TRIO Chapters Plan Special Events in April to Promote Organ Donation

By Presidential Proclamation, April is designated “Donate Life Month.” (See details at www.organdonor.gov)

During April, many TRIO Chapters report that they are holding special events to bring organ donation awareness to their communities.

The TRIO Akron-Canton Chapter will hold a seminar, “Before, During and After Transplant,” on Saturday, April 26 at North Canton Medical Education Building from 9 a.m. to 1 p.m. Speakers include Tom Behra, Chapter President – Heart Transplant, a Donor Family Member, a representative from LifeBanc, Dr. Marie Budev, Transplant Doctor, and Dr. Abeel Mangi, Transplant Surgeon.

TRIO Long Island Chapter is holding several activities to highlight Donate Life Month. Several chapter members will assist with and participate in Donate Life Walk at Stony Brook University on Wednesday, April 23, beginning at 12:50 p.m. The chapter coordinates Gift of Life Celebrations at the North Shore-LIJ Health Systems at Southside Hospital (Bayshore), Huntington Hospital, Harborfield High School, Staten Island University Hospital, LIF Medical Center, North Shore University Hospital, Franklin Hospital (Valley Stream), and Forest Hills Hospital. (See www.trio-Manhattan.org for details.)

The TRIO Manhattan Chapter will once again host its thirteenth annual “Remember and Rejoice” Ceremony at St. Patrick’s Cathedral in New York City. This year the celebration will be on April 5, from 2:00-3:30 p.m. The Ecumenical Service remembers donors and their families who so generously have given the “Gift of Life” and rejoices with recipients who have received this special “Gift.”

On Tuesday, April 8, Chapter members will participate in “Legislative Day” by traveling to the state capital in Albany to meet with state legislators to discuss ways to help increase organ, eye and tissue donation awareness. The widely publicized event is sponsored by the New York Organ Donor Network.

The Chapter’s Celebration of Life Dinner will be held on Tuesday, April 15, 6:00 – 9:00 p.m. (See www.trio-manhattan.org, for latest information.)

Nation’s Capital Area Chapter (DC, MD, VA) representatives will attend the Donor Recognition Ceremony, sponsored by the Washington Regional Transplant Consortium. The ceremony will be held at 2:30 p.m., on Sunday, April 6, at the National Presbyterian Church in Washington, DC. Usually, at the annual event, several hundred families and living donors and recipients attend, speak, celebrate and light candles in remembrance of organ donors. (www.trio-ncac.org)

The TRIO Northeast Florida Chapter organizes and, along with other area organizations, is active in promoting donor awareness through its annual Donate Life Day. This year the Chapter’s Donate Life Day will be held on Sunday, April 20, beginning at 10:00 a.m., at the St. John’s Town Center. The event includes numerous donor and transplant-related organizations, such as (… continued on page 6)

TRIO Representatives Meet with Delegation from the Netherlands

(See Article on page 5)
April is a busy time for TRIO chapters. National Organ and Tissue Donation month gives TRIO chapters a chance to promote donation and give thanks to our donors. Read the article on what various TRIO chapters are doing in the month of April. If your chapter isn’t mentioned maybe you can come up with an idea of an event for your area. It is amazing what different chapters do and how much publicity they get for Organ and Tissue donation. Thanks to all the members who volunteer for these events and help TRIO achieve its mission statement.

Sometimes I wonder if anyone reads my column or the articles in Lifelines. Again we are asking for members to volunteer to serve on National committees. We need member input in these committees to do what our membership wants TRIO to do. Without member input all your board can do is guess what the membership wants. And as hard as it is to believe, sometimes we make mistakes and don’t do what our membership thinks we should do. So, if the board of directors makes a decision you don’t like who is to blame if we don’t have your opinions? The only cost to serve on committees is time. All the committee business is done by telephone conference calls and TRIO National pays for the call. When the meeting date and time is set all you need to do is prepare and call a free 800 number to join the conference call. Read the article on TRIO committees and then call the chairman or me to volunteer. There are openings on several committees for chairpersons. Just think: as a chairperson you help set the course for TRIO for that committee. In order for TRIO to grow we need help, but most of all we need to know what our members want from TRIO. Please take some time to volunteer your talents for TRIO. We need them.

In this issue, we tell you how simple it is to use the bulletin board on www.trioweb.org. Please ask questions, share your opinions on transplant issues, answer members’ questions or just praise or give helpful hints for improving TRIO. This bulletin board can be a valuable benefit of being a TRIO member if we all use it and post our ideas and comments there.

April 16th is National Transplant Nurses Day. This gives you and your chapter a chance to thank that special transplant nurse or coordinator who went out of their way to help you with your transplant. Hopefully, your chapter will do something to thank these nurses. If your chapter doesn’t have anything planned then maybe this is another opportunity to use your talents.

At our May 3 board meeting at Mount Sinai Hospital in Manhattan, we will introduce two new board members. I am very impressed with the qualifications, dedication and enthusiasm of these new board members. Thank you Julie Fudoli of CVS PharmaCare and TRIO Vice President Ron Taubman for bringing these outstanding future board members to TRIO. If you know of someone who would make a great board member of TRIO just let anyone on the nominating committee know. Thanks to TRIO Manhattan for helping coordinate this meeting.

If you are planning to attend the Transplant Games in Pittsburgh in July, you might consider volunteering to work at TRIO’s booth. It is a great way to meet other recipients and donor families and a huge fringe benefit is that you can trade a lot of pins as the teams register. To volunteer, just drop me an email at jtrhodescpa@msn.com.

President’s Message
YOU ARE NEEDED: JOIN a TRIO COMMITTEE!

JOIN a TRIO Committee
to help TRIO make your voice heard!

Below is a short overview of TRIO’s Committees and contact information for the Chairs. To review the full Bylaws committee structure, go to www.trioweb.org and click on “About TRIO” and then on “Committees.”

To express your interest in participating in any committee activity, contact the below listed committee chair directly by email.

Budget & Finance: This committee works with the Development Committee to set adequate funding goals and prepares the TRIO annual budget. Members should understand the budgeting process and have some experience with formulating budgets. Knowledge of finance within the non-profit arena is helpful.

Chair: (Position Open)
Members: Linda Cheatham, Sylvia Leach, JT Rhodes, Elizabeth Rubin.

Chapter/Membership Development: Chapter Council President Alex Boyer (email: patricia.ann9@verizon.net) heads the TRIO effort to maintain chapter contact and develop new chapters.

The Scholarship Subcommittee, headed by Board Member and Past-President Elizabeth Rubin (email: pincusemr@steuber.com), functions under the Chapter/Membership Development Committee. Other subcommittees are Donor Family and Caregiver.

Other committee members are: Larraine DePasquale, Sylvia Leach, Virginia McLean.

Communications: Board Member Steven Levitin (email: stevenlevitin@sbcglobal.net) has recently accepted the position of Chair of the Communication Committee. The committee is responsible for overseeing TRIO’s publications and assists in managing communications with the transplant community and the public in general.

Communication Subcommittees are:
Lifelines newsletter: Lifelines continues to be published quarterly under the guidance of Managing Services Director Sylvia Leach.

TRIO’s newsletter is mailed to all paid members as well as to transplant centers and organ procurement organizations, along with other interested parties.

Website: Subcommittee member Harriet Weiss provides consistent updates from her ongoing review of our links. This cycle of reviewing and testing all 700+ links is being accomplished approximately every quarter with significantly fewer updates each time around.

Webmaster Jim Gleason continually updates TRIO’s website. TRIO’s Bulletin Board invites everyone to participate (see article on page X). The Opinion Papers section of www.trioweb.org offers an opportunity for members to present their thoughts on pertinent topics.

Liaisons: TRIO continues to maintain close relationships with many transplant related organizations. Go to www.trioweb.org and look at the “Resources” section to review a list of “Liaisons to Other Organizations.” Contact the individual liaison directly if you have issues or something to share involving those organizations.

Media: Board members Susan Morgan and Ron Taubman are actively following and responding to media portrayals on television and in newspapers.

Development: The Development Committee, under the guidance of Chair Ron Taubman (email: taubmanappr@dslextreme.com), functions as the fundraising arm of TRIO.

In 2007, the Committee was responsible for the successful management of the Mythical Ball and is currently working to solicit funding for the joint ITNS/TRIO Conference in St. Louis, September 25-27, 2008.

Non-profit fundraising knowledge is helpful.

Nominating: The Nominating Committee, under the direction of Chair Steven Levitin (email: stevenlevitin@sbcglobal.net) continues to actively pursue candidates for appointment to TRIO’s Board of Directors. Two candidates will be presented to the Board for vote at the May 3 Board of Directors Meeting in New York.

The committee seeks input from those who are familiar with non-profit board management and the paths to attaining Board members who

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Join a TRIO Committee!
(Continued from page 3)

bring experience and will make a significant im-
pact on TRIO’s growth efforts.
Nominating Committee members are: Elizabeth
Rubin, Ron Taubman and Sylvia Leach.

Public Policy: Under the leadership of Mike
Sosna, President of the TRIO Long Island Chap-
ter, this committee’s formal function is to keep
the Board of Directors informed of legislation and
policy pending before the US and state legisla-
tures and regulatory bodies and to develop pro-
posed responses or plans of action for Board
consideration. Through shared emails, Mike
continuously seeks input on current issues from
the Board, Chapters and various interest parties.
One of the best ways to be involved in public
policy issues is to share your thoughts on TRIO’s
bulletin board and to submit an “Opinion Paper”
for publication in a special section of TRIO’s
website. To become actively involved in a very
important part of TRIO’s work, contact Mike
(mike@sosproductions.com) and let him know
you are interested in serving on the committee.

Strategic Planning: Under the Chairmanship of
TRIO Vice President Ron Taubman, this com-
mittee coordinates TRIO’s strategic planning
process by developing TRIO’s goals and objec-
tives. Share your ideas directly with Ron
(taubmanappr@dslextreme.com). Join Ron and
committee member Susan Morgan in this very
important TRIO committee.

TRIO Board of Directors to Meet in
New York City on May 3, 2008

Trio’s second Board meeting of 2008 will be
held in Manhattan on May 3, 2008. With the
assistance of the TRIO Manhattan Chapter, a
meeting room has been arranged at Mt. Sinai
Hospital. Watch for meeting room information
and an agenda to be published soon on TRIO’s
website (www.trioweb.org).

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

98,508
waiting list candidates
as of March 23, 2008!
(United Network for Organ Sharing – www.unos.org)

Mark your calendar:
TRIO and the International Trans-
plant Nurses Society (ITNS) to
Hold Joint Conference in St. Louis,
MO, September 25-27, 2008

Planning for the joint ITNS/TRIO Conference in
St. Louis on September 25-27, 2008, is well
underway! TRIO Vice President, Ron Taubman,
who is managing the conference for TRIO, re-
ports that several nationally acclaimed speakers
have been invited to address luncheon attendees
on Thursday, Friday and Saturday about current
issues and topics related to transplant. In
addition, TRIO is scheduling two days of concur-
rent sessions to deal with pertinent topics at a
more personal, individual level. The smaller
‘break-out’ sessions will provide an opportunity
for attendees to share concerns and questions at
a one-on-one level with prominent panel
members and session leaders.

Ron and TRIO Past President Elizabeth Rubin
are currently auditing TRIO Chapter Presidents
and their families.

Please share your thoughts for suitable topics
with Ron (taubmanappr@dslextreme.com) and
Elizabeth (pincusemr@steuber.com).

You can also express your ideas and thoughts
for pertinent conference content and topics by
participating in TRIO’s online Bulletin Board. Go
to www.trioweb.org and click on “Bulletin Board”
and share your ideas! See the article on page 6
of this issue to learn how easy it is to join in--
express your opinion and have your voice heard.
Netherlands Delegation Visits TRIO in Philadelphia and Washington, DC

On February 25, 26 and 27, a delegation of transplant professionals from the Netherlands visited the United States to study the organ donation and transplantation systems in this country. This group had decided to travel to the United States, France, Spain and Belgium to gather information for a Dutch national Organ Donation Masterplan.

In addition to the the Ministry of Health, Welfare and Sport, the following organizations were represented in the delegation: the NTS (Dutch Transplantation Foundation), the NIGZ-Donorvoorlichting (Netherlands Institute for Health Promotion and Disease Prevention); as well as representatives from among doctors, patients and hospital personnel.

The focus of this trip was to learn more about how the subject of transplantation and organ donation is handled in the United States. Specifically, the group sought to learn about the legal system for organ donation and how moral and ethical views affect the motivation to donate; communication/publicity and education about organ donation and how it prepares potential donors and their next of kin to make the decision about donating organs and/or tissues; practice in hospitals of training doctors, nurses and transplantation coordinators to introduce best practices and quality assurance in the procurement and transplantation of available organs and tissues; and ways to minimize the barriers for living donation between family, friends and others.

During their visit to the United States, the Dutch delegation traveled to Washington DC, where they visited the Fairfax Hospital Transplant Center, and Philadelphia, where they visited the Hospital of the University of Pennsylvania and Children’s Hospital of Philadelphia. In both cities, they spoke with medical and ethical specialists as well as representatives of our government, and national and local transplant organizations about various aspects of organ donation and transplantation.

TRIO was represented by members Linda Cheatham from the Nation’s Capital Area Chapter, and Jim Gleason from the TRIO Philadelphia Chapter. According to Mike, Mr. Thewissen was “very impressed with TRIO as what he considers an effective ‘patient organization.”

During their trip in and around Washington, the Dutch delegation met with Dr. James Burdick from HHS/HRSA, Division of Transplantation, as well as with representatives from the local OPO – Washington Regional Transplant Community (WRTC). Linda Cheatham, who attended the meeting with the WRTC, reported that after the OPO had finished its presentation of how it works and how they approach families and allocate organs, etc., one of the gentlemen from the Dutch delegation (a kidney recipient) asked where patients were involved, as no mention had been made of them yet, and Linda responded by talking about TRIO’s and WRTC’s great working relationship. In particular, Linda described the Speakers’ Bureau, Candidates’ Forum, and patients’ attendance and service at the Cherry Blossom and other parades, and at various health fairs. She then spoke briefly about TRIO as an organization, what is done on the chapter level, and about TRIO’s four goals – Donor Awareness, Support, Education and Advocacy. In addition to Linda, there were two other patient representatives present from Washington, DC, one of whom was Tony Benedi, who, in addition to being a WRTC Board member and liver and kidney recipient, previously served as TRIO Board President in the 1990s. After the meeting at WRTC, the Dutch delegation spent some time visiting UNOS, as well as taking a tour of Fairfax Hospital, before going to Philadelphia.

Jim Gleason attended the meeting at the local OPO in Philadelphia, Gift of Life Donor Program (GOLD). In addition to representing the OPO, Jim had prepared a Power Point presentation which highlighted patient and volunteer activities with the OPO, and included details about ways he and other TRIO members participate in various donor awareness, support and education activities in and beyond Philadelphia. Jim reported that, despite schedule limitations, he was given a full 30 minutes to work with the group and felt that they were very enthusiastic about all they heard about the patient’s role in promoting organ donation,

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How to Join TRIO’s Bulletin Board

It’s really not complicated . . . just go to www.trioweb.org, click on Bulletin Board and Sign In. As with any other participation on the web, you will be asked to enter the usual ‘register’ items, such as user name, password, email address, etc. Don’t be frustrated; the system prompts you if you enter something it can not accept . . . it speaks nicely and clearly to you.

You can read other comments, but not post a comment until after you sign in. That’s all there is to it: sign in just one time and you’re on!

Membership in all the Bulletin Board communities is FREE! You can use these forums to discuss any items of interest within the community of transplant recipients, donor families, medical professionals and those on the waiting list for organ transplants.

Let your voice be heard (or even better: let your voice be read) . . . Join TRIO’s Bulletin Board community.

Dutch Visit to the United States

(continued from Page 5)

supporting fellow patients, and teaching the general public.

Everyone involved felt that the visit by the Dutch transplant delegation was extremely successful. Both the Dutch visitors and the United States hosts were able to share their experiences and learn from each other about ways to improve the organ donation and transplantation systems of their countries.

Chapter Special Events in April

(Continued from page 1)

LifeQuest Organ Recovery Services, the Southeast Tissue Alliance, St. Andrews Lighthouse, Florida Tissue Services, the Florida-Georgia Blood Alliance. (See website: www.trionefl.org)

Steven Okonek, President of the TRIO San Francisco Bay Area Chapter, wrote in a past issue of the chapter’s newsletter, LifeBridge:

“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 reread Isabel’s essay, “Finding Purpose” and think of how you find purpose in life after transplant. Have you changed because of it? I’d love to hear your perspective.” (www.bayareatrio.org)

Transplant Games to be Held in July of 2008 in Pittsburgh

Have you registered yet for the National Kidney Foundation U.S. Transplant Games? Isn’t it time for you and your family to either participate as an athlete or spectator? The countdown to the games is moving quickly and teams are getting ready to make the journey to Pittsburg, PA. You can’t escape them! The U.S. Transplant Games are coming again this July 11th to 16th 2008. Don’t miss them!

If you have never been to ‘the games,’ odds are there is a team already being formed in your area. Go to: www.kidney.org/news/tgames/usgames/joinTeam.cfm This link will take you directly to the Team Manager and their contact information. It’s not too late to join a team; as either a spectator, an athlete or, of course, as a donor family as well.

Did you know that each year, the number of donor families attending the events and cheering on all the athletes increases? Each year every donor family that comes decides to come back and encourages all new donor families in their area to attend.

Just ask Jan and Mark Jenca from Lombard, IL, who attended their first games in 2006. “After losing our son Markie at age 15 ½ in December 1999, we finally felt it was time to stop mourning his loss and to start celebrating his life and what he did for his recipient in terms of saving his life and giving back. It was something he had spoken to us about when taking driver’s education and as we look back, we’re so glad that we respected his wishes. Having had the opportunity to watch his recipient compete and win a gold medal was such a thrill. But even if his recipient hadn’t been there, it was just great meeting other families who had been through what we had gone through. It was so comforting. We came away saying that we will never miss a future Transplant Games, no matter where they are.”

This year the Jencas are bringing five other family members, plus they are talking it up in the Chicago area and hoping to get an even larger turnout of donor families this summer.

For those of you who haven’t attended, you should consider attending this year.

TRIO Scholarship Application Deadline is June 30, 2008. Go to www.trioweb.org, click on “Communications” then on “TRIO Scholarships” to print the criteria and application. Don’t miss this opportunity to ask TRIO to financially assist with your education!
TRIO Supports Request for Organ Donation Act Funding in 2009

In a letter, dated February 29, 2008, 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 letter requests $2 million be secured in the final FY 09 L/HHS bill to fund the ODA. As opposed to past years, this year the letter asks that the funding be allocated specifically for organ coordinators since DoT is already funding reimbursement of travel and subsistence expenses through a reallocation of their existing budget. Similar letters will go to both House and Senate Appropriations Chairman and Ranking Members.

The text of the letter, sent over the signature of the American Society of Transplant Surgeons, can be read in full at www.trioweb.org.

Taking Care of “Self” – Skin Cancer is an Important Health Issue!

I’d like to chat with you just a bit about cancer and the importance of sunscreen.

I have lung cancer that was caused by my “macho man” attitude towards sunscreen! And I had all of the warnings. In the first place, I had a skin cancer removed from my head late in 2005. It was called Squamous Cell cancer. Then early last year, the same type cancer was found on my left ear and I lost half of that ear. I used to say, “I’m all ears”, but what do I say now? And then in December of last year, the same type of cancer was found in my left lymph node and both of my lungs—all because I was too stubborn to put on a little protective lotion!

And if any of you say: “So what, they can cure that with Chemo”--well, maybe they can and maybe not. The one thing I do know is that the side effects of Chemo are very, very unpleasant, to say the least. I have now had some 12 infusions. Each infusion takes about 4 hours and costs a little over 5 grand. I have also lost all of my hair, but the good thing about that is that I no longer need to shave.

And then there is the steroid I take to keep my transplanted heart going, added to the steroid I get during my Chemo treatment and what do I get? An appetite beyond belief!

What little muscles I had left are now all but gone, I am loosing all of my finger nails and toe nails, and all of those same fingers and toes are totally numb. I can no longer drive, and I need a cane and maybe even a walker to walk.

Now if you think I am complaining, think again. I have a great home, the best wife and caregiver in the world and wonderful friends like all of you. I have had a great 70 years and I look forward to many more.

The above was written some six months ago and I want to bring you up to date. At this time, my cancer is in remission, thanks to The Man upstairs and a lot of you and your prayers. However, the chemo in my system lingers on. My finger nails and toe nails are coming back, but I sure can’t say the same about my muscle strength. I am still very weak and the numbness in my fingers and toes remains. If cancer comes knocking on your door, don’t answer it. And, by the way, I’m using a comb again.

I just want you to use sunscreen...Please?!?!

—Lon Bullman, Past President, TRIO Northeast FL Chapter

Make Your Voice Heard:
Your Comments Are Due to UNOS by April 30!

The OPTN strongly encourages all interested individuals—especially transplant candidates—to express their views on policy proposals by actively participating in the public comment process.

Ten policy proposals are now being offered for public comment. These proposals highlight proposed changes by the Kidney Transplantation Committee, Pancreas Transplantation Committee, Living Donor Committee, Membership and Professional Standards Committee, Operations Committee, Executive Committee, and the Pediatric Transplantation Committee. UNOS is requesting your input on these proposals by April 30, 2008.

After the public comment period ends on April 30, 2008, the sponsoring committees will review all feedback and make necessary modifications. The OPTN/UNOS Board of Directors will review and vote on these proposals at its June 19-20, 2008 meeting.

Go to: http://www.optn.org/news/newsDetail.asp?id=1014
You can also FAX your comments to 804-782-4986 or mail them to: United Network for Organ Sharing, Attn: Public Comment, P.O. Box 2484, Richmond, VA 23218
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 ___________________________

Annual Dues: Member at Large . . . . . . . . . . . . . . . . . . . . . $20.  Make your check payable to and mail to:
Additional Contribution . . . . . . . . . . . . . . . . . . . . . . . . . . . $_____.  Transplant Recipients International Organization, Inc.
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Thank You for your tax-deductible donation!  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).