Long-time UNOS CEO, Walter Graham, Retires

Longtime friend of TRIO, Walter Graham, announced his retirement effective December 17, just two months after being recognized at TRIO’s 25th Anniversary Gala with a lifetime achievement award for his longtime support of TRIO and transplant patients and recipients nationwide. In his keynote address in Pittsburgh, he explained that as UNOS’ Chief Executive Officer, he was responsible for overseeing all UNOS corporate and operational matters. He had responsibility for the work of all staff of the organization and interacted directly with UNOS’ Board of Directors and Officers. Graham also served as President and CEO of UNOS’ two subsidiary organizations, the UNOS Foundation and the TII Informatix.

Graham had served as UNOS’ Assistant Executive Director for eight years before taking on the role of Executive Director in 1995. He was a management consultant to UNOS for one year prior to joining the organization. Prior to that, as an attorney, Graham had more than 35 years of senior management experience in healthcare administration and served as a senior corporate executive at five different healthcare organizations.

Current UNOS COO, Brian Shepard, has been named as temporary CEO, filling Walter’s office pending a search by the UNOS board for a permanent replacement.

TRIO Welcomes New Chapter

TRIO is pleased to announce the chartering of the TRIO Maryland Chapter. The new chapter, headquartered in Baltimore, is the result of the hard work of Marty Maren and his wife, Michele Gregory-Maren.

Most transplant recipients feel the need to give back for their enormous good fortune and for the “Second Chance” at life. Marty and Michele feel that way and are volunteers at Johns Hopkins Hospital and The Living Legacy Foundation, the Maryland OPO. The desire to start a TRIO chapter in Maryland began when Charlie Alexander, President and CEO of the Maryland Living Legacy Foundation, following a conversation at TRIO’s 2012 summit about that need, suggested it to Marty.

The Marens, along with so many in the transplant community, feel there is a need for TRIO and for peer mentoring of transplant recipients, candidates and their families.

Marty said “TRIO Maryland Chapter, our Board of Directors and our members are so excited and pleased to become a chartered chapter of TRIO. We are anxious to get started and to identify and develop programs to support those in the Maryland area transplant community. We look forward to doing our share to improve the quality of lives touched by transplantation.”

TRIO Maryland Chapter Board of Directors (left to right): P. Mike Gahagan, Marty Maren, Michele Gregory-Maren, Zivah Ring, Christa Gahagan, Rodger Goodacre.

(Read Marty Maren’s Personal Story on page 7 of this issue.)
President’s Message

Jim Gleason

“Alone we can do so little, together we can do so much!”
- Helen Keller

Isn’t that what TRIO is all about, empowering each of us to leverage our desire to “pay back” in actions that go far beyond what the individual can do? Take the passionate power of the individual and multiply that with the TRIO family around you and there is no limit to what can be accomplished in reaching out and helping others.

Certainly that was the vision shared at our Fall Leadership Summit which is now available for your viewing on the TRIO web site (linked under “Resources”). Everyone agreed we need to host that now annual event again in 2013. While plans are only in the very earliest stages of discussion, you can expect to see a date set for a Friday and Saturday in late September (maybe Sept 20 and 21?). Again, two days of board meeting and educational workshops, with a new title that promotes wider participation beyond just leaders. The past three summits have been on the east coast, so thinking is we should host this one out west, like Kansas City or San Francisco as cities under consideration. Your thoughts on locations, workshop topics, and speakers are welcome (send them to info@trioweb.org) as we begin developing the event. Hope to see YOU there this fall.

TRIO enjoyed another banner year in 2013 in many ways, but I want to focus on just one aspect of that here. As you see in the “Welcome TRIO Maryland” article, as of January 1 we have yet another new chapter bringing us to 14 chapters, with several more moving closer to chartering in 2013. So please join me in congratulating Marty and Michele and their new TRIO members in what is a continuing growth in chapter development.

Will we ever get back to the numbers TRIO enjoyed back in the very early ’90s? One more at a time, and as is the goal in our new strategic plan, I hope to see that day again, growing in membership and chapters each and every year. If you want to feel the excitement of those “glory days”, check out the links to the YouTube videos of TRIO’s ’91 and ’92 conventions on our web site home page.

But again, it is up to you and all of us to spread the TRIO message and mission that will drive that growth and overall impact we as TRIO have in this transplant world of ours. Who have you shared that word with and/or invited someone to come out to a local chapter meeting? Imagine the impact if each of us brought in just one new (or recovered) member to TRIO! What is your personal New Year’s resolution to engage in support of TRIO to leverage your gifts and energy and personal passion to make that difference in our world?

An awesome and exciting thought, yes? So “Just do it!” as the ad goes.

In closing, let me offer a belated holiday greeting to each and every one of you, with a prayer that this new year of 2013 brings you and your family the blessings of good health and continued fulfilled living, whatever that means for your own life today.

As I say each morning upon waking, “Wow, above ground another day! This is going to be a good one!”—and every day it is, to my own amazement. May it be so for you, too.

Sincerely,
Jim Gleason
President, TRIO Board

Did you know?
There are 117,100 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)
TRIO Board Holds Quarterly Meeting

The TRIO Board met by teleconference on December 1. The organization continues to maintain a strong financial position as we approach the end of our 2012 fiscal year, but adopted a challenging deficit budget for 2013 due to anticipated grant and advertising cutbacks.

There was excitement in seeing a new TRIO chapter chartered in Baltimore, MD. Another potential chapter in Seattle, WA, is expected to make formal charter application in the coming months. Interest has been received for possible chapters in Staten Island, NY, and Oklahoma City, OK. TRIO is seeing growth across the country and that’s very good news!

Sylvia reported that checks for $1,000 each have gone out to the previously announced four scholarship winners.

A final report on the very successful 2012 Leadership Summit was accepted, with a suggested new name for a 2013 event to communicate to members a more inclusive outreach: “2013 Leadership and Education Summit.”

Other board reports are covered in articles elsewhere in this issue.

TRIOweb.org Provides Daily Transplant News

“A day in the life of a liver transplant program”, or news of “UCLA’s first ‘breathing lung’ transplant” and “UPenn’s 1000th heart transplant” -- all exciting news updated daily.

Those informative and interesting items appear in one place for easy access to exciting developments in our world of transplant. That’s the TRIO website home page news features, organized by category, with latest updates highlighted and all stories archived by category for later reference when you want to share a story with others but can’t recall where you saw it.

And then there’s chapter news and links to their newsletters, and to UNOS and Rx news or a link to the most recent TRIO e-news, all just a click away.

Make a note of that web address: http://trioweb.org. Check it out today.

Consider making your own contribution of a story or an idea. Contact info@trioweb.org.

TRIO Presentation Library Is Growing !!!

If you check the complete library listings on the TRIOweb.org site under Communications/Resources, you will see an AMAZING addition of eight new programs that will be delivered over the coming months to your chapter librarian.

It’s been a busy quarter for recording, editing and duplicating these interesting programs, listed below. All of these DVDs are already in stock. While scheduled for bi-monthly chapter delivery, members at large can contact the national office to receive any title now.

Also, a new feature on the website now provides the supporting informational flyer by clicking on its title on the TRIO Communications/Resources web page.

- Pgm 43: "The History of Heart Transplantation" (Jan 2013)
- Pgm 44: "Post-Transplant Intimacy" (Feb 2013)
- Pgm 45: "Corneal Transplantation" (Mar 2013)
- Pgm 46: "Finding Meaning in Death: Life as an Organ Donor Specialist" (April 2013)
- Pgm 47: "Xenotransplantation: Hope for the Future" (May 2013)
- Pgm 48: "Gene Technology: Biomarkers in Healthcare" (June 2013)
- Pgm 49: "Caring for the Caregiver" (July 2013)
- Pgm 50: "Living a Fulfilled Life Post Transplant through Goal-setting" (Aug 2013)

Personally, I am delighted to attend and record these presentation so generously offered by or speakers for TRIO’s use. Hopefully, your TRIO chapter will record a local speaker as its contribution to this growing library. If you see an interesting upcoming presentation, please suggest that it be recorded and submitted for consideration to be included in TRIO’s Presentation Library. --Jim Gleason, TRIO President and Webmaster
Social Security Disability Claims Can Be “Complicated”

It takes just a few seconds for Gail Kelly-Bushy to scoop ice into a little white cup, cover it with cherry red syrup and pass it through the small window of her family’s snow cone stand. But the shy smile of the eager little girl on the other side will stay with Gail all day.

“I love seeing the kids and talking with them about their day, and just seeing them smile,” says Gail, who has operated Island Sno-Balls in Fernandina Beach, FL, with her family since 2009. “That such a simple treat can bring even a little bit of joy to someone’s day means a lot to me.”

With her own quick smile and easy laugh, she has the customer service end of her business down cold. It’s no secret that she enjoys people. When she and her husband moved to Northeast Florida five years ago, she joined a church and began volunteering at the local Council on Aging, where she helps serve meals to seniors with dementia and assists with arts and crafts programs. Gail is a member of TRIO Northeast Florida Chapter. At 52, Gail is a mother of three and a grandmother to four.

But doctors told her to slow down. She suffered from a variety of illnesses, including rheumatoid arthritis and liver disease. Over the years, fatigue and pain frequently kept her from leaving the house, and work was often out of the question. Gail spent time in the hospital over the years, and recently the vivacious strawberry blonde was told by doctors at the Mayo Clinic in Jacksonville that she would need a liver transplant. Gail was diagnosed in 2004 with primary biliary cirrhosis, a disease in which the immune system attacks the bile ducts in the liver. As the ducts become damaged over time, bile builds in the liver, eventually causing it to fail. The condition runs in her family.

“The medicine is expensive and I was working very limited hours so there wasn’t enough money coming in to pay my expenses,” says Gail, who has been prescribed up to nine medications every day.

A minister suggested applying for disability insurance. Obtaining Social Security Disability benefits can be a difficult and complex process. Two out of every three applicants are initially denied. Gail was no exception. Unable to work, she applied for SSD twice and was denied both times.

“Most applications are rejected at the initial stage,” says Cynthia Arnett, an accredited disability representative and president of Disability Claims Services. Arnett helped Gail file her claim and represented her at a hearing before an Administrative Law Judge in September. Arnett points out that not every claim goes to the hearing stage.

Arnett explains that every situation is different. She says that many people walk into their local Social Security office expecting to sign some paperwork and start receiving a check. It doesn’t work that way she says. The process is complex, and the Social Security Administration has set strict criteria for a wide range of physical and mental illnesses that keep people from working.

Gail’s extensive and excellent work history, combined with her progressive medical issues, made her a prime candidate for Social Security Disability. Gail’s claim was approved in September. She also qualifies for Medicare.

“To look at me, you wouldn’t know I am sick, but the money will relieve some of the financial pressure,” Gail explains.

For now, Gail continues to undergo testing and is taking her situation day by day. “I was more nervous waiting to get my disability claim approved than I am dealing with the medical issues,” Gail says with a big laugh and smile. “I will do what I need to do and be ready for the transplant when it’s my turn.”

-- Cynthia Arnett, President
Disability Claims Service (www.dibclaims.com)

Chapter Fund Raisers Support TRIO
A very special TRIO “Thank You!” to chapters who hosted fund raisers, and as is our rule, forwarded 10% of the net funds in support of the national organization. The following chapters were our 2012 contributors: Akron-Canton, Greater Cleveland, Long Island, Pittsburgh, and Southern New Mexico.

If your chapter held a fund raiser, please remind the Treasurer of that sharing obligation. While 10% may be a small amount, when all contribute, that’s still an important income item in our overall national budget. We invite chapters to submit stories and photos from their events for our website and newsletter, as recognition of the great work TRIO chapters are doing. Send to info@trioweb.org.
Understanding the Affordable Care Act—How it Affects Transplant Recipients

Now that the election results have solidified the permanence of the Affordable Care Act (ACA), we should take some time to examine what this may mean for you. This brief article will be followed by the full article on TRIOweb.org, to be posted after the first of the year. So, please check there for a more expanded explanation after the first of the year. Putting aside politics and myth, my goal is to convey key points of the Act in an unbiased way.

The Affordable Care Act is a healthcare law that aims to improve our current healthcare system by increasing access to health coverage for Americans and introducing new protections for people who have health insurance. The Act was signed into law on March 23, 2010, and we have already seen portions of the law enacted. To name a few, the Act will accomplish the following:

- Expand access to health insurance coverage to most Americans
- Establish the personal responsibility to purchase health insurance
- Create state-based Health Insurance Marketplaces
- Create numerous Consumer Protections in private health insurance
- Close important coverage gaps in Medicare
- Provide preventive care with no co-pay or deductibles

From a transplant recipient’s point of view, perhaps the single most important feature of this Act is that beginning January 1, 2014, adults cannot be denied coverage due to a pre-existing health condition (children have enjoyed this benefit since September 23, 2010)! I know you all share my excitement regarding the multiple opportunities for healthcare coverage this will afford healthy individuals living with chronic conditions. For an extended version of this article, chock full of information, please see the article posted on TRIOweb.org.

(References: National Physicians Alliance and www.healthcareandyou.org )

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

TRIO Open to Medical Advisory Board Nominations

With the formation of a “TRIO Medical Advisory Board” (MAB), under the leadership of long-time TRIO board member, Dr. Tom Peters, we strengthen the TRIO national organization with the skills and consultant support of medical professionals across the country. Chapters are invited to nominate local candidates for consideration to be named to this national board, something that many professionals seek out as a proud addition to their resume/CV to participate with a nationally recognized transplant organization. It would be great to have at least one name offered from each chapter.

Of course, the first thing any candidate is going to ask is “So what is involved, what would my responsibilities be if I were named to this board?” Answers to that can be found on our TRIO website under the “Members” navigation link. There you can also download a PDF version of the “TRIO Medical Advisory Board” responsibilities document to email or hand to your nominee. Be sure you read it over yourself before you approach them, so you can give a quick summary to determine their interest.

Nominee contact information, along with a CV or a brief bio, should be sent to the TRIO Nominating Committee at info@trioweb.org.

Be sure your chapter is represented on this new and important support arm of TRIO.

Have You Visited TRIO On Facebook?

Thanks to TRIO’s Secretary of the Board, Susan Pincus, TRIO has a Facebook page!

On TRIO’s ‘page’ you can view photos, read and respond to comments, and post your own thoughts. It’s easy to create your own log-in. Just go to Facebook and follow the directions.

Several chapters also have Facebook pages found by searching on Facebook for TRIO or Transplant Recipients International Organization.

2014 Transplant Games

Just announced: the next US transplant games will be held in Houston, TX, from July 10 through 15 in 2014. So mark those calendars now, if yours goes out that far.
Self-Care and Medical Management in Adolescents Following Organ Transplant

Managing and adhering to recommended medical care following organ transplantation can be a complex process. Most transplant recipients whether adult or pediatric require multiple daily medications, frequent blood work, and clinic visits. For some patients other areas are also frequently monitored such as blood pressure and lung function. In addition, recommendations regarding physical activity and diet are often part of the process. Being successful at managing all of these areas of post-transplant care can be challenging. For adolescents who are also learning about who they are and in a developmentally demanding stage, effectively navigating care can be particularly complicated.

Effective self-care and medical management for adolescents requires high levels of support and monitoring from parents. Parents at times struggle trying to determine the appropriate level of independence that they should provide their children while also remaining supportive and involved in care. It is a fine balance that might be difficult to achieve.

Adherence to medical recommendations in adolescent populations requires the effective collaboration of family members and active participation by the adolescent. Research in this area has shown that adherence is typically worse in adolescent populations than among younger children. In addition, research suggests that when the family system is under significant stress and/or adolescents are experiencing behavioral problems/psychological distress that adherence to medical recommendations can be significantly affected.

Few studies have been undertaken in organ transplantation to help improve adherence among adolescents. New areas of exploration include the use of mobile health technology to improve adherence. We are very excited to venture into this area of exploration testing the effectiveness of a mobile health application in improving adherence among solid organ adolescent transplant recipients and their parents. Our hope is that if this technology is truly beneficial, we will be able to expand its use and improve long-term outcomes in adolescents.

-- Diana A. Shellmer, Ph.D.
Assistant Professor of Surgery and Psychiatry
University of Pittsburgh School of Medicine
Hillman Center for Pediatric Transplantation
Univ. of Pittsburgh and Children’s Hospital of Pittsburgh, UPMC

Stock Up on Good Readings for Those Snow Days Ahead!

For an inspiring read advocating living kidney donation vs. dialysis with proactive action planning advice, check out Risa Simon’s Shift Your Fate: Life Changing Wisdom for Proactive Kidney Patients with its new review on the TRIO web site’s book database. For an uplifting family search for a miracle to cure their young son’s rare Mitochondrial disease with a living liver donation from his mother, don’t miss grandmother Margaret McCarthy’s new book, Adam’s Journey.

For an insider’s view of the transplant center and how decisions are sometimes made, the reporter, Luis Fabregas, provides a rare insight in A Transplant for Katy, but be prepared, not every young person’s story ends with a lifetime of happiness despite a successful liver transplant. And, by the time you are reading this, there will be yet another review, this one of Noncompliant List: Transplants, Meditation and My Journey to Health, by 20-year liver survivor turned down for transplant, Kevin Hopf.

So we have quite a variety of new books to enjoy on those chilly or snowy winter days to bury ourselves in a warm blanket, hot chocolate within reach, and to just sit back and read. Check out reviews for books and movies (100+) under “Resources” on TRIOweb.org.

Are YOU Reading This???

As part of a readership survey to help reduce unnecessary expenses by finding out who is actually reading Lifelines and possibly reducing this costly mailing only to those who wish to receive it, we ask that you e-mail info@trioweb.org or call 1-800-TRIO-386 with your name to confirm that you wish to continue receiving this hardcopy Lifelines or would opt for an e-mailed color version.

If you do not respond, that will be considered an answer of: “I no longer wish to receive Lifelines”.

Note: Past Lifelines issues are archived on the TRIO web site, but beginning with this issue will be available on our web site about a week before the hardcopy goes to press for mailing and will be in full color. Members responding with e-mail addresses will also receive an e-mail notice and link when each issue is posted.
Organ Allocation, Part 3: The Transplant Program Role

(This is part 3 of a 3-part series describing the complex process of getting the donor’s organ gift to the waiting recipient. The full 3-part series can be read at trioweb.org.)

In part 1, we saw how UNOS plays a key role in the organ allocation process by maintaining the database of registered candidates (the “LIST”) and, as a contractor for the government, sets the rules by which that allocation is prioritized. In part 2 the role of the organ procurement organization (the “OPO”) was described in which the donation process is offered to a family and their gift(s) of donated organs become available for matching with listed candidates. Here in part 3, the beginning and ending of that process is explained whereby a candidate is listed and, hopefully, finally gets the lifesaving gift of an organ transplant.

A transplant center is a hospital that offers transplants through their transplant program(s), each dedicated to specific types of organs. So there may be one program (usually a kidney program, the most common organ transplanted, accounting for about 80% of all transplant candidates) or multiple programs for lungs, hearts, livers, etc. To begin the process, that individual transplant program evaluates a sick patient as a possible candidate for an organ transplant. If deemed sick enough to need a transplant, while being healthy enough to survive the transplant, the program will “list the patient,” making them a “candidate” in that UNOS database to await the donated organ (recovered by the OPO) and offered according to those allocation rules (UNOS again) and some day will find that candidate at the top of “the list.”

When that OPO has consent from the donor (or if not prior to death designated on a state registry, then consent is requested from the donor’s family) and the gift of an organ becomes available. Based on criteria set for each organ type, from that UNOS database, the famous “list” is generated, one list for each organ offered. Notifications are electronically sent out to the transplant program medical teams in order of candidate priority, with the topmost candidate getting “first choice” for that gift offer.

The transplant surgeon will make the judgment, often with the patient involved, whether that offer is the right organ for that candidate at that time. If not, then the process is repeated for the next on that list until someone finally accepts that offer and the transplant surgery takes place. There are many reasons why an organ offer might be passed over, such as the candidate running a fever, or maybe not being able to get to the hospital in time, etc. So it is not unusual that someone other than the top name on that list will get transplanted, as in Marty’s story below.

Once an offer is accepted, most often the transplant surgical teams travel to the donor hospital to work with other teams, each working in tandem to “recover” their allocated organ to rush it back to their transplant center for transplant surgery to take place.

As you can see, the path from the donor’s organ (the “gift”) to getting to a waiting (often dying) recipient is a complex one that can take many hours of tight cooperation between UNOS, the OPO and the transplant center. Today more than 117,000 candidates wait on that list for the process to work, moving them from being a candidate for organ transplant to enjoying a full life as a grateful organ transplant recipient.

Marty Maren's “Personal Story”

Marty is a native of Harrisburg, PA. He moved to Baltimore in 1999 when he married Michele Gregory. Marty has enjoyed a career as a manufacturer’s sales representative in the foodservice and steel industries.

Marty had liver failure in November 2009 due to acetaminophen poisoning. He was taken to Johns Hopkins Hospital on a Thursday morning and on Friday night he was #1 on the liver transplant list for the region. Michele was told that he had 72 hours to receive a transplant. It seemed impossible but Marty had a liver offered by Sunday morning. Unfortunately, when the doctors began the surgery, they determined that Marty was too unstable to survive a transplant. That organ went to the next recipient on the list.

Michele asked Dr. Andrew Cameron what options were now available for Marty to save his life. Dr Cameron made the unusual suggestion of removing Marty’s liver in the hope that he would stabilize. If Marty lived through the organ removal, his chances would improve to survive a transplant. Michele agreed and Marty’s liver was successfully removed. He now had 48 hours remaining for a transplant. A second liver was offered, at the 11th hour, and Marty had a liver transplant. After 56 days at Hopkins, Marty went home to work on getting his life back to normal or as close to it as you can.

Michele attributes Marty’s miracle to prayers made to St. Rita, The Saint of the Impossible. (See Maryland Chapter story on page 1)
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: ________________________________________________________________________________________

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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