The Year of 2009 Presents an Opportunity for TRIO Growth!

TRIO is moving into 2009 by developing programs to expand its current services and to promote several new chapter and community outreach programs. TRIO’s mission statement calls for us to do more for those in the transplant community. In its efforts to do so, some of the areas of expanded outreach in support of the individual and the chapters, for which TRIO is seeking funding, are shared below:

- **TRIO Speaker Library.** TRIO Chapter meetings offer an opportunity to record excellent transplant related professional guest speakers. During 2009 TRIO plans to offer Chapters the opportunity to share selected speakers. TRIO will select a minimum of four Chapter speaker events for the Speaker Library. The recordings will be duplicated and made available through TRIO’s website.

- **TRIO Virtual Library.** Other chapter guest speakers will be video taped and the sessions offered on TRIO’s website in the ‘youtube’ video format.

- **Audio Conferencing Panels.** Based on the extremely successful and lively interactive panel discussion sessions held at TRIO’s 2008 conference, TRIO will offer interactive audio conferences. A professional speakers’ panel will be convened to discuss a prominent topic. The quarterly sessions will be offered to the public through reservations. The sessions will be recorded and a CD of the session will be offered for a nominal fee.

- **Chapter Without Borders.** This virtual chapter gives focus to the Member-at-Large audience. With proper support, this group can be offered interactive organizational structure through audio conference meetings, thus promoting closer contact and developing expanded ability to accomplish TRIO’s mission in the interest of non-chapter members.

- **Developing Chapters through Contact Points.** Currently, TRIO’s ‘contact point’ program has developed 26 geographical points in 21 states (AL, CA, CO, CT, FL, IL, GA, KS, MI, MN, MO, NM, NC, NJ, NY, OH, OK, PA, SC, TX, VA). Under the guidance of TRIO national, contact persons in CA, FL, GA, KS and NM are currently working toward becoming chartered TRIO Chapters. The ABC’s of Chartering manual (with 80 pages of attachments) has been updated. Funding is needed to provide more substantive support to these volunteer leaders through audio conferencing, printed materials, and time investment from TRIO national.

- **Chapter Assistance and Promotion.** As a member-driven organization, TRIO’s chapter members are its lifeblood! In 2009, TRIO is seeking funding to provide assistance to its chapters in several areas, including:
  - website development assistance for those who currently have excellent sites and just need advice and for some chapters that do not have websites and assistance to re-vitalize those whose sites are outdated.
  - Mythical Ball project, whereby TRIO pays costs of printing and provides to chapters the ‘invitations’. This is an excellent fundraising initiative. In 2007-08, this project generated $9,871 with a percentage of the income shared with participating chapters.
  - chapter officer training
  - chapter leadership continuity (training for the future)

TRIO is also planning for several new outreach programs in 2009-2010 in the area of “Patient Needs Assessment” and in providing shared funding for an opportunity to bring members to Washington, DC, to meet with members of the Transplant Roundtable and with federal government leaders on Capitol Hill.

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**“Immunosuppressive Bill” Re-introduced**

TRIO’s liaison to the Washington Transplant Roundtable, Linda Cheatham, informs us that Senator Durbin’s bill, S. 565, has been re-introduced in the Senate. Rep. Camp has introduced H.R. 1458 in Congress. To read the bills and learn the current status, go to [www.thomas.gov](http://www.thomas.gov) (the official website listing legislative activity of the U.S. Senate and Congress).
April, Organ Donor Awareness Month, is here again. As president of TRIO I am very proud of what many of our chapters do in their communities to promote organ donor awareness. You can learn more of what TRIO chapters are doing by going to www.trioweb.org and clicking on “Community” then on “Active Chapters.”

**Long Island TRIO** has an annual Rose Garden Ceremony where hundreds of people get together at the garden and honor organ donors and their families while recipients thank them for The Gift Of Life. The chapter reports that this outdoor event is growing exponentially. Also, Long Island TRIO speakers’ bureau has given information on donation to over 9,000 students in their area.

**Ventura County/West Valley Chapter** holds an annual screen actor’s guild “Health Day” event where they promote organ donor awareness. The chapter also closely works with Donate Life Hollywood and their local OPO on many events. They also work on the Rose Parade Donate Life float each year.

**Akron-Canton Chapter** holds an annual Celebration of Life dinner and **TRIO Cleveland**, in conjunction with the Lifebanc OPO, is holding a Donate Life night at the Q with the Lake Erie Monsters to celebrate organ donation.

**TRIO Manhattan** is having their 14th annual Celebration of Life Dinner and the 14th Ecumenical Service “Remember and Rejoice” ceremony at St. Patrick’s Cathedral in April. This ceremony, honoring donors and donor families, will be attended by more than 1500 people!

**TRIO Pittsburgh** will have their 14th Annual Celebration of Life dinner in April.

**TRIO Northeast Florida** will hold a music fest at the Jacksonville Landing to promote organ, tissue and blood donations.

I think Steve Okonek, the president of our **San Francisco Bay Area** chapter summed up why we as transplant recipients should participate in Organ Donor Awareness Month in one of his **Lifebridge** chapter newsletter articles:

"In a recent chapter president’s call, a number of participants bemoaned the lack of participation despite efforts to bring in some top-notch speakers and topics. Some suggested this situation was due to the perception from many recipients that organ transplants aren’t a big deal anymore. Success rates have steadily climbed and many of us have donors who are very much alive and well. Those of us who spent months in the hospital following our transplant operations look in amazement at people who are released only a few days post surgery. Has this caused the personal impact of transplantation on an individual to decrease?

"It seems to me that regardless of how difficult one’s battle in surviving an organ transplant was, the idea of someone giving us the gift of life still permeates loud and clear. It’s the donor’s family making a decision at a time of immense grief that sticks with me the most. Perhaps one thinks about it more after spending so much time recovering. Our chapter speaker, Isabel asked us how we have changed since our transplants? I recall my wife telling me that "I hadn’t changed at all since my transplant." It hit me as one of the worst insults I’d ever heard. We’re supposed to change. Not necessarily in trivial matters such as our likes and dislikes. But, in a more fundamental way, it’s a sense of how we perceive and react to life.

"Are the changes transplant recipients ponder unique from those who successfully emerge from other health trials? My gut tells me yes, but I can’t quite put the logic into words yet.

"Donate Life Month could be an excellent time to dig deep into your psyche and figure out what the gift of life means to you in terms of how you go forward. I urge you to think of how you find purpose in life after transplant. Have you changed because of it?"

Thanks, Steve, I couldn't have said it better. Let’s all give thanks and purpose for our transplants.

--J.T. Rhodes, President, TRIO Board of Directors
TRIO Members Participate in UNOS Public Forums on Kidney Allocation

TRIO has been an interested party in the proposed kidney allocation policy revisions since The National Organ and Transplantation Act (NOTA) made it a requirement of the Organ Procurement and Transplantation Network (OPTN) to develop medical criteria for equitable organ donation. Over time, the kidney allocation process had become unbalanced. In the past, the allocation policy had balanced considerations of justice and utility in organ allocation.

During the last four years, The OPTN/UNOS Kidney Transplantation Committee has been considering many different concepts and approaches to kidney allocation that will meet the requirements of the OPTN Final Rule and the UNOS Statement of Principles and Objectives of Equitable Organ Allocation. The Kidney Transplantation Committee has invested thousands of hours in research and investigation in order to arrive at three concepts now being considered which would work together to determine a candidate Kidney Allocation Score (KAS) that will be acceptable to the entire transplant community.

These three concepts are: 1. Life Years from Transplant (LYFT), 2. Dialysis Time (DT) and 3. Donor Profile Index (DPI). In order to understand these three concepts, it is important for TRIO members to independently investigate each concept by visiting the KARS site at www.optn.org/kars.asp. TRIO promotes proactive action by our members, and it is up to all members to investigate the pros and cons of this vital concept being considered.

In February, 2007, at the first public forum meeting on changes in the National Kidney Allocation Concepts held in Dallas, Texas, TRIO was represented by Glenda Rosenbloom, Pat Beeman, John Harwood and Ron Taubman. As usual, all TRIO members paid their own travel expenses to attend this important meeting.

As TRIO maintains a tremendous interest in the proposed changes, I traveled to the Public Forum meeting, at my own expense, and am pleased to report the results of the meeting to the TRIO membership.

The meeting was moderated by Robert Higgins, MD, President of UNOS, who did an excellent job of keeping the subject matter on track and moderating questions from the audience. The first part the day's forum was utilized to explain the final preliminary KARS report to the attendees. Due to lack of article space, I can not detail the pros and cons of the KARS presentation. It is up to each TRIO member to research this data in order to be able to express an educated and informed opinion as to their individual position on this concept which will ultimately affect all transplant recipients.

I do not believe that there are any basic differences in understanding, by TRIO, of the concepts of LYFT as proposed by the Kidney Transplantation Committee and following the OPTN Final Rules as to obtaining the greatest success and longevity of each and every organ transplanted. However, the final format submitted for public comment by the Kidney Transplantation Committee had many concepts that still need to be removed and revised. This Committee needs to make the proposed changes more acceptable to the older transplant community and to the longterm Type 1 Diabetics on dialysis.

At the open public forum, comments were made to the attendees by recipient members of the National Kidney Foundation, The Renal Support Network, AAKP, TRIO and individual recipients and candidates who supported the concept that the KARS report, in it present state, still requires revisions. At my urging, The American Diabetic Association Chairman of the Board of Director's submitted a position paper to the committee for the public forum in which they expressed concerns as to the fairness of the anticipated revisions.

The Kidney Transplantation Committee was to meet the following day to discuss the public comments received at the January 26, 2009, forum as well as the public comments that they received from their September, 2008, national request for public comment. The Kidney Transplantation Committee previously stated that there is not a set timetable for policy development and the committee may revise, add or remove concepts as it continues to develop a policy proposal.

It is up to TRIO members to keep updated as to this committee’s progress on the KARS Report and continue to supply comments and suggestions to the committee via kidneypolicy@unos.org. Currently, the concepts detailed in the KARS Report are under review by the Department of Human Health Services (HHS) Office of Civil Rights (OCR) to determine if the concepts are consistent with applicable federal law including the Age Discrimination Act.

– Report Submitted by Ron Taubman, President, TRIO Ventura County/West Valley Chapter
TRIO Is Deeply Saddened by the Passing of Board Member Steven Levitin

The TRIO Board of Directors mourns the death of its longtime friend and fellow board member, Steven Levitin. Steven, who had a heart transplant on December 31, 1999, made the most of his second chance of life for the next nine plus years, but passed away from an infection in January as he waited for a second heart. Devoted husband to Kathleen, and father to daughters Rachel and Hilary, Steven also gave a lot of time to his passion – collecting Oziana (as in Wizard of Oz) artifacts. He once brought a bound catalog of his collection to a Board meeting and when the two of us were sharing time before dinner, he described in detail the colorful illustrations, pointing out what made the drawings in his collection so special.

An accomplished advertising and public relations executive, Steven was most recently employed at Riverside Graphics, in Chicago, where he helped get TRIO a special price for printing the *Lifelines* newsletter and other publications. Steven also gave a lot of time to the promotion of organ donation, speaking at what would have been his donor’s high school graduation, among other places. He enjoyed participating in the U.S. Transplant Games, where he won numerous medals in golf for Team Illinois. He also served as TRIO’s liaison to several transplant groups.

Steven served on the TRIO Board of Directors for the past eight years, most recently chairing the Nominating Committee, but also serving on the Fundraising and Development Committee and on the Communications Committee.

Although his health sometimes prevented him from attending TRIO Board meetings and events, Steven was nonetheless a very vocal and devoted member of the TRIO Board.

He is sorely missed by all of us who knew him.

-- Elizabeth Rubin, Secretary
TRIO Board of Directors

TRIO Forms Bulletin Board Alliance with Transplant Buddies to Enhance Web Resources

TRIO announces a newly formed partnership with Transplantbuddies to provide additional bulletin board capacity. TRIO members can go to our bulletin board link from TRIO’s home page (www.trioweb.org), where they will have the option to still use the existing TRIO bulletin board or link and post on Transplantbuddies. TRIO encourages all members to take advantage of this expanded opportunity to ask and respond to questions about transplantation.

TRIOweb.org opens New Section to Report and Highlight Chapter Events

Throughout the year, many TRIO chapters hold special events to highlight and promote organ donor awareness. To better recognize these chapter activities and to share information about the hard work of chapters, TRIO has opened a new section on its website homepage: TRIO Chapter Event News.

Chapters are urged to submit reports of their recent events to TRIO webmaster Jim Gleason (gleasonjim@aol.com) or send to TRIO Managing Services Director (sleach@trioweb.org).

TRIO’s 2009 Scholarship Application Deadline Is June 30

TRIO members are urged to apply for TRIO scholarships and to encourage their family members (children and close relatives) to apply for the deadline of June 30, 2009.

The full application can be acquired by downloading a .pdf from TRIO’s website: www.trioweb.org/TRIO2009Scholarshipapp010609.pdf, or by emailing info@trioweb.org.

Board of Director Meetings Scheduled

TRIO’s next Board of Directors’ meeting will be held by teleconference on Saturday, April 25, at 1 p.m. If you would like to attend, please contact Sylvia Leach at sleach@trioweb.org. To continue to curb costs, the summer meeting (usually held in July) will also be via teleconference.

101,201 ARE WAITING on the list for a Transplant!

--www.UNOS.org (March 23, 2009)
TRIO Japan Leader Quoted in Report on First 10 Years of Organ Transplantation

Since Japan’s first organ transplant from a brain-dead donor, under the nation’s Organ Transplant Law, was conducted on February 28, 1999, the Associated Press reports on Daily Yomiuri Online, that 81 organs have been recovered from brain-dead donors to help patients in need. It is reported that 65 of those patients received heart transplants. Five of those patients were less than 20 years of age.

The report further states: “However, a huge number of patients are still waiting in line for organs they need, with infants and children finding it especially difficult to receive organ donations.” In Japan, the law bans children under 15 years of age from donating organs.

The report states that “under such circumstances, Japanese patients continually travel abroad to receive organ transplants.”

In May of 2008, the Montreal based Transplantation Society endorsed the Declaration of Istanbul on Organ Trafficking and Transplant Tourism, which in principle bans the receipt of organ transplants outside a patients’ home country. The report goes on to say that “...response, the World Health Organization (WHO) plans to urge its member states to take measures to stop such a practice” by incorporating a clause in its guideline requesting member states to complete the entire organ transplant process in their own countries.

Donate Life Hollywood Makes a Difference in Transplant Media Portrayal

On a recent program of the TV series “ER” the subject of organ donation was dealt with in a more sensitive manner than in previous times and on some other series. Tenaya Wallace, of Donate Life Hollywood, reported that the writer of the episode, John Wells, worked extensively with Donate Life Hollywood on the scene.

According to Tenaya, Mr. Wells’ “consultation with OneLegacy’s LuCyndi Ramirez, who has become an expert in working with writers, led to this accurate and inspiring scene.” Tenaya went on the say that Donate Life Hollywood will honor John Wells and the entire writing staff of “ER” at the Donate Life Hollywood Film Festival.

The Donate Life Hollywood Film Festival will be held in Los Angeles on June 12-13. Tenaya explained that the one-day film festival and evening awards ceremony is “an opportunity to celebrate the entertainment industry’s accurate and in}

spiring organ and tissue donation storylines while showcasing real-life dramatic and entertaining stories of donation and transplantation. It also provides an avenue to build stronger relationships with and provide resources to writers, producers, network executives and others in the entertainment industry.”

You can become involved in this event by entering your organization’s best educational videos and recent documentaries on organ, eye and tissue donation. Tenaya also wants to hear from you if you have contacts in the entertainment industry who could be invited and benefit from the film festival.

To learn more about the film festival or to receive the “Call for Submissions,” contact Tenaya Wallace, Director, Donate Life Hollywood by email (twallace@onelegacy.org) or by phone (213-229-5659).
Recognizing TRIO’s First Chapter: TRIO Pittsburgh

TRIO began in 1983 when a small group of individuals, with the financial backing and guidance of Presbyterian-University Hospital of Pittsburgh, established the organization to help recipients and their families deal with the many problems they face. Out of the vision and leadership of Brian Reams, heart transplant recipient at the University of Pittsburgh Medical Center, TRIO was originally formed and designed as a local effort to serve recipients and their families in the Pittsburgh area.

In 1986, the Junior League of Pittsburgh and the transplant center at the University of Pittsburgh spearheaded a task force that determined TRIO could best serve more people through an independent, parent organization with local chapters worldwide. In 1987, TRIO was incorporated as a not-for-profit organization and the original group of members became the Pittsburgh Chapter, the founding chapter of TRIO.

In the more than 20 years since developing into the first TRIO chapter, the leadership and members of the TRIO Pittsburgh Chapter have continuously functioned and grown as an extremely effective and active force in the field of transplant awareness and support.

The chapter holds monthly support group and general meetings, provides local programs for donor education and awareness, holds an annual picnic and a holiday party. Other activities include celebrating Organ and Tissue Donor Awareness Week, a Recipient Parade through the hospital to visit hospital staff and patients and a Celebration of Life Memorial Service.

This year, the TRIO Pittsburgh Chapter will be hosting its 14th Annual Celebration of Life Dinner on April 20. The speaker for the event, to be held at the Pittsburgh Athletic Association, will be Ngoc Thai, MD, Chief of Abdominal Transplant at Allegheny General Hospital of Pittsburgh.

To learn more about the TRIO Pittsburgh Chapter, visit their website (www.trio-pittsburgh.org) or contact Chapter President Richard Koper at rjkoper@verizon.net.

University of Iowa Study Seeks Liver Transplant Patients Diagnosed with Age-Related Macular Degeneration (AMD).

Investigators at the University of Iowa are conducting studies to assess patients who have previously received a liver transplant and have clinically documented age-related macular degeneration (AMD). If you have both of these conditions (liver transplant and AMD) and you are interested in learning more about how you might be able to participate in this research study, please contact Dr. Greg Hageman or his assistant Sheri McCormick by telephone (319-384-9722), email (sheri-mccormick@uiowa.edu) or postal mail addressed to Dr. Gregory Hageman, University of Iowa Research Park, 2660 Crosspark Road, Coralville, IA 52241. If you have had a liver transplant and have had a liver transplant and have undiagnosed eye disease or vision loss but are not sure if you have AMD, please contact the above if you are interested in participating in the study.

According to published information, “Dr. Hageman has worked on the relationship between complement factor H (CFH) and age-related macular degeneration (AMD) for several years. He discovered that certain genotypes for CFH protected against AMD and other increased risk for AMD. He also helped develop the production of the protein made by the protective CFH gene with the thought that this may help treat or prevent AMD in those with the risk CFH gene. Dr. Hageman approached Dr. Collins in the transplant department to help design a study to test his theory in liver transplant patients. Because CFH is normally made in the liver, liver transplants potentially change CFH genotype. Together they are looking at liver transplant patients who have AMD to look for potential CFH genotype change after liver transplant and see how changing the CFH gene has affected the course of AMD.”

**Thomas E. Collins, MD,** is Clinical Assistant Professor of Surgery and Surgical Director of Liver Transplant, Division of Transplant & Hepatobiliary Surgery, Department of Surgery, University of Iowa Hospitals & Clinics

**Gregory S. Hageman, PhD,** Specialty: Ophthalmic cellular and molecular biology, Iowa Entrepreneurial Endowed Professor, Professor of Ophthalmology & Visual Sciences, University of Iowa.

NOTE: TRIO does not agree with, disagree with, nor participate in this study in any way. By publication of this information, TRIO is not recommending participation. Information is for evaluation by each individual. The decision to participate in any study is at the discretion of the individual.
The Aging Athlete

The word *aging*, as used here, refers to the process of getting older and is aimed at the athlete who is still competing past his or her prime. As we age, we lose muscle mass, our cardiovascular system declines, and the amount of oxygen our muscles can extract from our blood decreases. Thus, our performance declines every year.

Our minds, however, are not always in phase with our bodies. Indeed, we can have a young mind that says we can compete at the level of what we did 3 years ago if we train smarter and harder. Wrong! That’s not going to happen. I’ve unsuccessfully tried to do this for years and finally accept this fact. The older we get, the more we need to change our training methods.

One major change is the increase in time it takes for your body to recover from a stressful workout. The typical “one” day will increase to two or three or even more days. You will need to do easier workouts on these days. Your mind and body must be in harmony. On some days I find myself struggling and stumbling around the track. I’ve learned to stop and go home. Something is amiss and you should try to find out what and why. It is likely that you need more rest. You should feel strong during your workout (although some will be uncomfortable when training for a competition) and you should feel good after your workout. Learn to listen to your body.

Do your workout early in the morning, preferably before 10:00 a.m., when it is cooler. Eat a light breakfast—cereal, fruit, and coffee. Do not eat any fat for breakfast.

You should eat as soon as possible after a workout. Eat a high glycemic food (one that gets into your bloodstream quickly, such as Cheerios, waffles, baked potato) to replenish your muscles. Watermelon works great for me.

Your workouts need to be more frequent, more intense, and shorter. Consider 15- to 20- minute workout sessions. Long workouts can lead to injuries or an overload on your system.

Take notes as you train to monitor your progress. You should see improvement with time although there may be plateaus. If you reach a point where your performance is decreasing—stop! You have a problem that you must analyze. Consider longer rest periods and ease up on the intensity.

Establish a benchmark on which to judge yourself, such as a particular bicycle route or a 100M dash. Compare your performance to previous yearly records to see if they are in order.

Do some strength training for your core and legs. Core strength will increase your posture and performance. All motion starts with the core. Strength training will increase bone strength and promote overall good health.

Keep active but learn to treat your body gently as you age. You will enjoy the benefits.
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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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!

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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