



Lifelines

July 2013



Transplant Recipients International Organization, Inc.

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Rodger Goodacre Appointed to TRIO Board of Directors



TRIO is pleased to introduce Rodger Goodacre, the newest member of TRIO's Board of Directors.

From 1978 until his retirement in 2013, Rodger held various

administrative and management positions for federal health care programs with the US Centers for Medicare & Medicaid Services (CMS) headquartered in Baltimore, MD.

During his tenure with CMS, Rodger managed and led outreach and education for the Medicare program and directed the Office of Beneficiary Services. He also coordinated activities for CMS Program benefits for American Indians and Alaska Natives. In addition to holding various education and teaching positions, Rodger taught at the National University while serving with the Peace Corps in the Republic of Congo.

Rodger, who received a liver transplant in 1998 at the Johns Hopkins Hospital, lives in Gettysburg, PA. He and his wife, Christine, are members of the TRIO Maryland Chapter.

Rodger offers TRIO an extensive understanding and knowledge of how federal and state programs can work with transplantation, along with a background in public education and speaking to help increase public knowledge about transplantation.

In discussing his interest in serving, Rodger said: "Once I decided to retire from a career I had enjoyed my entire adult life, I knew I wanted to be more directly involved with the transplant community. The opportunity to serve on the TRIO Board is perfect timing for me to dedicate the time and energy necessary to do justice to the important job of informing the public and supporting transplant patients."

Have You Been Following "Sarah's Story"?

Pediatric Lung Allocation News

With ongoing daily news media articles and videos added each day to the TRIO web site (and that summary offered in the June TRIO E-News), hopefully, you have been able to keep informed on this important issue. As a TRIO member, and with your known relationship to transplant, you are a natural source for reactions to this story in your community, whether that be a request for a formal interview or questions from neighbors and friends. Thus, it is doubly important to keep up with the facts and fully understand what was (and still is) going on with this developing story.

First, let's understand that this really isn't a "Sarah issue." Her family found themselves up against the wall and, to protect their dying daughter, did everything they could to give her the best chance of surviving a dreadful chronic disease, cystic fibrosis. This is the same challenge faced by the now famous Stenzel twins. We have seen them use their inspiring lung transplant story to rally people around the world in support of organ donation. **And therein lies the real story and issue: there are just not enough donated organs to meet the ever-growing need for life saving organs**, an issue that is even more heart-wrenching and tragic in the world of pediatric transplantation. In Sarah's case, as she turned 11 just weeks away from death, the US allocation rules, while prioritizing lung donation for children under the age of 12 from the same aged donors, also had her as lowest priority for adult and teen lung offers.

Our organ allocation system is based on best outcomes, both in terms of least lives lost waiting and longest graft survival post transplant, for the community as a whole, not just for any individual.

(continued on page 4)

President's Message



“The greatest power that a person possesses is the power to choose.”

-J. Martin Kohe

Jim Gleason

Summer is here with some pretty crazy weather in recent weeks. With devastating tornados in the mid-west, torrential downpours and golf ball sized hail in others, heat waves well before normal, and locally here in my own New Jersey/Philadelphia area we see much promotion of the famous Jersey shore recovery from last year's super storm Sandy. Their theme is ***“We're stronger than the storm!”*** In mid-June my wife and I took our annual one-hour ride to Seaside, NJ, for dinner on the boardwalk. This “vacation” lasts for about two hours and then we drive back home, satisfied with our shore experience each year. The wooden boardwalk was all new construction. Many of the amusement rides were yet to be rebuilt as the amusement piers had been ripped apart and only huge construction cranes were visible now. But while still incomplete a week before the schools let out and the real summer season returns, it was surprising to see the power in businesses and home owners choosing to ***“be stronger than the storm”*** as beaches were dotted with families and surfers while the seagull population was back in force.

I see that same power of choice and amazing recovery in so many of our TRIO members' stories and in patients I visit in our 43 transplant programs in this Philadelphia area (yes, you read correctly, FORTY-THREE!). When we were so very sick, it took a lot to choose life in electing to list and wait for a life-saving transplant. Some don't make it, like 18 a day the stats tell us, while 28,000 a year do get transplanted, most from gifts donated anonymously in times of tragedy.

TRIO's mission is to help those who do make it to “pay it forward” in offering inspiration to others still waiting, showing the world that transplantation works and encouraging everyone to take action and register as organ donors. Only with that support will we ever see the day when stories like Sarah's lung allocation challenge no longer happen, when children and adults alike can enjoy the benefits of modern medicine, living fulfilled and productive lives, living out their chosen roles in loving families like yours and mine.

And that is why you and I and TRIO members across this country and world come together, leveraging the power of our choice and TRIO community strength to reach out and share that successful organ and tissue transplant with everyone who sees and listens to you, inspiring them to join our movement of becoming organ donors. That works with you and me reaching out and touching one person/heart at a time.

And we see this dedication and choice in so many of our medical and OPO staff too. Liz Shore, transplant social worker who recently completed her years of TRIO board service but chooses to continue working on TRIO's medical advisory board, is another example of that dedication. From all of us, ***“Liz, thank you!”***

In closing, without breaching anyone's privacy, please keep in prayers TRIO members who are dealing with really tough medical challenges again after years of successful transplant living, along with those waiting candidates and our donor families.

Sincerely,

Jim Gleason, President
TRIO Board of Directors

(See page 11: ***OPTN/UNOS Updates . . .***)

As we go to press: Kidney Allocation System (KAS) approved at June 24 OPTN/UNOS Meeting in Richmond!)

Lifelines is published quarterly by Transplant Recipients International Organization, Inc., 2100 M St., NW, #170-353, Washington, DC 20037, 800-874-6386, www.trioweb.org.

Lifelines is published by the Newsletter Sub-committee of the Communications Committee. The Newsletter Subcommittee consists of Pat Beeman, Jim Gleason, Elizabeth Rubin, and Dr. Tom Peters, Advisor. Editor: Sylvia Leach.

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Did you know?

There are **118,662** 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

TRIO's Quarterly Board of Directors Meeting

The TRIO Board of Directors held its quarterly meeting by teleconference on May 18, 2013, with Elizabeth Rubin, Board Vice President, presiding. In addition to the regular review of committee reports previously submitted, several other topics were discussed and decided.

The Board welcomed two new Board members, Harvey Mysel and Rodger Goodacre, as well as newly elected Chair of the TRIO Chapter Council, Marty Maren. The Board also accepted the resignation of Liz Shore as a Board member and thanked her for her service. Liz has agreed to continue to serve on the Medical Advisory Board.

All Board members and members of TRIO are urged to look within their own network of contacts for new opportunities for financial support and to report any suggestions to Sylvia Leach in the TRIO office. Many of TRIO's past sources of funding have either cut back or disappeared altogether, so we need some new sources of funding. As long as we continue to watch our expenses, TRIO's finances should remain in the black, at least for the time being.

Due to this lack of grant support so far in 2013, the Board voted to postpone the Leadership and Educational Summit until 2014, date and location yet to be determined.

TRIO is in the process of developing a new website, and the first prototype should be ready for committee review shortly.

TRIO continues to conduct a member survey asking for preference between online color versions and mailed copies of *Lifelines*. The Board is evaluating the impact of that survey. If you have not yet stated a preference for *Lifelines* delivery, please do so by emailing info@trioweb.org, stating your preference. (See article on page 7 of this *Lifelines* issue.)

Elizabeth congratulated TRIO Board member Merle Zuel, who has been appointed to serve on the UNOS Patient Affairs Committee, and Jim Gleason, who was recently elected to the UNOS Executive Committee.

The next quarterly Board of Directors meeting is scheduled for the fall (date to be announced) and will be a face-to-face meeting in Philadelphia at the offices of the Gift of Life Donor Program.

Any TRIO member is welcome to attend the quarterly Board of Directors meeting. Check TRIO's website for date and time announcements. Contact info@trioweb.org to register.

Your Daily News Source: TRIOweb.org

With daily breaking news on the recent "Sarah lung allocation" story, how can one keep up with it all? It's not easy, but so important to do so given our unique role in the community as advocates for organ donation. Fortunately, we have an answer at hand in the TRIO website with its daily updated news categories. When a story breaks as important as this one, we offer a special highlighted listing of news links gathered from many sources to give readers one place to find what's happening NOW. If you haven't seen this special feature, check it out today and add it to your web browser's list of favorites to easily check it out each day for the latest developments.

We should expect to see the newly redesigned site in the next few months for a new look and feel, more people-focused, easier to navigate and find what you may be looking for, highlighted with TRIO chapter/member photos.

We need your help by sending in TRIO related photos to support that redesign. Send that JPG formatted photo to info@trioweb.org today so we can consider it for use when the site is ready.

Don't forget that web address: <http://trioweb.org>. Check it out today.

You are invited to submit your own contribution of a story or ideas to info@trioweb.org.

Have You Been to the Library?

While we hope that our ever growing **Transplant Presentation Library** is being made available to you at chapter meetings (members-at-large can directly ask for titles via info@trioweb.org. With over 50 titles available for home use on a PC or TV DVD player, it is disappointing to hear that many TRIO members remain unaware of this valuable resource. Last year we revamped the way in which those DVD's were stored so there would be one easy-to-carry small case to bring to meetings. If you aren't seeing them, ask chapter leadership where they are so everyone can avail themselves of this great program.

Check the web site for a full listing of titles under Communications/Resources. Also, remember, if you see an interesting upcoming presentation at your chapter, suggest that it be recorded and submitted for consideration.

TRIO Chapter Council Is at Work

With recent and forecasted growth in the number of TRIO chapters, along with the election of TRIO Maryland's chapter president, Marty Maren, as council chair and several chapters installing new presidents (and co-presidents), new opportunities are opening up for what the council can accomplish going forward.

Currently the Council is offering a one-hour (approximately) quarterly evening conference call as a forum to hear a brief report from the TRIO president followed by activity reports from each chapter in attendance. These calls are scheduled to follow the national board's quarterly meetings, allowing for time to distribute board meeting minutes as background for discussion. As each chapter shares their activities, events, concerns, challenges and current membership engagement, others are then offered the opportunity to ask questions or offer suggestions. There is much mutual benefit to that open sharing, but to date there are no written records of council meetings to go out to chapters who were not able to attend the council meeting. Maybe now it is time to change that. Give it some thought.

Another communication resource that has been sporadically sent out is the E-News for Chapter Presidents. Hopefully, this can be expanded as a more frequent council's news vehicle used between the quarterly council meetings. How can the council, as another idea, help new chapters as they come alive with new members and leaders, to benefit from seasoned chapter experiences, both in terms of things to avoid, lessons learned, and proven "best practices" to adopt? What else can you see as potential for a more effective council role supporting both chapters and TRIO national?

The last council call was probably the best yet in terms of open discussion and critical feedback by some chapter presidents of then recent action or lack of actions by TRIO leadership. This dialogue was received as both healthy and as evidence of what the council can bring out when we come together to share thoughts on current issues of TRIO interest.

Chapter presidents are encouraged to send a representative to the call when they cannot attend in person. They are also invited to bring along other chapter leaders to listen in and participate as they see fit. This serves to both develop future chapter officers as well as bring more ideas and views to this forum.

Sarah's Story *(continued from Page 1)*

When this case was brought to the courts, a major threat to the system was created when a non-medical authority, a politically appointed judge, overrode the UNOS allocation process which is designed to not respond to any one individual be they celebrity, rich or in this case, a source of public empathy and pressure. The next day a second child was added to that order to allow both children to be double listed as both a child and an adult.

Emergency meetings of UNOS committees determined there was not an emergency situation that should cause immediate action, rather that the ongoing process of policy review with decision based on medical data should prevail. A temporary (one-year) UNOS policy was approved to allow pediatric lung programs to appeal to the existing lung review board for exceptions in such cases as Sarah's, thus creating a stopgap path for allowing under 12-year-old candidates to be listed also as adults for equal access to all lung offers. This allowed the regular review process to address the concerns brought out in this case to proceed while that review process was in place.

By June 14, the judge's temporary order expired, with both this work-around UNOS policy now in place and Sarah, at the very edge of death and, thus, top priority on the 'list,' receiving an adult lung transplant with that lung being downsized to fit her small body. Just days later that lung failed and Sarah underwent a successful second lung transplant (also from an adult donor). She now faces her long and complex recovery while that second patient waits for his chance on the adult list.

So what does this mean for TRIO members?

First, please keep Sarah, her family and the family whose loved one saved Sarah's life (and possibly others) with that decision to be an organ donor, in your prayers. Second, this story captured the attention of both our country and the world, offering a unique opportunity for each of us with our own amazing life story to raise awareness of the need for organ donors for more than 118,000 waiting patients while that story is in the spotlight.

Remember our message: *transplantation works and everyone needs to take action by registering as an organ donor and sharing that decision with their loved ones.*

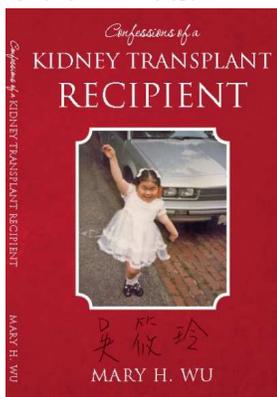
(Note: see the TRIO website (<http://trioweb.org>) for a timeline of links to stories and videos of this issue.)

It's Summertime and the Reading is Easy!

A respected Ohio kidney transplant research physician, Donald Hricik, turns to his other passion as a novelist, using stories based on some harsh realities in the world of academic transplant medicine. Be careful: once you pick up his books, time stands still, not getting your summer tasks done until reading that final page - I know since it happens to me. **Nothing to Confess** takes us on an all too realistic trail of discovery as a donor coordinator for the Ohio Organ Bank finds his successful record jeopardized when several recipients become ill within a month of receiving organs he coordinated. In his latest release, **Racing to Pittsburgh**, we follow intense drama as Dr. Dan Ulek, internationally renowned cardiologist, is isolated at a foreign conference when his US homeland is attacked by terrorists and all flights are suspended. This character name is only one of many places, events and name similarities you may notice if you are familiar with UPMC, real life doctors and recent news stories, this name being very close to the author's name, yes? But remember, these are works of fiction, something that may be hard to keep in mind due to the well written narrative by this gifted author.

On a very different note, TRIO's own Youth Circle leader, Mary Wu, has published her long-awaited book, **Confessions of a Kidney Transplant Recipient**. As a reviewer, I was able to preview each chapter as it was being written - 33 in all covering 551 pages of delightful personal sharing - and was constantly amazed at Mary's gifted writing skills and inspiring life story. I give her book "five stars" and hope that she continues to give us more books in the future. You really do owe it to yourself to buy and read her book, and if you know of any young people, ages 5 to young adult, dealing with kidney issues, this is a gift to give them, after you get your own copy, of course.

Final note: For summer viewing, check out a good family movie available on DVD that features inspiring stories of faith and a living kidney donation element, **The Grace Card** - a play on the "race card" - an essential part of this complex storyline.



TRIO E-News: Are You Getting Yours?

If you aren't seeing the monthly TRIO E-News in your on-line mailbox, that means we don't have your e-mail address! You can still see those monthly newsletters online at TRIOweb.org where they remain posted for 30 days under *News from TRIO National*. While we try to keep each issue short and to the point, the June issue was unusually long due to the nature of the important news surrounding that pediatric lung allocation story described on page one of this *Lifelines*.

These mailings are both colorful and informative, with June's being even more so with its graphical timeline of links to the unfolding story, insights from important UNOS and AST/ASTS statements, and reporting from on-the-scene and insider connections to the story.

Don't miss out! Send your email address to info@trioweb.org to be added to this monthly distribution and stay on top of important TRIO and transplant-world news!

Who Do You Know for the MAB?

So what's this "MAB" you ask? Well, become familiar with that term used to represent our TRIO Medical Advisory Board (MAB) since it will be playing an important TRIO support role as the years move on. With Liz Shore's recent resignation from our Board of Directors, she offered to continue her TRIO support of writing articles and speaking as she will be doing this month for our Presentation Library by joining our growing MAB. Liz joins Pat Folk and Dr. Tom Peters (Chairman of the MAB) in building out this new arm of our organization.

We again offer you the invitation to nominate medical professionals (doctors, transplant coordinators, social workers, OPO staff, etc.) for consideration to this national group. You can get a description of the MAB member role by writing to info@trioweb.org, then pass that along to your candidate so they know what's involved.

Most recently, for example, the pediatric lung allocation issue response that was sent to members was reviewed by the MAB before that was released. Other transplant issues that come up as controversial are also vetted with the MAB for possible TRIO reaction or voting as we do, given our organizational membership in the UNOS/OPTN. So give some thought and discuss it with your nominees.

Help the Transplant Community: Volunteer with UNOS



My name is Bill Lawrence and I have been Director of Patient Affairs for UNOS, the United Network for Organ Sharing, for the past 20 years. Almost all of you have heard of UNOS but not many transplant candidates or recipients get an in-depth understanding of its nature and

purpose, and even fewer actually participate in the ongoing creation of transplant policies.

UNOS is a dynamic and very important nonprofit organization that operates the Organ Procurement and Transplantation Network, the OPTN, as a contractor to the Department of Health and Human Services (HHS).

UNOS was formed 30 years ago, in the early days of transplantation, by doctors who realized that no one but them understood the ins and outs of transplantation. They organized themselves to begin the process of making voluntary policies about organ allocation, and collecting and sharing related data. Shortly afterward, Congress passed the National Organ Transplant Act (NOTA), a federal law designed to insure fairness and accountability in the conduct of the transplant community and to prohibit the buying and selling of organs.

To get all that done, NOTA requires HHS to issue a contract to a nonprofit organization with a board of directors and expertise in transplantation. UNOS has been that contractor since 1986. One absolutely essential component of the policy-making process was creation of committees. These OPTN/UNOS committees consider important issues and advise the Board of their findings and recommendations. Each committee has expertise in a specific area, so that today there are 20 committees including a Kidney Committee, a Liver Committee, a Finance Committee, a Patient Affairs Committee, etc. A full list of committees is shown on page 8.

I think that serving on a committee would be rewarding for any TRIO member. In joining TRIO, each of you has demonstrated an interest in the

greater world of transplantation beyond your own personal situation. We need the benefit of your perspectives and experiences and it's a great way to make a down payment of the gift of life that we received or hope to receive. I should add that at every TRIO meeting that I have spoken to there have been as many spouses as recipients. They are also welcome to offer their expertise since becoming a transplant recipient, as we all know, is a family affair.

The committees are comprised of doctors, nurses, candidates, recipients, donor family members, etc., all of whom are volunteers, and all committees include at least one candidate or recipient. As a brand new liver recipient, my first contact with UNOS was as a member of the Communications Committee. I first met your president, Jim Gleason, at a meeting he was conducting in Philadelphia and invited him to become a committee volunteer himself. Jim has now served on three committees and is a current member of the OPTN/UNOS Board of Directors.

The committee with greatest participation by candidates and recipients, and the most common point of entry to the committee system for recipients, is the Patient Affairs Committee (PAC). Recent activities by this group have included creation of "What Every Patient Needs To Know," a brochure intended to deliver critical information on the world of transplantation for people suffering from end stage organ disease. The PAC is also currently studying the problem of teenage recipient noncompliance. Importantly, the Committee members also review and comment on proposed new national policies before they are presented to the UNOS Board.

Almost all OPTN/UNOS committee meetings occur in Chicago because that is geographically central and air service is convenient. The meetings typically require the participant to arrive the day before, and all reasonable travel, food and hotel expenses are reimbursed by UNOS, so there is no cost to the committee members. There are usually only two meetings each year that actually require travel, with other meetings conducted by telephone as needed throughout the year.

Since the beginning it has been a hallmark of the transplant community that we make our own policies and govern ourselves. There is government oversight, of course, but these responsibilities are our own. If you want to learn more about this rewarding experience, why not contact me at (bill.lawrence@unos.org) or Jim Gleason at (GleasonJim@aol.com) and start the ball rolling?

The Gift That Keeps on Giving



My heart transplant six years ago gave me the opportunity to enjoy life once again. One of the things I enjoy most is being able to help other transplant recipients and donor families. Many transplant recipients feel compelled to do

something to show their gratitude for their new lease on life. One of the best experiences I had after transplant was volunteering to be a Patient Affairs Representative for UNOS. My time on the committee gave me a greater understanding of UNOS policies and made me feel like I was doing something worthy of my gift.

I served as the Patient Affairs Representative for Region 8, which encompasses KS, MO, IA, NE, CO and WY. The responsibilities include a regional meeting twice a year and a national committee meeting twice a year. Additionally, there were teleconferences and webinars that were part of my duties. Travel expenses are covered by UNOS for the national meetings where I met some wonderful, caring individuals. While on the committee, I helped revise the "What Every Patient Needs to Know" booklet that many of us received while waiting. I also participated and voted on the rewrite of the "Patient Notification Letter."

How can you get involved with a committee? I personally watch the announcements in the UNOS Update magazine for committee openings in my area. Each June, committee members roll off and new ones come onboard. Another way to stay informed is simply asking your local OPO staff about nominations and selection. My experience is they enjoy helping people from their service area participate in the policy making process.

There is a formal nomination process, which is not very difficult to navigate. It helps if you can have the support of your local OPO, many of whom are familiar with recipients through their own volunteer ambassador programs.

UNOS has several different committees divided into 11 geographic regions. Committee members can serve as a Regional Representative or an At-Large member. Each committee is made up of transplant and organ procurement

professionals, patient advocacy organization representatives, patients, donors, patient and donor family members and the general public.

If you do a little research on the various committees on the OPTN website (<http://optn.transplant.hrsa.gov/members/committees.asp>) you can find more information about the responsibilities of each committee. Each committee has a UNOS Liaison who could also be helpful in explaining the committee needs or makeup. Often it's as simple as being the right person at the right time for a specific committee opening and a willingness to give of your time. It is a volunteer position but you will reap the reward of personal fulfillment and knowing that you have made it a little easier for the next person who needs a transplant.

My wife and I often are amazed at the new opportunities that present themselves each day. With my gift, I am able to not only enjoy my life, but I can give back to the system which took such good care of me when I was at the lowest point in my life. If not for the donor families, transplant professionals and UNOS, I would not be here today. The best thing I can do as a recipient is to give of myself in return for the second chance I have received. One of the best ways to do that is to just get involved.

Maybe you don't want to serve on a committee, but you know one of your peers who would be perfect. Let them know about this opportunity; or, better yet, nominate them.

Serving on a UNOS committee will prove to be a very satisfying experience.

-- Merle Zuel, Heart Recipient
Member, TRIO Board of Directors
President, TRIO Kansas City Chapter

Have YOU Responded???

As part of a readership survey to help reduce unnecessary expenses by finding out who is actually reading *Lifelines* and possibly reduce 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: *Lifelines* issues are archived on the TRIO website, and are available on our website 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.

Mind Over Matter

When I first volunteered to write an article about my favorite motto “Mind over Matter”, I was dealing with a recurring and annoying (but not fatal) health issue. Since it had become a recurring issue in my 20+ life post-transplant, I was starting to get depressed about it, worrying that, even though my gastroenterologist had assured me that my stomach ulcer was not H. pylori or anything else specific, nor was it malignant, perhaps there was something else going on that could be ‘the death of me’. After all, I had recently heard of the deaths of two of my transplant peers, each some 20 years post transplant. Maybe that was all I should expect – not be too greedy for more.

But then again, no, I thought, I am tougher than that, and I have been through a lot worse. After all, don’t I live by the motto, “Mind over Matter”? This ulcer was not going to take me down any more than any other challenge I’ve faced over the past 50+ years of my life has. So, I determined, I needed to confront this latest challenge head-on. But how? First off, I should schedule that trip back to the Starzl Transplant Institute that I had planned to take in honor of my 20th Anniversary of my liver transplant, and, secondly, I should contact my transplant surgeon who no longer works at the Starzl Transplant Institute.

So I did both of these things, and, you know what, everyone I consulted said the same thing: although the ulcer was not something commonly seen among liver recipients, as long as I continued getting it biopsied every so often, the once-a-day Prilosec should keep the ulcer in check.

What does all this have to do with the theme of this article, “Mind over Matter”? In our everyday lives, all of us confront challenges, whether they be small, like deciding what to wear to a meeting, or large, like deciding whether or not to agree to surgery for an aging relative. No matter the size of the challenge, it is how we face it that matters. If we choose to let it consume us, and our worries about its importance take over, we will have a difficult time overcoming it. If, however, we take the stance that, “as an intelligent human being, I can figure out a way to handle it”, we will most likely be able to focus on finding a course of action



that will help us overcome the challenge at hand. For me, it’s almost like solving a puzzle: first I make up my mind I am better than the challenge; then I consider my options and figure out the best way to do so.

Thus far, this motto has worked for me. It empowers me: I use it in a variety of situations such as when I am juggling many different tasks and deadlines, or whenever I am facing something I don’t think I am capable of doing. Even when I think what I am facing is beyond my ability, believing in myself and having the confidence to beat the challenge usually helps me do just that. I’m sure there will come a time when using my favorite motto won’t help me overcome a challenge, but it certainly won’t be for lack of trying.

-- Elizabeth Rubin, Vice President,
TRIO Board of Directors
Past President,
TRIO Board of Directors

Current OPTN/UNOS Committees

For a complete description of each committee’s charter, membership and meeting minutes, go to <http://optn.transplant.hrsa.gov/members/committees.asp>

- Ethics Committee
- Executive Committee
- Finance Committee
- Histocompatibility Committee
- Kidney Transplantation Committee
- Liver and Intestinal Organ Transplantation Committee
- Living Donor Committee
- Membership and Professional Standards Committee
- Minority Affairs Committee
- Operations and Safety Committee
- Organ Availability Committee
- Organ Procurement Organization Committee
- Pancreas Transplantation Committee
- Patient Affairs Committee
- Pediatric Transplantation Committee
- Policy Oversight Committee
- Thoracic Organ Transplantation Committee
- Transplant Administrators Committee
- Transplant Coordinator Committee

Ad Hoc Committees

- Ad Hoc Disease Transmission Advisory Committee
- Ad Hoc International Relations Committee

Promoting Donor Registration

“Wow, lines out the door and down the street!”

As we crossed the street to a Philadelphia city motor vehicle registration office to man an information table promoting signing up to be an organ donor this last day of the month morning, we were surprised to see the length of that line. Maybe the office wasn't opened yet? No, the line continued through the door and another 20 people waited to get instructions from the welcome desk, important information since it seemed there were 16 service windows all open for business, calling out names and window numbers for the every-seat-taken crowd of clients.

The OPO had made introductions previously so we were expected and quickly set up our table and banner at the bend in the waiting line. We had cookies and candy for this captive audience who had no choice but to wait right in front of our table. Turns out we had lucked out. This was the last day of the month and it seemed like everyone had waited until the last minute to take care of their DMV business. Plus, it was mid-morning and our free cookies were an easy attraction for some hungry waiters.

We moved from behind the table, a key to engaging people, working down the line offering brochures with information about organ donation, nicely accepted by about 75% of this very culturally diverse line with nobody being put out by our approach. When possible we shared our stories of heart and lung transplant success that gained respect and interest more often than not. Some gladly responded saying ***“I'm already a registered organ donor!”*** providing more support for onlookers of our message. To those we offered a very sincere ***“Thank you!”*** and received smiles in return.



The hours passed quickly and the line dwindled by 1pm, so with a feeling of success we packed up and returned table and materials to the OPO office and returned home for lunch. Overall we touched about 300 families that day, many committing to say “Yes!” when asked if they wanted to be organ donors as they had photos taken for their driver's license, often stopping by on their way out to share that fact, with a smile and pride in their voices.

Studies have shown that today, this is the most effective donor registration recruitment environment, bringing our life saving message to the license application site. But we later learned that not every day is so productive, so choose the days that their office tells you they are the busiest, like that last working day of the month. Also, don't forget the cookies and candy; treats go a long way toward opening contact with that audience, especially if children are involved. In those cases we were careful to first ask parents if it was OK for their child to take a cookie. Once you had the kids, parents were involved and open to the message: ***“Register to save a life, become an organ donor! We're alive today because somebody did.”*** And don't just sit behind the table, move out and make direct contact. Oh, and finally, don't forget to say thanks to the DMV office staff before you leave, stopping at each of those 16 windows with a smile and ***“Thanks for what you are doing!”***

(PS: During Donate Life month, we recipients were honored to provide the “show and tell” of our stories, accompanying the New Jersey Commissioner of Motor Vehicles as he visited every one of 36 offices to personally encourage his local clerks to promote organ donor registration. Now that's commitment!)



TRIO Youth Circle Announces New Projects

The TRIO Youth Circle announces some exciting new projects planned for roll out in the upcoming months. We're looking forward to engaging the TRIO youth membership in the life of the organization, and we want to provide useful resources tailored to your needs. Here's what you should expect to see in the months ahead:

Online:

- Re-activating the TRIO Youth Circle Facebook group to connect members of the community to one another and to provide accessible content online
- A series of webinars on topics of interest to Youth Circle members
- Updating the TRIO Youth Circle web pages to provide useful pre- and post-transplant guidelines and inspiring stories of transplant youth accomplishments.

In-Person:

- See the Facebook for a flyer announcing an inaugural meet-up skating event in Philadelphia on July 12, where TRIO youth members can get to know one another in person. Hopefully, this will be the first of many similar events throughout the country. If you're interested in having a TRIO Youth meet-up in a location near you, let us know so we can pick the best places to roll out these events
- We'll be reaching out to co-host events with other transplant youth organizations, to be announced on the TRIO website.

T-Shirt Contest:

- We will be making TRIO Youth Circle T-shirts that will be buyable on the TRIO website and Facebook page. Before we print them, however, we'll be having TRIO members suggest some designs to be voted in the T-Shirt section of the next *Lifelines*.

All of these projects, however, are about getting you and other young people in the transplant community interested in joining TRIO and providing something useful for you to take away from the Youth Circle.

We'd love to hear from you. What do you want to hear more about in the webinars or in the next *Lifelines*? What events would you be excited to attend? What are the challenges you face that we might be able to help address and discuss?

Muran and Josh, Youth Circle co-leaders (see their stories on the TRIO website), are both very excited to get working on the TRIO Youth Circle and hope to hear from you soon. To contact them, send your email to info@trioweb.org with "Youth Circle" in the subject line and stay tuned for an exciting future together.

United Airlines Supports TRIO and The Transplant Community

Through the generosity of the United Airlines Charity Miles Program, TRIO is able to provide ticketing for transplant related travel. Eligibility for use of Charity Miles tickets is based upon financial need.

The program provides travel for transplant recipients, candidates, living donors and caregivers who could not otherwise afford to purchase tickets for transplant related travel. More specifically, use of the travel program must be for one of the following purposes:

- Medical treatment or consultation prescribed by the Transplant Team or physician (pre- and post-transplant);
- Travel by a living organ donor for the purpose of donation or for medical consultation or treatment;
- A caregiver accompanying a transplant recipient, living donor, or candidate who must travel and is unable to travel alone.

The application must be submitted approximately 30 days prior to requested travel. Therefore, unfortunately, this program is not open to 'call in' requests. All ticketing under this program is by email, so the traveler must have email access. All applications are verified with the Transplant Coordinator and/or Social Worker.

For more information about applying to this program, call TRIO at 800-TRIO-386 or go to www.trioweb.org and look under "Resources."

The availability of acquiring tickets under the program is limited to the number of Frequent Flyer miles donated to TRIO. We always need miles . . . so, please consider donating your United Airlines Frequent Flyer Miles to this program. To donate your United Airlines Frequent Flyer Miles to TRIO, you can call United Airlines at 800-421-4655 or go online to www.united.com.

*Please donate your frequent flyer miles and
When Possible, Fly United!*

Touched by Transplant: Generosity of the Human Spirit

I believe in the generosity of the human spirit in times of unbearable grief.

I have been the social worker on a heart transplant team for 19 years. I am deluged daily with patients clinging to life while they wait for a miracle (a donor heart). That miracle comes for my patients only when unfathomable tragedy strikes another family. This nameless, faceless family is faced with the decision to donate their loved one's organs while simultaneously trying to understand the death of their loved one—someone with whom they just ate breakfast or whose kiss is still fresh on their lips. Though the decision can be difficult, the grieving family knows that somewhere in a hospital bed lays another person whose health is failing. And so, organ donation happens thousands of times a year; lives are lost and saved within the span of hours.

Waiting patients are cleaved with desire for a heart and yet filled with guilt for the indirect anticipation of catastrophe for another. This is evident perhaps nowhere greater than in the letters written between transplant recipients and donor families. Recipient patients are overcome with emotion upon writing their letter. Factory workers and CEOs alike all struggle to find words that come close to expressing what is inexpressible: the gift of life they have been given as a result of the loss of another. The act of writing that letter is the single most honest and therapeutic interaction I will ever have with them, or they will have with themselves. I am humbled each and every time I am granted access to this exchange.

There is one particular letter—a response from a donor family—that is etched in my mind that captures the generosity of the human spirit like nothing else I have ever read:

I want to express to you, in case you have been having any doubts or conflict regarding this, that it is OK for to feel happy for the second chance you have been given. As my family moves through our grief, you and your family must celebrate life. I want to thank you for giving our family comfort in our loss."

It is in the pure altruism that I believe in the generosity of the human spirit.

--Liz Shore, MSW, CSW

Member, TRIO Medical Advisory Board (MAB)
and past member of the TRIO Board of Directors.

Liz is a clinical social worker for the Advanced Cardiac Transplant Center at Thomas Jefferson University Hospital in Philadelphia, PA.

TRIO Scholarship Applications To Be Posted in January 2014

Applications for TRIO 2013 scholarship awards closed on June 30. The 2014 application will be posted on TRIO's website in January.

The 2013 scholarships will be awarded in the fall. Each award is in the amount of \$1,000. Each applicant will be notified individually as to the result of their application.

The number of scholarships awarded is determined by the number of scholarships donated, primarily by TRIO Chapters. In 2013, an additional scholarship will be awarded in honor of two TRIO Board of Director members who died in 2013: Alex Boyer and J.T. Rhodes.

(As we go to press . . .)

OPTN/UNOS Updates

Among many actions, the UNOS/OPTN board approved for implementation the long awaited new Kidney Allocation System (KAS) at its June 24 meeting in Richmond. The first major overhaul of the deceased donor kidney allocation policy since its inception 25 years ago, and the product of a decade in development, the KAS incorporates much of the public comment and feedback from public forums.

The new KAS improvements cut a middle road balance of reduced waiting list deaths and longer years of graft survival after transplant while eliminating or reducing earlier concerns about age discrimination and other issues raised from the public feedback. It introduces a quality scoring of donated kidneys and matching of kidneys to those who can make the best/longest use of them.

While admittedly not perfect, this lays the foundation for easier modifications as experience and medical advances may dictate. KAS is anticipated to be fully implemented in about one year. For more details, go to the TRIO web site under UNOS News.

It should be noted that TRIO was involved at many levels in the development of this new policy with Ron Taubman (President of the Ventura County/West Valley TRIO Chapter) speaking at the public forum and serving on the OPTN Kidney committee, and TRIO president Jim Gleason, as a voting member of the OPTN board passing the policy. TRIO chapters also hosted information sessions as the policy was open for feedback, encouraging TRIO members to submit their public comment directly to the OPTN committee.

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: _____

YES, I wish to receive *Lifelines* mailed to the above address. **OR:** YES, I wish to receive *Lifelines* by 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	

I would like to participate on the _____ TRIO Committee. Please contact me.

Annual Dues: Member at Large \$20.

Additional Contribution \$ _____.

TOTAL enclosed \$ _____.

Thank You for your tax-deductible donation!

Make your check payable to and mail to:
 Transplant Recipients International Organization, Inc.
 2100 M St., NW, #170-353
 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).

Lifelines is published quarterly by:



**Transplant Recipients
 International Organization, Inc.
 2100 M St., NW, #170-353
 Washington, DC 20037-1233**