well and became good friends. I will miss him. I guess I do already.”



Public Policy Statement

(... continued from page 1)

By way of further example and concern, both the states of Washington and Florida have enacted budget cuts in their Medicaid support of transplant patients, eliminating drug benefits for (in Washington’s case) those expensive meds we so depend on for the first six months of 2011 (and who knows what they may do beyond that). TRIO NE Florida member, German Vivas, has been actively involved in the court battles to overturn Florida’s cutbacks.

Such actions, while driven by very serious financial conditions, are directly impacting our transplant community, and if not today, may impact YOU in the months to come. TRIO’s mission is to be the voice of the transplant community through advocacy on behalf of patients everywhere. Whether it’s Linda Cheatham sitting as TRIO representative to the Transplant Roundtable alliance, or Mike Sosna leading our chapter Public Policy champions as chair of the Public Policy Committee or individuals like German in Florida, TRIO is weighing in on these very important issues on your behalf. Ask your local chapter “Who is our chapter public policy champion?” and if there isn’t one yet, either volunteer yourself or nominate someone to take on that role so you are connected directly with that committee as part of the TRIO network carrying out this mission.

Note: If you would like to receive the monthly email member newsletter, send your email address to seach@trioweb.org. Newsletters are also posted on the TRIO website for everyone to read.

Winter TRIOWEB.ORG Highlights

TRIO's website home page continues to grow in content and length with new items of transplant interest just about every day. To make it easier for visitors, an Index to the various news sections has been added, allowing quick and easy access to dated articles. And yes, we now have a Facebook connection. You can either search Facebook for it or use the link from that Index on the home page to get there directly. Come and add your presence to our Facebook wall.

Come back often to keep up with the news! If you are not receiving the member e-blast newsletter, there is a link to a generic version in that website index. To get your own copy next issue, send your email address to the national office.

Looking for that *Lifelines* article you saw several issues ago? You can find it in the archived *Lifelines* section under Communications which was recently updated with past 2009/2010 issues, so you can always find that "lost article" when you need it.

TRIO Awards 2010 Scholarships

Through the generosity of seven TRIO chapters and the Board of Directors, TRIO awarded eight \$1,000 scholarships in 2010.

Forty-one scholarship applications were received in 2010—all excellent applicants. TRIO's Scholarship Sub-committee, chaired by Elizabeth Rubin (TRIO Philadelphia Chapter member and Vice President of the Board of Directors), works diligently to evaluate each applicant based on a set of strict criteria. Steven Binder (TRIO Northeast Florida Chapter), Sylvia Leach (TRIO Managing Services Director) and Susan Pincus (TRIO Philadelphia Chapter member and Secretary, Board of Directors) also serve on the committee.

Scholarships were donated by TRIO Chapters: Greater Cleveland, Northeast Florida, Long Island, Manhattan, Philadelphia, San Francisco Bay, and Ventura County/West Valley. The TRIO Board of Directors also donated a scholarship.

Scholarships were awarded to David Carroll (University of Massachusetts), Kara Durfee (Northeastern University), Alicia Greene (Columbia University), Catherine MacLean (Wesleyan University), Laura Nelson (St. Olaf College), John Truong (Saint Louis University), Melanie Wilmoth (University of Texas), and Daniel Wolz (Truman State University).

The 2011 application is now posted on trioweb. The deadline for submission is June 30.

TRIO Youth Circle to Offer "Job Seeking Service"

This Spring TRIO will be launching an exciting and timely new support service to TRIO Youth Circle members. Having recently identified a critical and widespread need for support in post-transplant youth experiencing frustrations in searching for employment in today's tough market, we will be conducting an audio conferencing based virtual employment workshop. This weekly 90-minute event will feature guest speakers for the first 30 minutes offering professional advice and counsel via a webinar format every other session, followed by 60 minutes of support discussion with job seekers and others who have successfully found jobs sharing best practices. Aimed at transplanted youth (ages 18 and up through late 20's), this free service will be based on the popular **What Color Is My Parachute** (2011 edition) book, along with its accompanying workbook. A special very successful interviewing technique will be studied based on the book, **Landing the Job You Want**, all of which will be supplied without charge to participants who will commit themselves to attending the full 13 weeks and completing weekly exercises which will be the basis for each session's discussion.

If you know of young transplant patients in need of this service, please have them contact the national office to register as soon as possible. We anticipate a limited number of openings and will begin a 13-week schedule based on registrations and the applicant's availability as to day and time.

To learn more about TRIO's Youth Circle, visit trioweb.org or contact Mary Wu, mwu82@yahoo.com.



J.T. Rhodes Assumes Chairmanship of TRIO Chapter Council

In his continuing desire to serve TRIO and the transplant community, immediate Past President, J.T. Rhodes, will serve as Chair of the Chapter Council. He encourages chapters to contact him (jtrhodescpa@msn.com) to discuss ideas or concerns. J.T. has also volunteered to chair the Membership Development Committee, while he continues as President of the NEFlorida Chapter.

Alex Boyer, who has served TRIO so diligently for many years, will continue to serve as a member of TRIO's Board of Directors.

Membership – +NEW or +Renewal: TRIO membership is renewable as of January 1 each year.

Please support TRIO and its important work on behalf of transplant recipients, donors, candidates and their families by joining us in this important endeavor. Thank you for your support of TRIO!

Name of Member: _____

Names of other family members: _____

Address: _____

City: _____ **ST:** _____ **ZIP:** _____

Phone: _____ **Fax:** _____ **email:** _____

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

Recipient Profile (Optional): _____

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

Donor Profile (Optional): _____

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

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

Annual Dues: Member at Large \$20.

Additional Contribution \$ _____.

TOTAL enclosed \$ _____.

Thank You for your tax-deductible donation!

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

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

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