



Lifelines

January 2015



Transplant Recipients International Organization, Inc.

13705 Currant Loop • Gainesville, VA 20155
www.trioweb.org • info@trioweb.org • 1-800-TRIO-386

TRIO Board of Directors Meet; Approve Budget, Elect Officers for 2015

The TRIO board met for its quarterly meeting via teleconference on December 10, designating this as its formal annual board meeting where both a budget and new officers were approved for the coming year.

New Officers

Officers for the 2015 year were elected as recommended by the Nominating Committee:

President: Jim Gleason

Vice-President: Steve Okonek

Secretary: Elizabeth Rubin

Treasurer: Susan Pincus

New Board Member

As detailed below, the Nominating Committee recommended and the board approved the election of Josh Morrison to fill the recently vacated seat of Harvey Mysel. As a Harvard educated lawyer and co-founder of the WaitListZero lobbyist team advocating for living donation, altruistic kidney donor and co-chair of the TRIO Youth Circle, Josh brings a youthful energy and passion to the board's deliberations.

Note: TRIO is always open to future candidates to serve on the national board. If you are interested or know another who is a good candidate, please send that name and contact information to info@trioweb.org for future consideration.

Improving Financial Condition

Following a positive fourth quarter summary financial report by Treasurer, Susan Pincus, the 2015 budget was approved as recommended by the Finance Committee. This budget essentially continues the current austerity program that has resulted in a dramatic improvement of our financial status from one of concern set back in the spring of 2014. Significant expense cutbacks, including this electronic *Lifelines* issue (saving \$12k per year versus the printed/mailed version), along with strong advertising revenues offset a severe drop in grant support and the cancellation of the 2014 annual leadership summit (which normally nets \$5k profit).

Chapter Growth

The board recognized the growth of chapters to now sixteen, while expressing concern over the lack of overall membership growth. The drop in members-at-large was attributed to the decrease in scholarship applications which require membership to apply and, thus, add new MALs in that process. The Chapter Council Chair will be working with chapter presidents in the coming months to offer support to specific chapters facing their own growth and activity challenges.

Other Board Discussion Items

Committee reports and other items of interest are the subject of separate articles throughout this issue, so be sure to closely read about Public Policy Developments, Scholarships, the Post-transplant Cancer Project, Caregivers, Etc.

Josh Morrison Joins TRIO Board



Josh is co-chair of the TRIO Youth Circle, a Cum Laude graduate of Harvard Law School (2010), and an altruistic kidney donor. He recently worked for a paired kidney exchange firm in Ohio.

At the current age of 29, Josh has formed his own firm, Wait List Zero (www.waitlistzero.org) dedicated to lobbying for donation and transplant related legislation issues. He has been working with TRIO's Public Policy Committee in recent months in that capacity.

The TRIO Nominating Committee felt that Josh's youth, energy, life experience and passionate effort in our field of common interest would make him a strong, active board member.

LOOK INSIDE: An update on TRIO's Post-Transplant Cancer Project; Public Policy; New Kidney Allocation System; Akron-Canton's Celebration of Life Dinner; Rose Parade Float Honors Ana Stenzel; Books; Movies . . . AND MORE!

President's Message



“Be determined to handle any challenge in a way that will make you grow.”

-:Les Brown

Can you believe it? Another year has come and gone and we are still here, all because someone said yes to being an organ donor. Your TRIO board joins me in sending you that annual greeting of joy with hopes for an even better 2015 year ahead.



Did you shed (as I did) some tears of joy this holiday season as family and friends gathered around you to celebrate life together? Some friends may not have been there, having died or due to health challenges of their own which serves to remind us of that blessing of our heart, lung, kidney, liver and pancreas transplants. It's at times like those that we look around and quietly give thanks for still being here, especially as we stop to celebrate and reflect on New Year's Day. If you haven't taken that time to reflect, please do so now, adding a prayer of gratitude and concern for the donor and their family behind that gift of life you enjoy for yet another amazing year of living.

So what lies ahead for you this year? As I am constantly surprised when my two weeks of pills are empty again, it reminds me of how fast time is passing us all. Without a plan or some goal setting, before we know it, another year is over and we find ourselves looking back and wondering where that went. Now is that traditional time to look ahead and dream of the possibilities we can accomplish/enjoy in 2015. What are your dreams with this extended life we share with our transplants? Want to know a secret? The way successful people turn their dreams into reality is by writing down those dreams and supporting that dream with a plan of action. Sounds too simple, doesn't it? But that is what study after study has shown, writing it down is the transforming action between success and failure to

achieve those dreams. You and I have been given a gift of life. What are we going to do with it? Tough thought to reflect upon, but there is still time, especially now at New Year's to do exactly that. Go get that pen and sit down for some quiet time alone and close those eyes and let your dreams flow. Nothing is impossible, so let your imagination out of its small box and smile as you see that dream in your mind. Now, quickly, write it down. There, you are on your way. Go share it with a loved one or friends, but don't let them take your dream away. Make your dream real, getting closer to its fulfillment each day of the new year. Next New Year's you will be able to look back on that special accomplishment with an even bigger smile, because "You did it!"

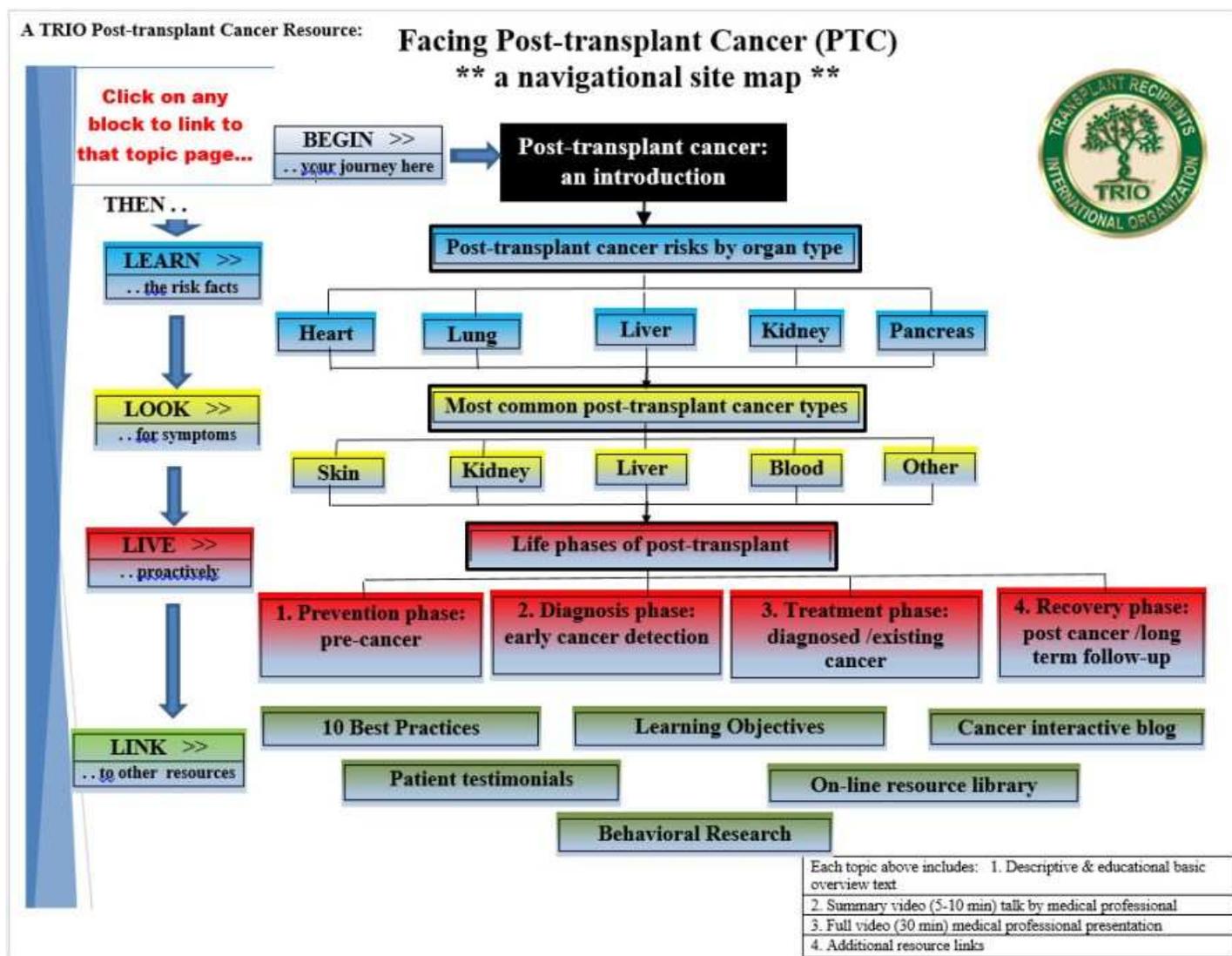
Now I want to add another challenge to that exercise. How about coming up with a dream accomplishment about how you can make a difference in your local TRIO chapter? Every chapter, some more so than others, needs YOU and your support to maintain its vitality and growth. Is this the year that you bring in some new members to your group? Is this the year you share an idea – one fun new idea or maybe one old idea that dropped off the chapter calendar years ago that can be restarted? Are you able to step up to leading a committee or joining one to support that committee's goal? Maybe your dream is to pay it forward by mentoring a waiting candidate or newly transplanted recipient? How can you support your chapter more in 2015? It's up to each individual to make that team become what it can be, and you are that individual in this message now. And don't forget to write that goal down so it doesn't fade over time, rather it will become your reality to the benefit of all.

Speaking of sharing, be sure to read that cancer project article with its opportunity to help others with your inspirational testimony. That's one of my goals for this year, to fill that PTC web site with support for so many who will face the challenge of cancer in their post-transplant lives, with your help.

As for me, on this New Year's Day and every day, I repeat: ***“Wow! above ground another day. This is going to be a GOOD one (again)...”*** as I pray it will be for you, too.

Sincerely,

Jim Gleason, TRIO president



What Can We Do About It?

What started out as a simple question is slowly growing into both a huge challenge and a TRIO project that will hopefully save many lives and enable recipients to live even more fruitful years than if they hadn't been concerned about dealing with the higher risk of cancer in their transplant lives.

Let's face it: nobody wants to think about cancer. But we can't just put our heads in the sand and ignore the medical facts of life. It's a fact that we, as transplant recipients, statistically live our extended lives with a higher risk of cancer than the average population; and that risk can be significantly higher, in some cases as much as 50% and more higher.

So far, we have identified four initiatives that TRIO members and TRIO as an organization can do to make that difference. The first of these is to develop a "Post-transplant Cancer Education" web site that the TRIO board has approved for going forward over the coming year. As seen in

other articles, we are into deep research developing the content for that resource, finding the facts that all recipients need to be aware of so they can look for signs of cancer and take actions to prevent, diagnose and treat early. In this way, by taking action early, the impact of those cancers can be minimized, allowing us to live long and fulfilled lives, overcoming that higher risk with proactive steps as detailed in what we are calling the "10 Best Practices" for dealing with that risk.

Several have stepped up to join the research team beginning in January to work with findings to fill that web site with the needed videos and information. Also in January, our web designers will begin development of that new web site that is currently expected to have 24 topics that will provide learning, recognition and action steps along with other resources in support of those goals.

(... continued on page 4)

TRIO's Public Policy Initiatives

The Public Policy Committee continues to meet regularly with many other coalitions to promote the transplant process. TRIO is a member in the Coalition for Part D Access to continue to protect access to medications for transplant patients and has recently become active on its communications subcommittee to work to ensure everyone continues to understand the importance of maintaining this benefit. TRIO participates with the Transplant Roundtable which is a forum where organizations representing patients, professionals and institutions can promote funding for transplant and protect the transplant community's interests in federal legislation and regulation. We also participate with the Chicago Transplant Ethics Consortium and several other organizations on living donation and continue our involvement with several UNOS subcommittees.

TRIO is also actively working with WaitListZero in that organization's work to bring parity to funding for living donation outreach and education with that for deceased donation efforts. TRIO will be accompanying WaitListZero representatives to a meeting in Washington with high level staff at the federal Health Resources Services Administration (HRSA) to discuss this proposal.

You can help to support TRIO's and Waitlist Zero's efforts by sending individual letters of personal support to HRSA. To read the instructions for sending a letter, along with a sample letter of support from a recipient and a sample letter of support from a family member/care-giver, [click here](#). Your individual letter will be invaluable to moving this effort forward.

We want to let you know about a number of recent developments that affect all of us in the transplant community, especially those waiting for a transplant. These changes include the implementation of the newly revised kidney allocation policy now in place and upcoming changes to the lung allocation policy scheduled to take effect in February of next year. UNOS continues to review the current liver allocation policy with revisions that were proposed last year undergoing further study and new proposals to be announced sometime later in 2015.

The Public Policy Committee needs your help and involvement. Each TRIO chapter should consider identifying a member or members who have an interest in public policy. Those individuals can both help review national issues and monitor state and local activities that affect the transplant community. TRIO needs input

from all chapters when considering any national position our organization might take. Each chapter is also more familiar with and better positioned to understand the impact of legislation at the state level. Contact Rodger Goodacre at rodger.goodacre@gmail.com or Ted Lawson at tedlawson0105@gmail.com for more background and to become part of the Public Policy Committee.

*--Rodger Goodacre, Member, TRIO Board of Directors;
Chair, Public Policy Committee*

Facing Post-Transplant Cancer: What Can We Do About It?

(... continued from page3)

Today you can see the initial concepts as laid out and linked off our existing TRIOweb.org site. Look to the topmost (black) navigation banner for that preview link. In the months ahead, those topics will be filled with the real information to guide visitors through this learning maze to prevent and treat cancers when they do appear.

You can help

If you have a post-transplant cancer life experience to share, we are gathering video testimonials so that others may learn from your experience. Send in a short summary of that story along with your contact information to info@TRIOweb.org for consideration. We will be getting back to you in the Spring to collect stories as we build out that patient testimonial section of the new site. Stay tuned!

Can You Make a Difference?

TRIO needs volunteers! We have no support staff, other than our Managing Services Director. TRIO needs just a small amount of your time each week . . . to do research, to clean up database files, etc.

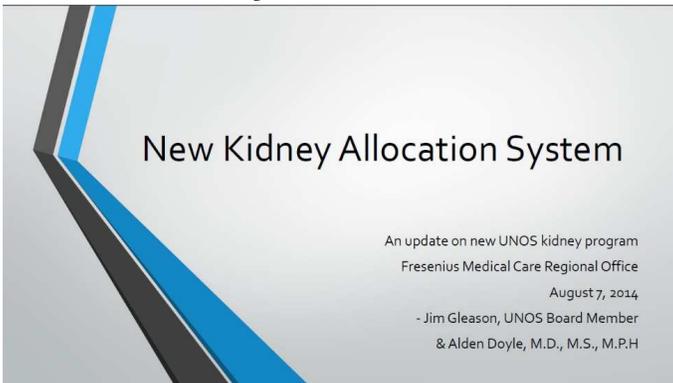
If you would be interested in making a difference as a volunteer, contact us at info@trioweb.org.

Lifelines is published online by Transplant Recipients International Organization, Inc., 13705 Currant Loop; Gainesville, VA 20155, 800-874-6386, www.trioweb.org.

Lifelines is published by the Newsletter Subcommittee 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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UNOS Launches New Kidney Allocation System



After twenty-five years UNOS has finally approved and, on December 4, launched the new kidney allocation system. This has been a long time coming with many opportunities for patients and medical professionals to preview and comment on the various proposals over recent years that led to this implementation. The past year has seen much education for kidney program staff and patients to see how the system will affect current candidates, while many feel it will have no significant change for most on the current waiting list. However, for some who had been on dialysis for a long time before being listed, they will gain waiting time as that start of dialysis now is the start point for accruing wait list time, still a key factor in allocation.

The big difference is that the best kidneys (those in the top 20%) will first be offered to patients with the best chance of using those kidneys for the longest time. This in turn will reduce the number of re-transplants, making more kidneys available for the rest of the candidates. Also, certain hard-to-match patients will now get extra points to better balance their chances of getting an offer. Those are the goals of the new process, with the results being carefully watched and compared to the simulations that predicted the expected benefits, allowing for adjustments to those formulas if they don't turn out that way in future system tweaks.

To watch a video explaining the new system, enter this address or just click on: <http://vimeo.com/107481347>

To download a slide presentation (no narration, just slides) used recently to educate dialysis social workers on the new system, click on the cover slide above.

New Titles in Transplant Library

In time to prepare members for the launch of the new UNOS kidney allocation system on December 4, we shipped out to each chapter's librarian the out-of-sequence but very timely presentation topic (Program #64): "A Changing Kidney Allocation System" We hope you can view this presentation if that is your topic of interest or know someone on the waiting list who can benefit from that educational viewing.

If you've never watched at least one of TRIO's 68 [Transplant Presentation Library DVD programs](#) (← click here to see the growing index of titles), you are missing out on one of TRIO's many services offered free as part of your annual membership dues. Each chapter has a full library of these interesting videos that can be used for group or individual home viewing. Those libraries are about to outgrow the carrying case each chapter was sent five years ago, so a new case will be coming soon to hold the programs that are just now being released along with twelve more each year thanks to the support of our sponsors, Astellas and Genentech. Members at large, write to info@TRIOweb.org to request a DVD title (free!).

Now we even have a few programs that you can watch on-line by clicking on the title as indicated below.

New Releases:

- Program #64: "A Changing Kidney Allocation System"
- Program #65: "Starting a Kidney Transplant Program in a Region of Hyper-Competition in an Era of Hyper-Regulation"
- Program #66: ["Staying Healthy Years after Heart transplant: Change in Focus of Care over Time"](#) (← click to view on-line)
- Program #67: ["Choosing Life, A Donor Sabbath talk example"](#) (← click to view on-line)
- Program #68: ["The Importance of the Caregiver's Role in Transplant"](#) (← click to view on-line)

Continuing Communication Challenges



How does a national organization reach out to all its members? We continue to need YOUR help in increasing access to our program of TRIO communications resources.

Each day, we add material to the TRIO web site. Each month we mail out electronic E-News to almost 1,000 members who have provided their e-mail addresses for that mailing. Each quarter we mail electronically this *Lifelines* newsletter of anywhere from 8 to 12 pages of articles of interest to our TRIO members and their families and to many transplant professionals. While we get an above the industry average of 45% who OPEN those electronic communications, the actual click-through to the *Lifelines* is a much smaller 15% of that total mailing. YOU are the choir, as they say. So, I'm not preaching to YOU, rather asking you to help improve those numbers by promoting and spreading the word of the value and useful information in those e-mailings to your local transplant network.

We invite your feedback on our efforts, offering suggestions for improvements and even contributing ideas or articles you might write for future mailings. Your story is a possible inspiration to others. Your life experience can be a learning to others in need as they face similar transplant life challenges. Write to info@TRIOweb.org with your thoughts and suggestions. Meanwhile, we will continue to use as many means of communication, especially through the support of local chapters who encourage and pass through our messaging to their chapter members, for which we say "Thank you!" Together we can personally touch so many more.

- Jim Gleason,
TRIO President

Do YOU have a story to share?

Lifelines welcomes your article contributions for consideration by the editorial board. Suggestions for an article, either one you write or a topic you would like to see authored by someone else, should be submitted to info@trioweb.org in summary form.

The editors will respond and, if accepted, you would then write the full article for use in an upcoming issue.

***Become a part of the action!
Offer your ideas today!***

A "Trio" Represents TRIO at the American Society of Nephrology's Summit

A special thanks to our national treasurer, Susan Pincus, who along with living donor, Sue Kelchner, and her two-time kidney living donor recipient husband, Bob, represented TRIO at the **American Society of Nephrology's 2014 Summit of US Kidney Organizations** held in Philadelphia this November. They joined in providing patient input to the 2015 KCAD campaign planning.

The full day event brought together the kidney community to discuss current policy initiatives, review Kidney Community Advocacy Day 2014, generate a list of issues to highlight during KCAD 2015 and identify a single approach to estimating the total number of Americans with kidney disease for consistent public health messaging. Current policy initiatives include The Chronic Kidney Disease Improvement in Research and Treatment Act of 2014 and The Comprehensive Immunosuppressive Drug Coverage Act of 2013.

Pictured below are Bob Kelchner, Susan Pincus and Bob's donor wife, Sue Kelchner.



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Akron-Canton Chapter Holds Celebration of Life Dinner



Our annual TRIO Celebration of Life Dinner has become a family tradition for many of us. The Craig family attendance has grown over the years and this year brought 8 family members. The Scolaro family also looks forward to this annual get together and little Morgan, who is now 15, grew up attending meetings. She called the day before to make sure she was able to attend even if her mother was not feeling well. The Price family not only attend every year, but this year supplied the door prizes.

In December, our monthly meeting grew from our usual 15 to 20 members and a pot luck dinner to a feast with 3 long tables of food, 2 desert tables and a turnout of 50+ TRIO friends and family.

The meeting opened with a prayer, including the thoughts: *We have been blessed more than many others, none of us know the reason we needed a transplant nor do we understand the complex series of events that must occur in perfect harmony to achieve a successful transplant. . . . Watch over us as we return to our homes, grateful for our present circumstances and looking forward to more life, brought about by transplants. . . .*

There were two Donor/Recipient Quilts on display from LifeBanc thanks to Dianna Phillips. Many of the blocks on the quilts are from Akron Canton TRIO members.

Dianna described the opening of Transplant House of Cleveland's "Phase One" housing--7 apartment suites in University Circle and reminded us that the 2016 Transplant Games will be in Cleveland.

We heard the inspiring story of 2-1/2 year old David Gorham from his mother Kimber (supported by Mike, his father). David fell into a lake at a picnic and medics were unable to save him. His life became a tribute to the medical team's kind support of his family – providing a bed so that his family could hold him and finding a photographer in the middle of the night so that they could have a family photo with David and his brothers Nicholas and 10-week-old Josiah . David donated his kidneys, cornea and heart valve.



Our meeting closed with our members dedicating ornaments on our Donor Tree provided by the Gordons. It is always a blessing to meet the families and friends who have taken this transplant journey with us.

As Tracy pointed out to all of us, the word "family" extends to people we love and honor and for her and Mary, Dick was family and we miss him.

-Walter Hinkle, Co-President with wife, Nancy,
TRIO Akron-Canton Chapter

Gary Foxen Dies at Age of 79



Gary Foxen with wife Lois

Gary Foxen, the man who developed the idea of the Rose Parade Donate Life organ donation float and the Fallen Soldier Donor Memorial Campaign, has died.

Gary died in November at the age of 79. At the time of his death, his transplanted lung, which he received at UCLA in 1999, was still functioning; but he succumbed to an aggressive adenocarcinoma (Squamous Cell Cancer) in his lung.

He was a United States Air Force Veteran, serving from 1954-1958 and was a loving husband to his wife Lois, a wonderful brother to his sister Adrienne Envall, proud father of his son Nickolas and granddaughter Isadora.

Gary was a 13-year member of TRIO Ventura County West Valley Chapter. He was very committed to advocating organ and tissue donation throughout Southern California and supporting and educating the transplanted, candidates waiting for a transplant, and their family members.

Seeing a need for a transplant support group in the Orange County area, about 10 years ago, Gary assumed the leadership of "A Gift of Life" Heart Transplant Support Group. He then expanded this support group to include all types of organ transplant recipients.

After receiving the lung transplant he wanted to show his appreciation of his "Gift of Life". In 2001, he wrote a letter to OneLegacy, the federally designated Southern California organ-donation network, and proposed a float to honor organ and tissue donation.

Over the next 3 years, OneLegacy, the California DMV, and Gary worked to get approval to have a Donate Life Float entered into the Rose Parade. The Donate Life Float made its debut in

the 2004 Rose Parade and has been a regular every year since.

TRIO VCWV Chapter has proudly supported the yearly float as a Contributing Sponsor for the previous 11 years. Gary was an honored rider on the 2006 Donate Life float. Foxen believed that the float in the parade garnered positive attention for organ donation and put a "human face" on the wonders of organ and tissue donation.

Gary's next project was establishing the Fallen Soldiers Memorial Campaign which would honor our military heroes who became organ and tissue donors. These brave men and women succumbed to their injuries at the Landstuhl Military Hospital in Germany.

OneLegacy Foundation, with the help and support of the United Network For Organ Sharing (UNOS), have partnered together to correct this oversight by proposing the construction of military donor memorials at the National Donor Memorial in Richmond, Virginia, and the Landstuhl Military Hospital in Germany to recognize the lives of these brave men and women who have made organ and tissue donation their last act of public service.

The TRIO organization has lost a good friend and he will be greatly missed.

A Memorial Service in honor of Gary's life is planned for Sunday, January 11, 2015 at Rose Hills Memorial Park 3888 Workman Mill Road, Whittier, CA 90601. (562) 699-0921.

Donations in honor of Gary Foxen may be sent to:

Fallen Soldier Donor Memorial Contribution
2015 Founders Rose Dedication

*-Ron Taubman, President
TRIO Ventura County/West Valley Chapter*

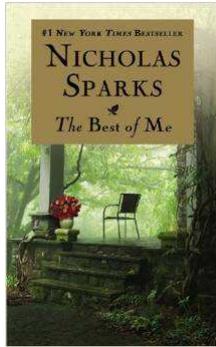
TRIO Scholarship Application Available

The 2015 TRIO scholarship application is now available on-line at www.trioweb.org, under "Resources." Any TRIO member or family member can apply. The deadline for submitting the on-line application is June 30, 2015.

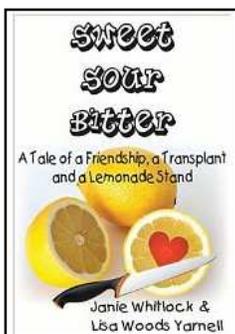
The TRIO Scholarship Committee is chaired by Elizabeth Rubin. Volunteer members of the committee are: Steve Binder (NEFla Chapter); Suzanne Himes (Greater Cleveland Chapter); Dorene Kray (Akron-Canton Chapter); Susan Pincus (Philadelphia Chapter); and Sylvia Leach (TRIO Managing Services Director).

Recent Movies and Books of Interest

You never know where you are going to find them! On the recent occasion of my heart transplant 20th anniversary, my wife, Pam, and I took in a movie we had been waiting for, one based on the Nicholas Sparks book, **The Best of Me** (movie of the same name just recently released). We love his writing and the movies are usually equally good. As we sat in the theater that Sunday evening, we both were aware that twenty years ago at that hour I would have been coming out of transplant surgery. Imagine our mutual and complete surprise when at that time in the movie's storyline, there was a heart transplant part of the story! As we left the theater reflecting on that surprise, our words spoken at the same time: **"God sure does have a sense of humor!"**



When we got home, I searched to find out how I had missed reading that book because, as a fan, I always order his writings for their day of release delivery. Found it in my library, confirmed that that same heart transplant story was in the book as on the screen. Turns out my wife had straightened out my library and this unread novel had gotten filed with the others already read. My recommendation? Read the book and then go to see the movie. I really haven't revealed enough to spoil your experience.



Recently I read and reviewed a new book about a caregiver friend and the patient, a very short work titled: **Sweet Sour Bitter: A Tale of a Friendship, a Transplant and a Lemonade Stand** by Janie Whitlock (the liver candidate) & Lisa Woods Yarnell (the caregiver friend). They offer a

unique insight into how a friend and candidate come together at a time of need, after a long-ago college friendship. Both authors are well written and offer a very personal, balanced reading style as they share their life challenge events from both perspectives: those of a caregiver friend and the supported patient, a very interesting dual story reading. You can find the book on Amazon.

Be sure to use your Amazon Smiles account when buying it.

–Jim Gleason

What's New on TRIOweb?

As we move into a major design effort in support of the Post-transplant Cancer project this spring, you can 'watch through the hole in the fence' that was so familiar when new construction hit the town years ago (and still in big cities these days). Just look to the VERY topmost navigation banner, the one above the bright green one visitors usually focus on, to that black navigation line where to the right you see the clickable "[Post-transplant cancer site map](#)" – that's the 'hole in the fence' where you can see the full draft of that new educational resource as it builds out in the months ahead. Right now it's a concept to be used by our web designers to create a full sister site similar to the current TRIOweb.org site, focused on this significant life-saving issue. As our research develops that content over the next year and more, the 24 modules of information and supporting videos, will become real in a phased updating process. In the meanwhile, you can see both the concept and that information as it develops, along with an invitation for YOU to help with your own stories. Check it out!

Links, links and more links!

The most active section of our web site continues to be the daily addition of timely transplant related news stories and video links. Along with the **700+ resource links**, there are now over **500+ searchable news items** to help you keep current on the ever- changing world of organ donation and transplantation. Stay informed with regular visits to see the top three stories in each of the highlighted six categories of news collected from many sources in the news media and medical journals/blogs, etc. A one-stop place to stay current on issues.

And for anyone not on the list for our monthly **TRIO E-News** and quarterly **Lifelines** electronic distributions, links to each are always highlighted on the site's home page at [TRIOweb.org](#). Of course you are welcome to add your e-mail address to those distributions just by sending your request to info@trioweb.org

–Jim Gleason

A Caregiver Shares:**Who Would Have Thought?**

When I was young, I was a gutsy girl with big dreams. I imagined a life of adventure. I would be a world traveler or perhaps a firefighter (yes, I was a tomboy!) or even a journalist crossing the globe telling tales of war and humanity. I never once, in my wildest dreams, imagined that my biggest adventure, my hardest battle, would be a fight for life . . . the life of a loved one that I hold so dear.

This is a real live fight . . . it is facing life and death every single day. It is not knowing if my loved one will even make it to the next day! That is how sick he is. This is my fight to get him what will hopefully be a life-saving doubled lung transplant.

It seems like a dreary fight some days. I spend much of my time asking, begging friends, family, and strangers for assistance to help fund the surgery and the astronomical costs that come with it . . . expenses not covered by insurance. It is convincing a transplant center that his life is indeed worth saving. It is assuring my sick and weary partner each day that there IS a future for him and then convincing him that I want to be a part of it. It is definitely the hardest job I have ever had to do. Being a caregiver is more often than not a thankless job and definitely not the glamorous life I had anticipated. But it is a worthy fight: saving a life, or at least, doing everything in my power to do that.

And even on the toughest days, I know that the real fight will be in the operating room, when that time comes, for the surgeons and medical staff. The thought of them removing the lungs of my dear Michael and replacing them with new ones seems, well, strangely normal after so many years of working towards getting him a second chance.

We were both elated when he was accepted at the Cleveland Clinic in July. His quality of life has declined to the point where we are willing to trust these surgeons to open him up, remove the organs that keep him breathing and give him a second chance at a new life.

Lung transplant surgery is highly risky with 83% of lung transplant patients surviving the first year. The biggest risk is rejection and infection. The lungs are the largest human organ in our bodies that aren't exposed directly to the outside world. Since lungs are not sheltered or

protected like the other organs, the risk of infection is high.

Michael will have to avoid crowds, sickness, mold, dust, and many other things that most people take for granted. He will be on costly anti-rejection medication for the rest of his life. These medications that will save his life and help keep his body from rejecting this new organ can also eventually destroy some of his other organs. He will most likely need another transplant down the road. Many transplant patients end up getting a second and, even a third, transplant of kidneys or liver due to the damage done by the medications that make his new lungs work. Many develop secondary illnesses, such as diabetes. Yet, after years of watching his health decline and seeing his ability to breathe on his own being taken from him, we have both agreed after many heart-wrenching, late night conversations that this second chance is the right one and worth all the risks that accompany the surgery. What is life if you can't breathe on your own and you are tethered to a tank to sustain life?

While I am often weary from the constant battles we have faced during this journey and often miss that dream life that I had hoped for, there is one thing that keeps me going: seeing Michael get a second chance at life.

-Jeanne Apelseh, Caregiver
sunchaser@rap.midco.net

United Airlines Partners with TRIO to Offer Flights for Pre- and Post-Transplant Medical Events

TRIO is very pleased to be one of approximately 30 non-profit organizations eligible for ticketing through United Airlines. These tickets are for frequent flyer seats and are not always the most convenient schedules.

Available seats can be used by TRIO members and non-members—anyone who has financial need can apply. The requirement is that the tickets are issued for pre- and post-transplant travel for transplant related medical events. An information page is available on trioweb.org, explaining the parameters for applying. The only charge to the passenger is a direct charge from United Airlines for the security fee (usually \$10-\$20 per passenger).

For more information, contact info@trioweb.org

How We, As Individuals, Are Part of a Meaningful “Club”

My involvement with TRIO started with my liver transplant 22-1/2 years ago.

I first learned about this organization as a patient in the University of Pittsburgh Medical Center Transplant Center (now called the Starzl Transplant Institute) in 1992, when a few members of the Pittsburgh chapter came to visit me as I waited for my transplant. They invited me to attend their next meeting, which would be held in the hospital. By the time that meeting took place, I was so weak that I had to be wheeled into the meeting room. I was physically only able to stay at the meeting for a brief while; however, I took away from it the optimism and hope of its members and the true camaraderie of the group. They were very welcoming to me--a “newbie” in the world of transplant--and invited me to attend events they were planning for the following year. Since I was still on the waiting list for a liver, I had no idea how long I’d be in Pittsburgh, but I vowed to start a chapter in Philadelphia if/when I returned to my real home.

I returned to Philadelphia later that same year, with a transplanted liver, but was physically unable to follow up with my promise until the following year. My transplant surgeon, John Fung, had given me the names of a few people he knew in Philadelphia, but my two young daughters and my own physical limitations prevented me from following up with any of them. It wasn’t until 1994 that I was able to put together a core group of people who were interested in starting a TRIO chapter in Philadelphia. Most of the transplant-related individuals I met in Philadelphia seemed satisfied with their local connections and groups, while I felt strongly that all of us transplant recipients, no matter where we were living, needed to connect through a national organization such as TRIO to become a stronger voice in the transplant world. After all, there were only 35,000 on the national waiting list in the early 90s, so the number of recipients was considerably lower than it is today.

Once I had a few interested people in Philadelphia, I reached out to TRIO national, who gave me some ideas of ways to engage people in my city, and who also connected me with leaders in other TRIO chapters to help me form a chapter. Initially, in Philadelphia, we focused on helping patients, by setting up visitation programs at many of the transplant hospitals in

the Philadelphia area. In addition, we held events to increase donor awareness. By 1997, with the help of our local OPO and much guidance from TRIO national, TRIO Philadelphia Chapter had its charter. As its founding president, I felt proud to be an integral part of something larger, an international organization whose mission was to help people navigate through the transplant system and to help educate the greater public on the need for organ donors and about the success of transplantation.

In all the years I have been involved with TRIO, I have to admit that I have continued to feel the need for all of the members to communicate with each other, to share our experiences, and to help each other every step of the way. Some of my happiest times have been at the conferences my husband Bruce and I attended in the early years. These were annual events, held in such places as Boston, Nashville and Seattle. As many as 350 people might attend from TRIO chapters from all over the world. Of course, it was a different time, when it was not nearly as easy to get information and connect with people online. Initially, as a TRIO chapter president, and later as a TRIO board member, I learned so much at the conferences, from the professionals who spoke, as well as from my fellow transplant recipients, who shared their own personal stories and the experiences of their TRIO chapters.

Today, even though face-to-face meetings are more difficult and more expensive to set up, I still believe in the value of TRIO. For me, the reason to belong to TRIO continues to be to connect with others who share a similar experience, to help each other, and to learn as much as we can so that we can continue this fulfilling life on earth as long as possible.



*Elizabeth Rubin,
Founding President of
TRIO Philadelphia Chapter;
Past President, TRIO
Board of Directors;
Currently, Secretary of
TRIO Board of Directors*

Rose Parade Float Honors Ana Stenzel, Two-time Double-Lung Recipient

Our longtime San Francisco Bay Area TRIO Chapter member, the late Ana Stenzel, will be honored in the 2015 Tournament of Roses Parade in Pasadena, but not as a transplant recipient. Instead, her picture, on a florigraph--a portrait made from flowers--will be included on the Donate Life Float, marking one of her last wishes: to be a donor.

Ana, twice a double-lung transplant recipient due to cystic fibrosis, died of cancer in September 2013. Upon her death, her corneas helped give the gift of sight to two recipients in Maryland.

A reception at Lucille Packard Children's Hospital on December 8 unveiled the florigraph that will be part of the float. In addition, family and friends remembered Ana as a woman who "lived a life with intention, determination and gratitude." Among those gathered were Ana's parents, Reiner and Hatsuko Stenzel, her husband Trent, and twin sister Isabel Stenzel Byrnes.

The theme of the 2015 Tournament of Roses Parade is "Inspiring Stories," and the Donate Life float is titled "The Never Ending Story." It features 60 butterflies--one for each life that can be transformed by a single deceased donor--emerging from an open book. The butterflies ascend above 72 volumes of books adorned with florigraph portraits of deceased donors, whose legacies are nurtured by their loved ones. Walking alongside the float will be 12 living donors. Seated on the float will be 30 organ and tissue recipients.

Stenzel, with her twin sister Isabel, are the authors of "The Power of Two," and appeared in a

motion picture of the same name. Isabel also received a lung transplant due to cystic fibrosis.



Isa admires florigraph of sister Ana. Also shown is Kathy Clark of CRDN.

Cathy Olmo of the California Transplant Donor Network (CTDN) noted the importance of the float's appearance in the Rose Parade for the Donate Life Cause. The parade is second only to the Super Bowl in terms of audience. She noted how the number two seemed to pervade Ana's life: twin sister, double lung transplant twice, donated two corneas, and the Power of Two!

Isa recalled her sister's unique capacity to push herself, in fact, actually thriving on it. Even while facing cancer, "helping others seemed to give her a brief respite from her own illness."

Gerald Seery, CEO of Tissue Banks International, the world's largest supplier of ocular tissue in the world, described the conditions faced by the recipients of Ana's corneas. He noted that even transplant recipients could be an important part of the miracle of donating life, now from the giving side.

-Steve Okonek

Member, TRIO Board of Directors

Building a float:



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: _____

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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 \$ _____.

Make your check payable to TRIO and mail to:

Transplant Recipients International Organization, Inc.
13705 Currant Loop
Gainesville, VA 20155

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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