Donate Life America Launches Campaign to Register “20 Million in 2012”

Donate Life America, the national organization promoting organ, eye and tissue donation, is launching a bold new initiative to register an additional 20 million people in 2012 on their state donor registries.

“Donate Life celebrated 100 million registered donors in 2011, which means 42 percent of individuals age 18 and older are registered as organ, eye and tissue donors,” says David Fleming, President and CEO of Donate Life America. “With the majority of individuals in the United States wishing to be organ, eye and tissue donors, the biggest challenge to meeting our goal of 20 million will be getting people to take action and register today as an organ, eye and tissue donor at www.DonateLifeAmerica.org.”

“20 Million in 2012” was first introduced during Donate Life’s largest national program, the Donate Life float in the 2012 Tournament of Roses Parade®.

The year-long “20 Million in 2012” campaign will focus on registering donors on their state registries and includes four events: the Donate Life Flash Mob on March 24th, Donate Life Blue and Green Virtual Fashion Show on April 20th, Donate Life Champions in Fall 2012 and Donate Life Linking Hands for Life all year long.

TRIO members can initiate any of the 2012 events in their local communities. Contact Tenaya Wallace, “20 Million in 2012” campaign chair, at twallace@onelegacy.org for a guide on how to implement the 2012 activities.

The “20 Million in 2012” campaign will also launch Donate Life America’s “I am HOPE” story project, featuring 365 incredibly powerful stories of people personally touched by organ, eye and tissue donation. Each Donate Life State Team will have one week of 2012 to promote stories of hope from their state and disseminate them through the Facebook pages and websites of Donate Life America and its partners.

TRIO members are encouraged to join the “20 Million in 2012” campaign by becoming a Donate Life America Facebook fan to keep updated on the roll-out of all the 2012 events! To be part of this initiative, go to www.facebook.com/DonateLife. Individuals can join their state donor registry by visiting www.DonateLifeAmerica.org.

TRIO’s 25th Anniversary: Our Anniversary Year Is Here!

Your anniversary planning committee has made its recommendations and at the November Board of Directors meeting, they were approved.

The official site is Pittsburgh, PA, the birthplace of TRIO in 1987. The dates are Friday and Saturday, September 28 and 29 (with breakfast on Sunday for any who elect to stay over).

Detailed hotel information will be sent in the weeks ahead. Friday night, September 28, is the big gala dinner event with honorees, TRIO and transplant history show, plus much more.

Go to page 7 to learn more about the details, conference workshops, table exhibits for TRIO chapters, and special 25th anniversary year foil stickers for each chapter.

Start planning now!
President’s Message

“TRIO: Looking Back and Moving Forward”

That theme as chosen by the Anniversary planning committee really does set the tone for our 25th year celebration in 2012 and beyond. TRIO boasts a long tradition of dedicated and talented leaders going back a full quarter of a century of support in carrying out its vision of acting as “the voice of the transplant community” that continues even today. It is that proud heritage that serves us as we turn our eyes to the future, building off a foundation of service as we are developing plans that will both revitalize and grow TRIO as the numbers and success of transplant continues to climb. From 1987 when UNOS was first developing that small list of candidates to today’s world of a UNOS database with a constantly growing waiting list candidates numbering over 112,700, TRIO has played an important support role that is even more important with that huge surviving population of transplant recipients increasing every day. That is the goal behind our recent strategic planning meeting held in Philadelphia this past November, to position TRIO with short and long-range action plans that are realistic with measurable results to insure we accomplish the goals as set out for these coming years.

In this issue you see fruits of that work and in our monthly and quarterly communications, along with the web site resource, you will see more detail and specific initiatives that grow out of that planning as 2012 unfolds. TRIO thanks you for all you are doing as leaders and supporters all across this great country of ours. We encourage you to tune into these communications to find effective ways to continue that “attitude of gratitude” that drives the support we offer those who follow in our footsteps of successful and fulfilled living with our lifesaving gifts of transplant. Together we can support, as one example, the Donate Life America celebration of 100 million donor registrations recently achieved along with the new goal of adding 20 million more registrations in 2012 with exciting events planned to drive individual action to register new donors.

There is great power in numbers, and in service through TRIO, together we can make a difference, changing the world for recipients, candidates and families, empowering you, the individual, with the resources that thousands of TRIO members add to your efforts and gifts of service.

Be sure you are a full TRIO member, i.e., dues paid up. Check with your chapter today to confirm that you are registered as a TRIO member in our national database. If you aren’t receiving this Lifelines directly to your home address, that’s a sign we don’t know you as a TRIO member. Note: Members-at-large pay $20 dues directly to the national office and are thus already part of “One TRIO.” Be sure your 2011 dues have been submitted and at the same time, make that 2012 dues payment to your local chapter or for MaL’s mail them directly to Sylvia Leach at TRIO: 2100 M Street, NW, #170-353; Washington, DC 20037.

PS: Read about all the other exciting TRIO action-based news throughout this issue and in the e-mailed news updates between these quarterly Lifelines’ mailings. If you are not receiving that monthly TRIO E-News, send your e-mail address to INFO@trioweb.org to be added. Meanwhile, you can see the latest e-News linked under News from National at www.TRIOweb.org.

Did you know?
There are 112,809 waiting list candidates!

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

UNOS Resources
UNOS welcomes your questions, requests, comments and suggestions: 888-894-6361
(Monday-Friday, 8:30 am – 5:00 pm; Eastern Time)
Committee Progress Reports

Your committees have been hard at work these past months. Along with articles elsewhere in this issue, below are some of their progress highlights.

Nominating: A slate of candidates for 2012 Board of Director officers was presented and voted in at the November board meeting. This committee is always open to suggested candidates to serve on the national Board of Directors, so submit names for consideration to info@trioweb.org.

Strategic Planning: A full day meeting was held in Philadelphia to put together the finishing touches on work from earlier phone conference sessions, as you will see communicated in Will Oler’s article on this page. This is a very intensive and fruitful experience under Will’s skillful leadership, providing a guide for TRIO moving forward into its second 25 years.

Anniversary: Under the leadership of Pat Folk and Mary Alice King, this planning committee is defining the 25th anniversary events that will help chapters celebrate in their local areas as well as create the big conference event announced in their article for September 28-29 in Pittsburgh, the birthplace of TRIO. Be sure to read that article (beginning on page 1) and make your own plans to join us for this very exciting time of “Looking Back and Moving Forward” (the theme for the 25th Anniversary celebration).

Scholarship: After much teamwork over the past months, awardees have been selected. Be sure to read the article on page 4.

Communications: As we work towards a re-design of the TRIO portfolio of communications resources (i.e., web, Lifelines, e-News, etc.) please keep an eye open for opportunities you may come across to send potential sponsors and advertisers to help fund these projects and the overall operational budget.

Chapter Development: Have you seen the growing number of ‘contact points’ on the website? Each of these support groups has the potential of growing into future TRIO chapters with Sylvia’s on-going support and encouragement. This can be another year of chapter growth as these mature into solid groups.

Fundraising: Lou and James continue developing several creative ideas, such as an on-line TRIO auction.

If you see something above that raised your Interest level, why not get involved? Contact our national office and volunteer your service.

ONE TRIO Revitalization Planning

Your committee (Jim Gleason, Sylvia Leach, Susan Pincus, JT Rhodes, and Elizabeth Rubin) completed the final steps of the plan during a focused session on November 19 in Philadelphia. The committee developed specific, measurable, and attainable objectives. These are being carefully reviewed and will be communicated to you in the next update.

We now have a strategic foundation enabling us to strengthen and improve TRIO. Now is also the time for action. As we have asked before, your help is essential in achieving our collective goals. Some of you have responded to previous calls for action in this vital effort. There is plenty of opportunity for others to join us in making a difference. If you want to participate, please contact Jim Gleason at: GleasonJim@aol.com or Sylvia Leach at: sleach@trioweb.org Again, we will organize action teams to work on the final goals that will be published in the next update.

TRIO’s Virtual Chapter: Members-at-Large (MaLs) Are Getting Engaged

As a result of the “Virtual Chapter e-News” communications, several Members-at-Large have come forward to volunteer their services in support of the overall TRIO mission.

Will Oler, MaL from Virginia, now living in Florida, offered his professionals skills to chair the Strategic Planning Committee. In November, Will facilitated the day-long face-to-face session in Philadelphia. Dennis Fogarty, an MaL from Ohio, volunteered to serve on the TRIO “Office Procedures Review” project, using his skills from the corporate world to help update and add to our organizational processes. Both Dennis and existing web team member Harriet Weiss will be researching websites and identifying best practices as input to our web re-design project.

Lou Reardon from Florida and James Mateiko from Long Island (both serving first terms on TRIO’s Board of Directors) have teamed up to lead our fundraising efforts.

The overall good news is that MaLs are a growing and vital part of TRIO, currently representing about 10% of TRIO membership.

MaLs need to maintain membership with annual dues of $20 to the national office. And, don’t forget, MaLs can write to info@trioweb.org to get their DVD of any program from the Presentation Library (see listing on the TRIO website).
TRIO Announces 2011 Scholarship Awards

TRIO is pleased to announce the award of six $1,000 scholarships in 2011. TRIO scholarships are awarded on a national basis, under a set of criteria applied equally to all applicants. The number of scholarships awarded is based on donations from TRIO chapters, Board of Directors members and individuals.

The Scholarship Committee, under the leadership of Elizabeth Rubin (Chair), is composed of Steve Binder (Northeast Florida Chapter), Dorene Kray (Greater Cleveland Chapter), Susan Pincus (Philadelphia Chapter), and Sylvia Leach, Managing Services Director. TRIO expresses deep appreciation to these committee members for their dedication of time and thoroughness in reviewing all the applications received.

Below is a brief introduction of the 2011 scholarship recipients.

Lauren Faye Edwards. Lauren is a Senior at the University of Arizona. At three months of age, Lauren was diagnosed with Cystic Fibrosis. When she was 16 years old, she received a living donor double lung transplant at Children’s Hospital of Los Angeles: one lobe from her father and one lobe from her step-father. The scholarship awarded to Lauren was contributed by the members of the TRIO San Francisco Bay Chapter.

Lauren Ford. Lauren is a kidney recipient, studying nursing at Misericordia University in Dallas, PA. She was diagnosed with renal failure at the age of six and received a kidney from her Aunt in 2005. Lauren was awarded a scholarship donated by members of the TRIO Board of Directors.

Bethany Goralski. Bethany is the daughter of a kidney recipient and the sister of the donor. She attends Bradley University in Peoria, IL, where she is enrolled in the School of Nursing. The scholarship awarded to Bethany was contributed by the TRIO Akron-Canton Chapter in memory of Connie Armour, a nurse and kidney recipient.

Josh Goralski. Josh, the brother of Bethany Goralski, donated a kidney to his dad. Josh attends Rockhurst University in Kansas City, MO, where he is double-majoring in Non-Profit Leadership Studies and Accounting. In his statement on how transplant has affected his life, Josh said: “God gave me a second kidney for a reason – to grow it, raise it and give it. For the rest of our lives we will be father and son on a whole new level.” The scholarship awarded to Josh was made possible by donations from the TRIO National Capital Area Chapter and from Elizabeth Rubin, TRIO Board of Directors.

Joel Gorman. Joel was a kidney recipient at 14 months of age and now attends Texas Tech University in Lubbock, TX, in their Honors Program, and works part-time. Joel’s Dad was his donor. The scholarship awarded to Joel was contributed by members of the TRIO Northeast Florida Chapter in memory of Ronnie Oliff, a transplant recipient, a long-time chapter member and ardent supporter of the TRIO scholarship initiative.

Deborah Kowatch. Deborah graduated from Ohio State University. After teaching art for five years, she was diagnosed with renal failure and received a kidney-pancreas transplant in 2004. Deborah is now studying nursing at Cleveland State University. Deborah says: “The experiences of having diabetes, renal failure and a transplant will allow me to have a unique perspective in nursing.” Deborah eventually wants to become a transplant coordinator. She is very active in organ donation initiatives and was selected to ride on the Donate Life float in the 2010 Rose Bowl Parade. The scholarship awarded to Deborah was made possible by a donation from the TRIO Greater Cleveland Chapter.

The TRIO Board of Directors held its quarterly meeting by teleconference on November 19. The next Board of Directors meeting is scheduled for Saturday, February 18. For confirmation of date and details, see the announcement on TRIOWEB.org.

If you are a member of TRIO and wish to attend, contact Sylvia Leach at our national office for specific time and how to join the teleconference.
Exciting Topics Added to TRIO Transplant Presentation Library

“Presumed Consent: Could It Improve Donation in the U.S.?” and “Men Are From Mars, Women are from Venus: Even in Transplant” are the latest additions to our 30-program TRIO Transplant Library of DVDs that are available through your chapter or, if you are a member-at-large, by direct request to info@trioweb.org.

Both are exciting presentations by world-renowned transplant experts on interesting and controversial topics. Howard Nathan of the Gift of Life Donor program presents strong statistics in support of his views on the presumed consent topic. In the other new program, heart transplant cardiologist Joyce Wald (DO, FACC) of the Heart Failure and Transplant Program at the Hospital of the University of Pennsylvania talks about the special challenges faced by many women post-transplant as well as caregiver issues.

As a TRIO member you are entitled to take any of these home free for private viewing on your PC or TV. Each chapter has been invited to nominate their own local “chapter champion” to pass along news about each latest release and to funnel chapter feedback to improve this exciting program. (Maybe YOU would be interested in taking on that role?) Each chapter is invited to record their local presentations to submit for consideration to be included in this growing library. If you see something of interest at your chapter, ask if it is being recorded for that purpose.

TRIOweb.org Update and Invitation

How is the new design of the home page, with links to the categories of stories, working for YOU? With articles now date-stamped, can you find the most recent news items without going into stories or articles you’ve already read?

We continue to look for grant funding to do a professional re-design to bring this very resource-rich web presence into today’s more modern “look and feel” to make things even easier for you and our many website visitors. In preparation for that work, several members have joined the web committee to do reviews of other web sites to help develop our own ‘best practices’ website elements to guide this re-design work.

Please continue to send in your chapter stories and photos to make this resource even more TRIO member driven in its content. You can send your information to info@trioweb.org. Again: What would you add about your local activities as a resource or inspiration to others?

Did You See TRIO’s Mary Wu?

Hoping you caught TRIO’s Youth Circle double kidney transplant recipient, Mary Wu, in the recent Rose Bowl parade on TV on New Year’s Day. Surely we saw her wave to TRIO members as the Donate Life float (#42) passed by. Maybe she will share her experiences along with a float photo for our next issue. In the meanwhile, see the TRIO website for what we can find to show you the parade event. Mary’s presence on the Donate Life float was sponsored by the University Kidney Research Organization. Ron Taubman, TRIO Ventura County/West Valley Chapter, is a member of the UKRO Board of Directors.

Public Policy: Chapter Champions Needed

Another congressional session has passed without action on the immunosuppression drug legislation. However, there is good news: a growing number of legislators who now understand the benefits of that bill have come forward as co-sponsors. That should improve the possibility of future passage with much transplant organizational and individual member support. The fight will continue, but we need your help.

While a few chapters have nominated their chapter champions, many have yet to do so. These local chapter members serve as the representatives for a distribution list that goes out to them from such focused TRIO initiatives as “Public Policy.” These chapter champions are responsible for being tuned into the activities of that interest group, reporting updates and following up on proposed actions plans with their local chapter as well as feeding back chapter support or concerns in that area.

In addition to Public Policy, chapter champions are needed for 25th Anniversary Planning, the Transplant Presentation Library and the Primary Care Physician initiative. There are no committee meetings to attend, just emails to read and react upon and sharing that news with your chapter.

Are you ready to fill any of these exciting, in-the-know “chapter champion” roles? Talk to your chapter president to be nominated and your name will be forwarded to the national office to be added to the distribution list.
Diabetes: Recognizing the Symptoms

(This is the second in a series of articles about Diabetes. The first, “Are you ‘at Risk’?”, was published in the October 2011 issue and the third, “Living with Diabetes,” will be published in the spring.)

Diabetes is one of those hidden medical issues since people seldom openly share that they are a diabetic, but rather, deal with the growing epidemic in private, silently. As an involved heart recipient of many years, when it was suggested that this was an important transplant issue, I denied that since I didn’t see it in my daily interactions with the transplant community. In switching medications several years ago to offset the side-effects that were affecting my kidneys, I developed insulin-dependent type 2 (“new onset diabetes post-transplant”). Quickly I came to understand how prevalent this condition is among transplant recipients, affecting approximately 15-20% in the first year post-transplant and continuing to be a high risk thereafter.

Diabetes can be life-threatening and certainly comes with severe complications if not recognized and treated effectively—so, recognizing it is a critical first step. Although it is possible to develop diabetes without noticing symptoms, more commonly you would have one or more of the following symptoms:

- frequent urination
- excessive thirst
- extreme hunger
- tiredness
- tingling or numbness in hands or feet
- sudden vision changes
- irritability
- unexpected weight loss
- slow healing cuts
- constipation or infections

After 14 years post heart transplant, I noticed the weight loss and felt it was good, since I was overweight (a risk factor). Losing weight (10 pounds) was a welcome although unearned change for me. I was also getting up through the night (not noticing it was happening during the day, too) for multiple trips to the bathroom. I drank a lot of water and felt that was the cause of those trips. After all, I was getting older and that is what happens, right? Looking back, I now see that I had ignored other signs also, such as itchiness (just dry winter skin?) and insatiable hunger (but, I’m always hungry!).

Finally, I brought these factors to the attention of my family physician who wisely ordered a blood test “stat!” A few hours later he called to direct me to go immediately to the local ER. My blood sugar level was above 900, not that I knew then that normal was 100 and that this was a very dangerous situation. At the ER I was treated with high doses of Insulin to lower that extreme level and transported to the transplant center for special care to protect that transplanted heart.

I had ignored symptoms that were not part of my list of things to watch out for and that could have been disastrous! Now, five years later, I am well educated in how to live with this condition. I am careful in its treatment as I am in my disciplined care for this heart, living an active and healthy life post-transplant.

My word to the wise: Ignorance is not bliss in this case, so keep a watchful eye out for those symptoms and take action with medical support when they arise. Diabetes can lead to fatal outcomes as was the case with my own younger brother just last year. He rejected everyone’s observations of his obvious symptoms and sadly reacted too late to save a heart damaged by diabetes.

--Jim Gleason, President, TRIO Board of Directors
President, TRIO Philadelphia Chapter
(For further information, read the excellent booklet at: http://www.itns.org/pdfs2009/ITNS_Diabetes_Booklet.pdf)

TRIO Recommended Reading:
Books of Transplant Interest

“The Next 15 Minutes” is an inspirational narrative by a liver candidate’s caregiver spouse, Kim Kirchner. Kim tells their story in parallel with her experiences as an EMT and a ski patroller. That adds a very different and exciting perspective to how they used those survival skills to keep her husband alive until the successful surgery.

“A Heart Like Mine: Finding God’s Will for Your Life” and the second in what will eventually be a trilogy, “A Heart Like Yours: Understanding God’s Will for You Life” are inspiring books by heart recipient Cindy Valenti-Scinto, sharing how her many medical challenges opened her eyes and heart to God’s exciting plans. This is great reading for anyone facing their own dark times in life, offering hope and encouragement. In a similar vein, check out “Another Second Chance: God’s Story” in which Troy Lewis shares “how a stranger’s kidney saved my life . . . and my brother’s life, too.”

Explaining transplant to children is made easier by a series of small and beautifully illustrated books by Stacy Raye Waibel who uses her poodle, Rudy, as the character who faces the transplant challenge. The series includes such titles as “Rudy Gets a Transplant,” “Rudy’s Check-up” and “Rudy’s Incredible Kidney Machine.”

Look at the growing 100+ book review database under “Resources” on the TRIO website.
Primary Care Physician Program Update

Designed to raise awareness and gain donor registrations, the PCP initiative offers individual members the resources to engage their family physician with the question: **“Doctor, do you talk to your patients about organ donation?”**

A planning session was held on November 19 Philadelphia to finalize plans while taking into account that similar initiatives, undertaken by other organizations, have failed. The simplicity of our grass roots approach will hopefully succeed, but that will be up to our TRIO member participation. While the fall anniversary conference will be a major launch for this initiative, there will be opportunities for testing the process with chapters who may wish to prototype the program’s effectiveness, prior to launch. In addition to that testing opportunity, all chapters are being invited to name their PCP chapter champion to carry the message and process to local members.

Food Safety Posting Goes Viral

In a recent late evening online Facebook transplant group, a posting appears under the title: “Food Safety For People Who Are Immunosuppressed.” Immediately, the reactions began coming in as members posted comments. Nothing unusual about that, except that within 15 minutes, more than 100 responses had been posted. By the next morning, 200 responses were submitted. It seemed that a real chord of interest had been struck with the long list of “not allowed” foods.

Below is the posting that generated so much excitement. It has also been added to the TRIO website’s bulletin board to give our readers an opportunity to add their own comments to the global conversation.

Posting by Fran Lieberman Miller, heart recipient: *My husband saw on a website that transplants are not supposed to eat aged cheese, anything from a deli, lox, roasted nuts in a shell, among other things that I have eaten over the 5 years since my heart transplant. I was never told any of this by my transplant team. Have you been told to avoid these foods? The link to the website is: [http://www.uihealthcare.org/2column.aspx!id=226442](http://www.uihealthcare.org/2column.aspx!id=226442)*

Mateiko Elected TRIO Treasurer

James Mateiko has been elected Treasurer of the TRIO Board of Directors, replacing Mark Jackson, who will remain on the board as a Director at Large. TRIO expresses deep appreciation to Mark for his service and looks forward to working with James.

TRIO E-News:

**It’s Been a Good Year!**

With improved communications for the TRIO membership, another benefit has been advertising in the monthly member e-news and website that contributed more than $20,000 in revenues, making this another good year in both regards. Many have commented on the value of those news resources. If you haven’t been taking advantage of them, check both out on the TRIO website. To receive your own personalized e-news, send your email address to info@trioweb.org. Many of those colorful and informative short articles are linked to even more information on the TRIO website. If you want to know what those e-new blasts are about, you can see the latest edition through the link under “TRIO National News” on the website home page.

TRIO’s 25th Anniversary (continued from page 1)

Educational, informative and inspirational conference workshops are planned from Friday morning through Saturday. Shortly we will list topics under consideration and offer TRIO members an opportunity to add others. Already the excitement is building with the possibilities and great speakers.

Along with sponsored exhibits, we are working to make this a true TRIO chapter opportunity, with tables for each chapter to exhibit their local activities. So, start collecting those event photos to populate your table. Each chapter will have space in the dinner program to feature their stories and history. A slide show of chapter event photos is another idea for the dinner event.

The first 25th year celebration resource is special foil stickers being sent to each chapter for use by members to help promote and celebrate our 25th anniversary year. Where to use them is up to your own creative imagination.

We have so much to celebrate and YOU are key to this special year of activity. We hope you can join us in Pittsburgh, so start making plans by marking the dates of September 28-29 on your calendar. To lend perspective, a video will soon be posted on the TRIO website featuring early 1990-1991 TRIO conferences. We fully expect this 25th anniversary conference to be bigger and better than those of two decades ago. For current information as it develops, your 25th anniversary chapter champion will be your local source for details in addition to Lifelines, e-news and web announcements.
Membership – ☐ NEW or ☐ Renewal: TRIO membership is renewable as of January 1 each year.

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

Name of Member: ____________________________________________________________

Names of other family members: __________________________________________________

Address: ____________________________________________________________ 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 . . . . . . . . . . . $ ______. Transplant Recipients International Organization, Inc.

TOTAL enclosed . . . $ ______. 2100 M St., NW, #170-353

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).