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Lifelines

July 2010



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

Pat Folk Named to TRIO Board

Please join us in welcoming our newest TRIO national board member, Patricia G. Folk, RN, BSN, CCTC. Patty is the In-house Clinical Liaison for Abdominal (liver, kidney, pancreas, intestine) Transplant Program at the Thomas E. Starzl Transplantation Institute, University of Pittsburgh Medical Center. Patty joins the board with a long history of TRIO support. She helped found the Pittsburgh Chapter in '87 and, when working on the West coast, she was involved with the LA TRIO Chapter and TRIO Las Vegas ("Red Rock Chapter"), later serving on the Communications Committee of TRIO national in 2000.

Over the years you may have run into her or received support from her in her many roles: as a liver transplant coordinator at the Starzl Transplant Institute in Pittsburgh, Cedars Sinai Medical Center, or St Vincent Medical Center in Los Angeles. Or, you may have received her services behind the scenes as a Transplant Nursing Specialist with the Clinical Division of Stadtlanders Pharmacy.

During her more than 20 years devoted to transplantation, she has been honored many times, including being granted Honorary Life Time Membership in ITNS (International Transplant Nurses Society) in recognition of her many years of service to that organization which included being President of their Golden Triangle Chapter, President of the International ITNS organization and recipient of the 2004 ITNS/Roche Transplant Nursing Excellence Award. Patty is a graduate of Pennsylvania State University, where she was on the Dean's List and a member of the Golden Key National Honor Society.

Patty has been active in a long list of transplant related organizations including the 2002 US Transplant Games "Team Pittsburgh," the American Board of Transplant Certification,

(... continued on page 3)

Leadership Summit Brings Nationwide Exchange of Ideas

More than 25 attendees and speakers gathered in Philadelphia at the end of April contributing to a very exciting and successful first TRIO Leadership Summit. Almost every TRIO chapter was represented. Supporting scholarships and no registration fees eased the individual cost of participation, thanks to our sponsor, Roche.

Over opening lunch, well-known keynote speaker Howard Nathan, President and CEO of the Gift of Life Donor Program, inspired and entertained with his 30-plus-year history of innovation and leadership in the organ donation and transplantation field. With the meeting being held in the beautiful offices of this OPO program, within one block of the almost completed new family transplant house, Howard shared his very personal life experience of making his dream become a reality, the theme of our two day event. Subsequent speakers supported the same message with their own examples of similar success in hopes of inspiring the audience to return to local chapters with their own dreams and plans to be turned into reality through action, making a difference in communities around the country in support of the TRIO mission.

(... continued on page 3)



Some attendees and speakers at the Leadership Summit

President's Message



J.T. Rhodes

TRIO is very pleased to introduce the most recent addition to our Board of Directors: Patricia Folk. Patty comes to the board with an extensive background and service in the field of transplantation. We appreciate her joining TRIO's board and look forward to working with her. See the article about Patty that begins on the front page of this newsletter.

TRIO is also pleased that the TRIO Kansas City Chapter is nearing completion of the chartering process and should be a fully-accredited chapter very shortly. Welcome, Kansas City TRIO! If you are interested in starting a chapter in your area, please contact TRIO Managing Services Director, Sylvia Leach at sleach@trioweb.org.

At our most recent Board of Directors meeting, held in Philadelphia, the TRIO board revised the 2010 Budget in view of the current economic conditions. We have recently learned that one of our general operating support grants was significantly reduced. However, our Treasurer, Jim Gleason, reported other revenue streams already in place to make up for the shortfall. We now have additional sources of income from Lifelines and website advertising. Our Presentation Library project and the Leadership Summit are funded through grants from Roche and Astellas. We deeply appreciate their assistance in making these programs available to the TRIO members.

Our Leadership Summit, held in Philadelphia, was a great success, with inspiring speakers and discussion sessions. The sessions were very informative and allowed time for chapter leaders to discuss common concerns such as leadership,

volunteerism and funding at the local level. Please read the article in this issue of the newsletter to learn more about the Summit. My thanks to Jim Gleason, the Gift of Life Donor Program, TRIO Philadelphia and the support from Genentech/Roche Pharmaceutical. I do hope this will become an annual 'must-attend' event for chapter leadership.

I continue to get positive comments about *Lifelines* and our website. We have started using Constant Contact for our members who want to receive timely information on topics of interest. If you are not receiving the Constant Contact emails and would like to, please send your email address to TRIO national (sleach@trioweb.org).

Thanks to former board member Ron Taubman for securing funding for a new essay contest, geared toward high school students. This project will not only increase TRIO's status in the transplant community, but also offer an opportunity for our local chapters to help promote organ and tissue donation in high schools. A lot of work needs to be done, so if you are willing to serve on this committee, contact Ron Taubman by email at: (taubmanappr@dslextreme.com).

Our new awareness program for primary care physicians was presented at the Leadership Summit. We are currently seeking funding and hope to roll out the full-blown program in early fall. Check TRIO's website for more information (www.trioweb.org).

TRIO is progressing, busy, and doing a wonderful job promoting organ donor awareness. I am proud of all the work TRIO chapters do in this area. If you have any questions or concerns, please let me know.

And don't forget: TRIO will have a booth at the Transplant Games in Madison, WI, July 30-August 4. Stop by booth #208 to visit us! Or, better yet, call Susan Pincus (215-726-9100) to volunteer to help with staffing the booth.

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

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2010 TRIO Leadership Summit Well Received (. . . continued from page 1)

Faith Cortright, Volunteer Coordinator, challenged our organizations to be sure our members are not just members in name only, but become involved volunteers who are actively engaged in the projects and programs each chapter offers in carrying out its support role.

Pam Gleason, vice president of the American Liver Association's Mid-Atlantic Division, shared her thesis research on effective volunteerism, adding yet another dimension to this important topic. Later, Deborah Roberts, Transplant Family House Director, gave examples of successful fund raising events that have made this dream of a 30-room hotel-like facility become a reality, another of Howard's long-term dreams.

The first day concluded with attendees either opting to spend the evening touring historic Philadelphia or to attend a dinner dance sponsored by Second Chance, a local heart transplant support group, with some 300-plus heart recipients and their families for a fun filled night of music and dancing. The TRIO table along with the local chapter's ad in the program book gave testimony to TRIO's role in this important transplant community.



Summit attendees participate in a workshop discussion.

On Saturday the challenge of re-invigorating a chapter was the subject of a panel that included local Philadelphia ITNS chapter leaders and officers of the recently re-established TRIO Philadelphia Chapter. These panel discussions promoted open dialogue with the audience. By this second day the discussion focused on an inspiring sharing of best practices among the varied members of the audience.

Based on the closing evaluation survey, the overwhelming response was one of learning, excitement, and fun. Participants expressed their enthusiasm with requests that this become an annual TRIO event.

Thank you to everyone who supported this very successful summit of committed TRIO leadership. We look forward to expanding this opportunity in the years to come when hopefully *YOU* can join us.

*-- Article by Jim Gleason, Treasurer,
TRIO Board of Directors*

Pat Folk Joins TRIO's Board of Directors

(. . . continued from page 1)

ITNS, NATCO, United Liver Association, National Kidney Foundation, and American Liver Association. Her long list of publications and many TV/media interviews (CBS, CNN, etc.) fills out 24 pages of an extraordinary CV.

Patty brings to the TRIO national board twenty-plus years of clinical expertise helping to identify new issues in transplantation, interpreting medical information, writing patient directed articles, and providing a coordinator's point of view. Patty states: ". . . having worked in both Los Angeles and Pittsburgh and having been an active member of several transplant professional organizations, I can assist TRIO with my networking skills and resources, offering professional contacts around the country and world that can assist with chapter development, marketing of TRIO, speaker contacts, and fund raising efforts."

What a wonderful history of service that further strengthens this TRIO national board as we grow and move forward through 2010 and beyond.

*-- Jim Gleason, Chair,
TRIO Nominating Committee*

What Can TRIO and United Airlines Do For YOU?

TRIO is most fortunate to be one of only 20 organizations partnering with United Airlines to allow frequent flyer seats for transplant-related travel AT NO COST. Do you or someone you know need to travel for pre- or post-transplant related medical visits? Does a transplant recipient or living donor need to travel with a care-giver? This is an open, public program, not limited to TRIO members. PLEASE take advantage of this wonderful program, generously provided by United Airlines! Call 1-800-TRIO386, go to TRIO's website www.trioweb.org or email us at info@trioweb.org.

TRIO National Services Survey Is Officially Closed for Analysis of Your Responses

A very special thank you to everyone who shared their views in our spring survey of TRIO national's services and level of service delivery. That survey is now closed and the data submitted is being analyzed.

A preliminary look at responses was presented at the recent Leadership Summit which showed a representative cross-section of participation from almost every chapter in the country and every level of active membership, broken down by years of service.

As would be assumed, 80% of responses came from transplant recipients (that is approximately the general makeup of our membership). While most indicated they were reasonably active within their chapters, there was also a cross sample from every level of member activity. Reporting based on this member cross-section is critical to our gaining insightful perception both of the quality and quantity of services offered. Recognizing this cross-section of membership activity levels also reveals the perceived value of such services against the long list of existing service offerings.

There was minimal response to the open-ended question of what additional services members might suggest as being needed. It is hoped that in the proposed *chapter town meetings* where the full analysis of survey results will be offered at the local chapter level, that open dialogue will offer additional opportunity for member input on this critical topic.

Free webcams have been distributed to chapter representatives attending the Leadership Summit and will be mailed to remaining chapters. If your Chapter President has not received the chapter's webcam, please contact Sylvia Leach, Managing Services Director, at sleach@trioweb.org or call 703-743-2178 (direct office line for Sylvia). The webcams, provided to each chapter at no cost, will allow TRIO board members the opportunity, either in person or virtually, to participate in your meeting and hear your direct feedback.

Stay tuned in coming months for the next steps in this ongoing process: fully analyze the results; process the findings; create chapter presentation; offer chapter town meetings (in person or via free webcam); schedule presentations and invite feedback; develop TRIO national initiatives based on chapter town meeting feedback.

TRIO's Board of Directors Meeting Held in Philadelphia

On April 30, TRIO's Board of Directors met at the Gift of Life Donor Program offices in Philadelphia. TRIO officers attending the Board meeting were J.T. Rhodes, President; Susan Pincus, Secretary; Jim Gleason, Treasurer. Also attending were Board members Mark Jackson and Ex-officio Board member Sylvia Leach, Managing Services Director. Joining the meeting by teleconference were Board members Brian Funge and Alex Boyer, Chapter Council President.

The next TRIO Board of Directors meeting will be held by teleconference, currently scheduled for July 18, at 1:00 p.m.

If you, as a TRIO member, would be interested in joining the July 18 teleconference, please contact Sylvia Leach at sleach@trioweb.org to make arrangements.



TRIO Board at Philadelphia Meeting: (L to R) Sylvia Leach, Managing Services Director (Ex-officio Board member), J.T. Rhodes, President; Jim Gleason, Treasurer; Susan Pincus, Secretary; Mark Jackson (Board Member at Large).

Visit TRIO's Booth at the Transplant Games

TRIO will be located in Booth #208 during registration at the Transplant Games. Please come by and meet new TRIO friends and greet old friends. Rally towels will be given to the first 500 booth visitors. We will have beautiful Cloisonne pins available, also. Purchase TRIO pins to add something special to your pin-trading cache to help with one of the 'hot' activities during the Games.

If you can help with the booth or if you have questions, please contact Susan Pincus by email (susan@carbonatorrental.com) or by phone (215-726-9100).

Returning to Work After Your Transplant

For many transplant patients, establishing disability via Social Security can be an uphill battle. Once confirmed, related benefits such as Medicare follow. So when your transplant team “clears” you to return to work, how do you re-enter the work force without upsetting the fragile construct of income and benefits? For many, staying a step ahead can be the answer.

There are numerous programs available to people who do not wait for Social Security to re-evaluate their disability status. Once you and your transplant team have discussed the conditions under which you may return to work, consider some of those options available to you.

For patients who need a new skill set after their transplant, most states offer **Vocational Rehabilitation** free of charge. Vocational Rehabilitation (VR) is a federal-state program that works with people who have physical or mental disabilities to prepare for, gain or retain employment. VR is committed to helping people with disabilities find meaningful careers. Engaging in VR should not affect your SSDI/SSI benefits. Look under your State government’s website for ways to access the program.

Social Security also offers a program called the **Trial Work Period** which allows you to test your ability to work for at least 9 months. During your trial work period, you will receive your full

Social Security benefits regardless of how much you are earning as long as you report your work activity and you continue to have a disabling impairment. In 2009, a trial work month was any month in which your total earnings were \$700 or more or, if you were self-employed, you earned more than \$700 (after expenses) or spent more than 80 hours in your own business. The trial work period continues until you have worked nine months within a 60-month period. Other benefits related to the Trial Work Period (Extended Period of Eligibility, Expedited Reinstatement, Continuation of Medicare and Work Expenses related to your Disability) are all part of this benefit. You can access these benefits at www.ssa.gov under the Heading of “Working While Disabled-How We Can Help” or by calling 1-800-772-1213.

As always, you can contact your Transplant Social Worker who will be glad to guide you through this process. Remember that there are so many benefits to returning to work after your transplant; but, proceeding with caution and staying a step ahead can be the key to a seamless transition from being disabled to once again being gainfully employed!

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

TRIO Presentation Library Ships Last of Year-One Programs

As we close out the very successful first year of the TRIO Transplant Presentation Library with the recent shipment of program #11 (“Mechanical Assistance of the Heart as a Bridge to Heart Transplantation”) and #12 (“NDRI: National Disease Research Interchange”) local chapters have 12 DVD programs available for member use. Most chapters bring the library notebook to their monthly meetings to make it easier for members to review and check out programs. If that is not the current practice, talk to your chapter president about making them available in that way.

It is exciting to note that we already have 11 more programs ready for the second year’s library, so go to TRIO’s website for upcoming releases which go out to chapters bi-monthly. If you are not a member of a local chapter, i.e. you are a TRIO Member at Large, contact the

national office (email: sleach@trioweb.org or call TRIO at 1-800-874-6386) to arrange viewing of any programs listed on the website as released and available.

Numerous Scholarship Opportunities Available for Review on www.TRIOweb.org

Even though the TRIO scholarship application deadline for the current year closed on June 30, the TRIO website lists numerous other scholarship offerings, with varying deadlines. Go to www.trioweb.org and click on “Communications” and then on “TRIO Scholarships” to see the opportunities remaining available from other organizations.

In the coming months TRIO will publish criteria for a new essay program under which high school students can submit essays about organ donor awareness to compete for monetary awards. Watch the TRIO website for details.

If You Think It's "Just the Flu," Think Again! (and check with your Dr.)

(Editors Note: The following account was written by J.T. Rhodes, President, TRIO Board of Directors. Approximately six weeks ago, J.T. thought he had a light case of 'ordinary flu' but ended up spending more than two weeks in the hospital and two to three weeks recovering at home. See his latest health update at the end of this article.)

As a transplant recipient, I am very compliant with my meds and will not change dosage unless my doctor approves. I also call my doctor with any problem before it develops into something bigger. I exercise six days a week to stay in shape and to help me physically and mentally. For almost 16 years of following this routine, I did not spend a night in the hospital.

However, about six weeks ago, I woke one morning with flu-like symptoms (fever, chills, body ache, head ache, diarrhea and total lack of energy). My temperature was around 101.5. I know I should have called my doctor, but I felt that bed rest would cure my flu-like symptoms. For two days I stayed in bed and drank lots of liquids. My fever was consistently between 101 and 101.5.

On the evening of the second day the fever broke and I began planning on going to work the next day. When I got out of bed the next morning, I could hardly walk; the lower portion of my left leg was hot and red so I called my doctor. He advised me to go the emergency room immediately, where I was admitted with a diagnosis of something called 'cellulitis.'

Later, based on research of various websites, I learned that cellulitis is a bacterial infection of the skin that is usually caused by a streptococci or staphylococci bacteria. It can result from a cut, insect bite, or dry skin condition. Being immune suppressed puts a person at higher risk and makes it more difficult to eliminate the infection from the body.

The more obvious symptoms are fever, red spots or rash (usually on the legs or face), and the skin is hot to the touch. Usually, pain results from touching the red skin. Sometimes it can manifest as flu-like symptoms and cause swelling in the infected area.

The infection is cured by antibiotics given orally in less severe cases and through IVs in more serious cases. Rest and keeping the infected area elevated above heart-level is also recommended.

My case was pretty severe and I spent 14 days in the hospital where I received many IVs and

was even taking oral antibiotics. As it began to heal, the skin on my leg started to peel but the swelling was less severe. Of course, one of the side effects of taking so many antibiotics is that other infections and rashes can occur. These occurrences were treated with different antibiotics.

After my discharge from the hospital, a home health nurse came to my house twice a day for two weeks to administer IV's; and twice a week, draw blood. The IVs were 12 hours apart (at 10 a.m. and 10 p.m.). Each home IV session lasted about two hours but it sure beat being in the hospital!

My infectious disease physician stated that being immuno-suppressed caused the infection to be more difficult to cure and to last longer than most cases.

My suggestion to transplant recipients is: if you develop flu-like symptoms, at least call your doctor to let them know. And, if you have any red spots, itching or swelling in your legs, you should monitor closely and, if you see no improvement, call your doctor as soon as possible. If redness, pain and heat are felt in the infected spot, you should go to the emergency room as soon as possible.

Update: On June 17, J.T. reports that:

After two weeks of antibiotics administered at home, along with taking oral antibiotics, I will stop taking oral antibiotics on Monday, five weeks after being diagnosed with cellulitis. If all is well on my Thursday visit to infectious disease doctor, I will be discharged from his care.

It's amazing what an infection can do to your life and body . . . and I thought it was 'just the flu.'

UNOS RESOURCES

108,134

Waiting List Candidates on June 20
(www.unos.org)

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)

TRIO Looks Forward to Chartering New Chapter in Kansas City

Spearheaded by the interest and efforts of heart recipient Merle Zuel, a group in Kansas City is starting a new TRIO Chapter. The TRIO Board of Directors is expected to officially sanction the chapter at their next board meeting. Check TRIO's website for the 'official welcome.'

By way of introduction, in the photo below: (left to right): Lois Winningham, Treasurer (Transplant Financial Coordinator, Kansas UMC); Mike Dempsey, Membership (heart recipient); Rebecca Renard, Secretary (Mike's wife); Kim Zuel, Membership (Respiratory Therapist, Merle's wife); Merle Zuel, President; Rick Coomes, Vice President (Pharmacist).



TRIOWEB.ORG Highlights

Be sure to check out the ongoing updates of transplant presentation programs with new titles being added monthly. Each chapter has its own library of over one dozen DVDs that members can check out for home use on their TVs or PCs. Members at large should contact the national office to "check out" programs from this index of titles maintained on the TRIO website. Don't forget, we welcome recordings of your own chapter presentations as possible additions to this library.

Looking for activity ideas for your local TRIO chapter? Chapter activity reports are linked from each chapter's name in the Active Chapters list (under **Community** at the top of any web page). There you can find interesting and creative ideas from what other chapters have been doing around the country. Of course, we look forward to photos and stories from your own chapter's activities, so come share the wealth.

TRIO's Youth Circle Is Growing!

The TRIO *Youth Circle* expands! We now have a section on TRIO's website where you can read inspiring articles and news stories from youth around the country. Go to (<http://trioweb.org/storyYouth.shtml>) to check out resources: stories of youthful life experiences about transplant and donation and read the Q&A written by and for young people. Also, if you missed the recent MTV true life episode on the challenges of real life youth having a transplant, you can access that from the TRIO youth webpage.



Please submit your own transplant stories and experiences for posting on the site. Your story can help motivate and inspire others. It's the struggles in life that show us who we are and what we are truly capable of as a person. We have lots of support here in the *Youth Circle*, so if you have any questions or just want to chat, please don't hesitate to contact us. We would love to hear more stories about your transplant experiences, as well as any issues pre- and post-transplant that you may have questions about. It's always nice to know that someone your age has been through a similar situation and that is why we are here: to give other youth, donors & families hope! Come join the *Youth Circle* and submit your story, read inspiring articles and ask questions of people who know what you are feeling.

You can meet our Youth Circle Coordinators, Valen Cover and Holly Werlein, on the trioweb.org youth page.

In future issues of the *Youth Circle* column we will be discussing issues and topics of interest to our younger transplant community. Let us know what you want to talk about!

And, remember that the U.S Transplant Games are coming up July 30-August 4 in Madison, WI. We hope to meet some of you there.

- Valen Cover, Youth Circle Coordinator,
Member, TRIO Board of Directors
(email: pkdwillnotbeatme@yahoo.com)

- Holly Werlein, Youth Circle Coordinator,
(email: hwerlein@hotmail.com)

Membership – NEW and 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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