TRIO Plans Conference in St. Louis, MO, for September 25-27, 2008

J. T. Rhodes, President of TRIO’s Board of Directors, is proud and excited to announce the scheduling of a joint conference to be held by the International Transplant Nurses Society (ITNS) and Transplant Recipients International Organization (TRIO). This conference will be held September 25-27, 2008, at the Millennium Hotel in Saint Louis, Missouri.

The ITNS is the premier transplant nurses organization in the United States and Europe. The transplant nurses who are members have completed the rigorous educational requirements required by the ITNS in order to proudly display the designation “CCTC” (Certified Clinical Transplant Coordinator) beside their names. The ITNS is expecting over 300 transplant nurses from around the United States, Canada and Europe to attend the convention in 2008.

TRIO members will have the opportunity to attend any of the workshops presented by the ITNS and, in turn, the ITNS members can attend any of TRIO’s workshop presentations. TRIO President of the Board of Directors J.T. Rhodes said, “Our TRIO organization is planning many interesting and informative sessions at our convention, which will be of great interest to the transplant recipient, those waiting for a transplant along with their family members.”

The TRIO Conference Planning Committee is Co-Chaired by Ron Taubman, Vice President of TRIO’s Board of Directors and Chair of the Development/Fundraising Committee, and Elizabeth M.P. Rubin, Immediate Past President and Secretary of the TRIO Board of Directors.

Some of the sessions being considered as viable subjects that affect the transplant community include: advances in immunosuppressant medications; changes in Medicare coverage; aftercare of the transplanted patient; changes being discussed by OPTN/UNOS regarding the allocation of organs to the aging population; effective ways to communicate with local, state and national elected officials to promote issues important to transplant recipients and people waiting for a transplant; current and new trends in transplantation such as therapy to reduce antibody levels. Other session topics being considered are Donation After Cardiac Death, Presumed Consent, and financial incentives to donor families.

The Committee welcomes from TRIO members additional ideas for session topics to be considered for inclusion in the conference program. Please e-mail your session ideas to Ron Taubman at taubermanapp@dslextreme.com. Guest presenters will represent a cross section of the clinical and surgical/medical profession as well as representatives of the government and private sector involved in transplantation.

The planning committee is working to make the cost of attending the conference as reasonable as possible and will be announcing the fees in early 2008. The conference fee will include continental breakfasts, speaker lunches, all of the conference seminars and hopefully, the joint banquet, to be held on Friday night, September 27, 2008.

(. . . continued on page 4)
Happy new year and welcome to the "Year of TRIO Growth" in 2008. The board is working hard to make TRIO the organization that its members want. With your help we can grow the organization to become a stronger voice for all transplant recipients and donors.

The board is excited about the potential conference with ITNS. This will give our members a chance to meet with many transplant nurses from around the world as well as attend a very educational conference at a reasonable price. Please make plans not to miss this important event.

Our website has been re-designed. If you haven't visited it in a while please take the time to go to www.trioweb.org and view the information on the site. We have also expanded the topics for the bulletin board discussions and urge you to post your questions on this informative board.

Mike Sosna is working hard on TRIO public policy and transplant issues. He can use help in drafting our voice on transplant issues. If this area interests you, please let Mike know (mike@sosproductions.com) so you can have a voice in shaping TRIO opinions. TRIO is also one of the members of The Transplant Roundtable in Washington, DC. The Roundtable promotes transplantation issues in the United States House and Senate.

TRIO is very active in the Donate Life Hollywood coalition that monitors TV programs, advertising and movies concerning the proper communication methods and facts about transplantation. If you see or read anything that does not properly promote organ donation or is not a fair portrayal of organ donation just let TRIO know and we will address the issue with the producers. Donate Life Hollywood is becoming more proactive by meeting with writers, producers and advertising executives to be sure they have the correct facts about transplantation and donation. TRIO is the only recipient organization that is a member of this coalition.

TRIO will continue to publish Lifelines quarterly and continues to improve this publication. If you have any suggestions for articles or have any ideas for improvement of Lifelines, let us know.

Our TRIO chapters are the backbone of TRIO. Please take your time to attend your chapter's meetings and help with their many wonderful projects. Most importantly, be sure to renew your membership in TRIO.

TRIO can grow only by serving its members. We need your help to grow. Look at National committees and volunteer to serve and make your and your chapter's voice heard in TRIO decisions. Your National board needs your input on issues which interest you. Don't be shy...speak up and help your fellow recipients.

If you don't have a chapter in your area consider starting one. Just call our 800 number (800-TRIO-386) and we will help you lay the groundwork for a successful chapter.

Your board is working to improve TRIO's financial position and is looking forward to a very productive and successful year for TRIO in 2008.

Help TRIO GROW in 2008!!!
TRIO Supports Request for Congressional and House Organ Donation Act Funding for FY 2008

In a letter, dated November 20, 2007, TRIO and other representatives to the Transplant Roundtable, signed on to reinforce the need for and to support a request for funding of the Organ Donation Act. TRIO is a member of the Transplant Roundtable, an informal group of organizations concerned with monitoring congressional activity and support in the transplant arena. To learn more about the Transplant Roundtable, contact TRIO’s liaison to the Roundtable, Linda Cheatham, at email: linda@cheatham-cpa.com.

The text of the letter, sent over the signature of the American Society of Transplant Surgeons, reads:

The Honorable Tom Harkin
Chairman
Senate L/HHS Appropriations Committee
Washington, DC 20510

The Honorable Arlen Specter
Ranking Member
Senate L/HHS Appropriations Committee
Washington, DC 20510

Re: Organ Donation Act Funding for FY 2008

Dear Chairman Harkin and Ranking Member Specter:

The undersigned organizations representing the “Transplant Roundtable,” a working coalition of transplant patients, professionals, and research foundations wish to thank you for including funding for Organ Donation and Recovery Improvement Act of 2004 (ODA) programs, P.L. 108-216, in the FY 2008 Labor/HHS Appropriations bill. In these tight budget years, Congress had not yet appropriated initial federal funds for this law until your action in recent weeks.

The ODA was enacted to address financial disincentives to living organ donation, better coordinate organ donation in hospitals, and improve the practice of organ recovery. It authorized $25 million in FY 2005 and “such sums as necessary” for FY 2006 through FY 2009 to build on existing, successful organ donation programs at the Division of Transplantation (DoT) within the Health Resources and Services Administration (HRSA) and to authorize new and innovative programs such as reimbursement of travel and subsistence expenses for living donors.

Now the need for funding is more critical than ever. The DoT has received cuts or level funding over the past four fiscal years in spite of the Office of Management and Budget’s goal of doubling the number of transplanted organs by 2013. It is simply not possible for DoT to achieve such a goal without additional funding.

As such, we sincerely appreciate the initial $1 million in funding for these programs (a compromise after the Senate proposed $2 million and the House proposed no funding) that was included in the final L/HHS appropriations bill passed by the House on November 8, 2007. Every $1 million of travel and subsistence expenses for low income living donors translates into an additional 400 transplants, allowing greater numbers of donor recipients to be taken off the lengthy organ donation waiting lists. Such funding will help the HRSA as it budgets funding for these and other organ donation programs.

With the recent presidential veto of the final bill in mind, we ask you to maintain the $1 million allocation secured in future versions of the FY 2008 L/HHS Appropriations bill. On behalf of organ donors and transplant patients, we look forward to working with you in the future to secure this initial funding for the Organ Donation Act programs in FY 2008 and additional funding in years to come.

Only with adequate appropriations will the ODA allow the federal government, states, and other public and private entities to expand their current organ donation efforts and create new, effective organ donation programs. Thank you again for your past support and for your consideration of this request.
TRIO 2008 Conference

(Continued from page 1)

A block of guest rooms is available at the Millennium Hotel at a low convention rate for TRIO members and their families of $139 (plus tax) per night; the same room rate that ITNS members receive.

The meeting location of St. Louis, Missouri, is an excellent choice due to the mild weather conditions during the latter part of September. In addition to being a center of commerce, St. Louis has many excellent entertainment attractions for the entire family. St. Louis is an airport hub center, thereby providing many reasonably priced airlines flights from any location within the United States.

Please join TRIO and ITNS in St. Louis in September, 2008, to discuss important transplant issues, to spend time with transplant nurses and to meet many different transplant recipients, donors, candidates and their family members from around the US and the world.

If you have any questions, please contact Sylvia Leach, Managing Services Director of TRIO at 1-800-TRIO-386 or sleach@trioweb.org.

TRIO Board of Directors to Meet in Washington, DC, in January 2008

After an extremely informative and successful Board of Directors meeting in October of 2007, hosted by the Cleveland Clinic, TRIO is looking forward to its first Board meeting of 2008. The meeting will be held at the Hyatt Crystal City (VA) on Saturday, January 12, 2008. Meetings begin at 9 a.m. and usually continue until 5 p.m. The Hyatt Crystal City provides rooms at a rate of $95 per night ($78.75 per night for AAA members or ‘seniors’—those 62+). All rates are plus tax. To secure these rates, the reservation must be made online at http://crystalcity.hytatt.com/hyatt/hotels/index.jsp.

All Chapter members and Members at Large are invited to attend or provide written input on any agenda item.

2008 Transplant Games Set for Pittsburgh, PA, in July of 2008

It’s time to take a swim . . . it’s time to get in the starting blocks . . . it’s time to walk up to that first tee and aim for the middle of the fairway.

Yes, it’s that time again. The U.S. Transplant Games are coming again this July 11th to 16th 2008 to Pittsburg, Pennsylvania.

For those of you who have never attended, you should consider attending this year. As a heart transplant recipient myself, I can attest to the fact that next to receiving your transplant, this will be one of the most significant events you will ever attend. Where else can you walk into a stadium filled with people from all over the US and be recognized for your greatest achievement: that of surviving and living with transplantation!

Of course, a more significant event at the Games is when all of the donor families walk in and are greeted by the entire crowd in the stadium. It is an event of great impact for everyone who is attending. It’s also one of the most significant events that is held with love and gratitude in the heart of everyone when they go back home to tell others about the greatness of the U.S. Transplant Games. It’s nothing less than perfection!

The National Kidney Foundation U.S. Transplant Games are open to all recipients of life supporting allografts and hemopoetic cell transplants from other individuals or species which require or have required the use of immunosuppressive drug therapies. Competitors or athletes in the games must have been most recently transplanted for at least nine months, with stable graft function, be medically fit and have trained at the events in which they have entered. And the best part is that there are no age limits. Whether you’re 3 or 93, if you qualify, you can compete.

If this is for you, you should contact your local OPO or transplant center or the Games’ website http://www.kidney.org/news/tgames/index.cfm.

This year there are more sports to participate in than ever before! Consider competing in track and field events, bowling, tennis, golf, swimming, cycling, table tennis, racquetball, basketball and much more. Sign up begins early 2008.

See you all there!

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98,131 waiting list candidates as of December 26, 2007!
(United Network for Organ Sharing – www.unos.org)
Transplant Recipient Inspires Others, Runs the Marine Corps Marathon

Terri Lynne was born with Tyrosinemia. By the time Terri approached her teenage years, the disease had caused liver cancer. After being on the transplant list for about two months, 16 years ago, Terri received her transplant at Emory University in Atlanta. While she downplays the high level of inspiration she generates as a transplant recipient, Terri decided to go do things “just because” she can! And one of the ‘things’ she did was to run the Marine Corps Marathon after only one year of training!

Terri started her track career with the Transplant Games in 2000. She says: “I believe the games have shown me really what it means to be a transplant recipient. . . . Because I didn’t know any others like me until the games, I guess I didn’t realize how hard some people really have it. . . . I figure there must be a reason I’m still alive. I’m not sure what it is, but how can I not take advantage of it! I want to know that I did everything I wanted to and used my gift the way it was meant to be used.”

Terri started running seriously in 2005 and finished her first full mile in September of 2006. She says, “. . . and that provoked me to do this. I wanted to see how far I could go. Also, being a transplant recipient, I wanted to show other recipients that you can do whatever you want and not to think of yourself as ‘sick.’”

After only two years of ‘serious’ running, Terri entered the prestigious Marine Corps Marathon in 2007 . . . and she finished in 6 hours, 6 minutes! The Marine Corps Marathon, covering 26.2 miles, is the 4th largest in the United States. It is held each October in Washington, DC. In 2007, more than 21,000 runners participated.

Each runner has two bibs. True to her cause, on one bib Terri wrote “Liver Transplant Survivor – July 2, 1991,” and in celebration of her friend’s sister (who had received a kidney transplant four days before the marathon), Terri wrote: “Terri *4* Janet.” She also wore her Arkansas Razorback pin, in honor of her donor.

Terri says “I read somewhere that you run the first 20 miles of the marathon with your legs and the last 6 miles with your heart. Why did I choose to run the Marine Corps Marathon? I wanted to know if the same girl who couldn’t run a lap around the track had it in her . . . I did it because I can!”

Terri Lynne, liver transplant recipient, crosses the finish line at the Marine Corps Marathon in October of 2007.

Terri says that she would like to run another Marine Corps Marathon, but right now she’s busy getting ready to compete in the Transplant Games in Pittsburgh in 2008.

Terri Lynne is a true inspiration to transplant recipients and she doesn’t even realize what great good she has done! Just don’t dare her to do anything . . . or she’ll just go out and do it!

To read more about Terri’s experiences, in her own words, go to her blog at http://sisterpeach.blogspot.com/2007/11/beat-bridge.html. Learn more about the Marine Corps Marathon at www.marinemarathon.com. See the 2008 Transplant Games article in this issue on page 4.

TRIO Website Update

- **TRIO’s website has been re-designed.** Please visit www.trioweb.org to see the new banners and look . . . Please let us know what you think about the new design and the new content by sending comments to info@trioweb.org.
- **TRIO’s website Bulletin Board discussion topics have been expanded.** Go to www.trioweb.org and click on Bulletin Board. The discussion topics have been expanded to include transplants by organ name, living organ donations and families, health: fitness and nutrition, and thank you’s to donor families.
- **New Hotlink:** visit a new website to assist living donors: www.livingdonorassistance.org. This site assists living donors in applying for financial assistance and provides information about living organ donation.
Thoughts about Depression . . .

. . . (from a transplant recipient who’s ‘been there; done that’)

Depression can be a serious problem after you have had a successful transplant. I know! The tribulations that you went through before and during your transplant, the medications, and the life-style changes after your transplant can cause mental overload. Returning to work can be a source for worry and depression. Depression can occur at any time during the first year or even longer. Numerous events can trigger it.

I’ve found the following ideas helpful in resolving depression issues.

★ Do those activities and hobbies you enjoy the most. Just doing something is better than doing nothing.

★ Aerobic exercise at an increased heart and breathing rate does wonders. It increases blood flow which carries more oxygen and stimulates your brain to release endorphins—happy hormones. With sufficient energy expenditure, endorphins kick in after about 30 minutes and produce a happy and natural “high.” Suddenly, the world seems right. Your thoughts are clear and senses are sharper. Solutions are found for insolvable problems.

Physical activity promotes physical and mental health.

Brisk walking is a fine exercise.

★ Hang out only with those people with whom you can joke, laugh with and have fun with. Stay miles away from all others.

★ Listen to music. Music has never failed to help bring me back and make me feel better. When I returned home after my transplant, the first song I heard was “When I’m Back on My Feet Again” by Michael Bolton. It had a profound affect on me. Music is highly personal. Find your own “sole” music—it can make a big difference in your feelings and in your recovery.

★ Quit feeling sorry for yourself. Think how fortunate you are to be alive. I have been seriously sick several times in my life, but I did not have to look very far to find someone I would not trade places with. After my first heart surgery, not my transplant, I saw a woman in a bed in the hall of the hospital. She had no arms, no legs, no family, and no friends. The hospital was trying to get rid of her—they could not keep her any longer. And you think you have it tough? Make an effort to maintain a positive attitude no matter what.

★ Keep your self-esteem. Another cause for depression is low self-esteem. You are a person and have feelings too. Your self-esteem is part of your essence and belongs to you. Don’t let anyone ever take it away. Let them take your money, your house, your car, and perhaps your spouse . . . but when they threaten your self-esteem, that’s where you draw the line—a very hard, sharp line! Never back down on this.

★ Talk to your doctors about your problems. If they don’t listen, find new doctors. Review your medications with your doctor for possible causes of depression. See a dermatologist for skin problems, etc. Your physical health affects your mental health.

★ Develop harmony within your body. When all factors are satisfied the whole becomes greater than the sum of the parts. You become wholesome and alive.

— Don Ehnot, Member, TRIO Board of Directors

TRIO Chapters Participate in Quarterly Teleconference

In a well-attended Chapter Presidents’ Teleconference, held on November 5, TRIO Board members and Chapter representatives discussed issues and ideas pertinent to the ongoing services provided by TRIO to its members and chapters.

President J.T. Rhodes shared information about the potential co-conference with ITNS, scheduled for September 25-27, 2008. Board Vice President Ron Taubman detailed his long-term plans for development, fundraising and cash infusion.

Chapter representatives attending the teleconference were: Tom Behra (Akron-Canton), Suzanne Himes (Greater Cleveland), Mike Sosna (Long Island), Linda Cheatham (Nation’s Capital Area), J.T. Rhodes (Northeast Florida), Elizabeth Rubin (Philadelphia), Steve Okonek (San Francisco Bay Area), Dave Courtemey (Texas Panhandle), and Ron Taubman (Ventura/West Valley). In addition, Chapter Council President Alex Boyer and Managing Services Director Sylvia Leach attended the teleconference.

Current Chapter Reports can be viewed on www.trioweb.org by clicking on the “Activity Report” under Chapter’s name.
Legislative Initiatives: Immunosuppressive Drug Coverage

The “Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patient Act of 2007-2008”

The Bills:
In the United States House of Representatives: H.R.3282
In the United States Senate: S. 2320

To expand Medicare coverage of medications needed to reduce the likelihood of organ rejection among transplant recipients.

Kidney Transplant Recipients- Section 226A(b)(2) of the Social Security Act (42 U.S.C. 426-1(b)(2)) is amended by inserting ‘(except for coverage of immunosuppressive drugs under section 1861(s)(2)(J))’ after ‘shall end’.

Background Information:
As we know, organ transplant recipients must take immunosuppressive drugs daily for the lifetime of their transplant to reduce the likelihood of organ rejection. For all intents and purposes, taking immunosuppressive drugs daily is a matter of life and death with respect to the transplanted graft.

The Facts:
The Medicare ESRD (End Stage Renal Disease) program pays for dialysis and transplantation for over 350,000 kidney disease patients.

Dialysis costs the program over $67,000 per-patient per year and a renal transplant costs an average of $100,000 per recipient. Thousands of patients receive a Medicare covered kidney transplant each year. They are eligible for Medicare benefits for the first 36 months following their transplant, including the coverage of their immunosuppressive medications. After that 36 month period, recipients who are aged 65 or older or disabled will continue to receive coverage of immunosuppressive medications as covered by Medicare Part B.

However, those who do not qualify for Medicare or Medicaid no longer are able to receive Medicare coverage of their life sustaining immunosuppressive medications.

Unfortunately, many of these recipients are left without any insurance coverage for the purchase of prescribed immunosuppressive medications. There are some state assistance programs available but if one is not below the federal poverty line (and in some cases if one owns their home or has an asset even without an income above the federal poverty line limit) these recipients are not eligible for any state or pharmaceutical assistance programs whatsoever.

This has created a critical issue where the life-sustaining transplant is actually at a greater risk of rejection. If there is rejection, the recipient will subsequently undergo Medicare covered dialysis or be put on a waiting list for another Medicare covered renal transplant. If you think this sounds odd, you are correct because the fact is that the annual cost of immunosuppressive medications (although expensive) is a very small percentage of the cost of Medicare covered dialysis or the cost of another renal transplant.

Extending immunosuppressive coverage beyond the 36 month ESRD limit would improve kidney transplant success rates and kidney recipient survival rates and enable more kidney patients with low-incomes to consider transplantation.

Let’s be clear and concise. TRIO has always supported Medicare’s coverage of immunosuppressive medications for all transplant recipients. What is being discussed in Congress right now is extending Medicare coverage of immunosuppressive drugs beyond the 36 month limit for all ESRD transplant recipients through Medicare Part B. Renal transplant recipients would pay the full Part B premium and Medicare would act as secondary payer for those recipients who have another form of health care coverage. With the exception of the coverage of immunosuppressive medications, all other health care expenses would remain subject to the current legislation with respect to the ESRD 36 month coverage limitation.

In the United States House of Representatives, The “Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patient Act of 2007-2008”- H.R.3282 has been introduced by Congressman Camp (R-MI) and Congressman Kind (D-WI).

In the Senate, S. 2320 has been introduced by Senator Richard Durbin (D-IL) and Senator Thad Cochran (R-MS).

TRIO call to action:
TRIO is providing a sample letter for you to send to your Congressional Representatives and Senators and this letter is available for viewing and download on our organization’s website www.trioweb.org. It is very important that you personalize this letter and include your personal story. We are providing facts and guidelines but it is your personal story that potentially helps the reader understand the importance you place on these legislative bills currently in committee.

Please visit www.trioweb.org for additional information as well as updates on the progress of these important bills currently in Committee.

What else can one do today?
While writing a letter is extremely important you can also telephone Capitol Hill via the congressional switchboard: (202) 224-3121. First: request to speak to your Senator and then request to speak to the Medicare legislative assistant in the office.

-- Mike Sosna
Chair, TRIO Public Policy Committee
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): ______________________________________________________________________

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Annual Dues: Member at Large . . . . . . $20.
Additional Contribution . . . . . . . $ ______.
TOTAL enclosed . . . . $ ______.

Thank You for your tax-deductible donation!

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).