



# Lifelines

Spring 2014



Transplant Recipients International Organization, Inc.

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## Charlie Alexander Joins TRIO's Board of Directors



TRIO is pleased to announce the appointment of Charles E. Alexander (RN, MSN, MBA, CPTC) to its Board of Directors. Alexander is currently the President and CEO of The Living Legacy Foundation of Maryland (LLF) where he has also served as Director, Clinical & Hospital Services; Director,

Program Development & Donor Services Center; and Director, Hospital Development.

During his extensive 17-year career, Alexander has served the transplant community through numerous affiliations: as founder, President and CEO of Lifelogics, Inc., founding board member of Donate Life Maryland, and through affiliations with the Cowley Shock Trauma Center in Baltimore and The Johns Hopkins Hospital Intensive Care Unit. During those years, he served in various capacities with the United Network for Organ Sharing (UNOS/OPTN), The Organization for Transplant Professionals (NATCO), and the Association of Organ Procurement Organizations (AOPO).

Alexander, who lives in Bel Air, Maryland, received his formal education at Towson University and The Johns Hopkins University.

Jim Gleason, President of TRIO's Board of Directors said "As TRIO continues its resurgence, we are excited at the opportunities that Charlie brings to our organization with all his skills and career experience of leadership and passionate personal dedication to the donor and transplant community."

## CMS Drug Issue Was a Good Example of What YOU Can Do!

TRIO's mission calls for advocacy on transplant and donor related issues. A recent example of TRIO in action was our individual and organizational response to the CMS threat to our transplant community. Over the past few months, TRIO played a significant role with multiple coalitions in engaging support for the protest to CMS about a proposed 2015 removal of protected class status for immunosuppressant drugs.

With the alarm raised to TRIO national by Ron Taubman shortly after the CMS proposal announcement appeared in the Federal Register, he and his chapter's team of advocates became the focus of many communications on the topic to fellow chapters who in turn used TRIO E-News alerts and updates to spearhead a public response that finally reached the 5,000 mark of public comments to the CMS web site.

TRIO joined with hundreds of other organizational supporters participating in weekly conference calls to plan the campaign and sign on to joint letters addressed to CMS leadership and key politicians raising the concern with such lobbying groups as **The Partnership for Plan D** and Washington-based long time TRIO participation with the **Transplant Roundtable**.

We reached out to our Medical Advisory Board (MAB) for their professional guidance and input. TRIO listened in on the government hearings' speakers, reviewed transcripts of testimonies given there and met with key leaders of organizations such as the American Society of Transplant Surgeons (ASTS) and politicians to support them in publically speaking out at those committee hearings with facts and patient stories.

Members reached out in their own grass roots efforts to engage local Congressional Representatives with personal appeals.

(... continued on page 6)

## President's Message



***“Live daringly, boldly, fearlessly, embrace the challenges, so that you may feel the exhilaration of victory.”***

*-author unknown*

What a challenging yet exciting time we live in, both as a TRIO organization and in our individual lives. Medical advances like the one featured in our **iDoctor** piece and advances in organ preservation (as in the earlier “**in-vivo** lung” story) are just the tip of the iceberg that will be making our own transplanted lives more fulfilling, longer lasting and healthier. Changes in the insurance world, like no exclusion for prior conditions and the slowly closing infamous ‘donut-hole’ for drugs, are just some examples on the financial side. Another challenge for all of us is the two-fold increased risk of cancers that comes along with our life-saving immunosuppressant drug regimens (and thanks to our gift of a new organ, advancing age!).

TRIO is challenged with supporting our transplant community in finding ways to help and that cancer issue is one that is coming up on our radar as we meet with researchers and practitioners to search for possible initiatives in that area. The past year was a year of financial challenge for TRIO, but in just the first three months of 2014 we see that turning around thanks to aggressive work by our managing services director, Sylvia, and the support of an active grant committee and a concerned board. Much work needs to be done, but we remain optimistic as we move forward with funding for our **Fall Leadership & Educational Summit** as described in the article on page 3. We do hope to see you in L.A. this September 19-20. You do not want to miss this exciting event.

Speaking of excitement, how about the news that UNOS is going to have a patient as its president in 2015! As noted in our UNOS article on page 4, not only was our TRIO president one of the two nominees for that vice-president role (defeated in that election), but TRIO was also mentioned three times in their recent UPDATE news. As we transition to this electronic *Lifelines* version, UNOS just announced a similar move for their UPDATE magazine. It has just become too expensive to print and mail for all organi-

zations, and as good stewards of funds, we have to make changes. But in that change, how exciting are the opportunities that come along with that technology as you see in this issue - clear color photos, ‘hot’ links to deeper information on topics, quicker distribution, etc. And, yes, we know that comes with challenges for the ever shrinking population who lack internet access or email addresses, but the tradeoff of \$12,000 a year saving in this tight economy is forcing that progress across the country for all groups. Hopefully, our readers will both adapt and reach out to help those who don’t have e-mail or internet access by printing out a copy for them.

How about that recent CMS drug coverage challenge! How exciting it is to see TRIO join with so many other groups, providing awareness and enlisting membership public comment support (that’s YOU!), to get a reversal of that proposed change. That’s our mission and whether it’s the UNOS kidney allocation changes or the CMS issue, you get to understand the issues and be heard through resources and messages sent out from TRIO. Thanks to every-one who took that challenge and helped in this campaign.

It’s exciting to see our latest TRIO board member addition, Charlie Alexander. In the near future, look for other news about upcoming additions to our Medical Advisory Board (MAB). Along with the excitement of new TRIO chapters, it was my personal pleasure to visit recently with Northeast Florida chapter president, Paul Winter and his wife. My ‘donor mother’ wife, Pam, and I were guest speakers at their November meeting in Jacksonville. They are challenged with revitalizing a chapter after the loss of its longtime leader, JT Rhodes, a challenge many face in the life of a chapter when leadership changes for any reason. With changes, just as our fading snowy winter is now changing into another beautiful spring, come fresh opportunities (new ideas, different thinking, new direction). And that is what our organization thrives on, with your accepting and supporting change, as we each faced with our transplant, new challenges and new life.

Let’s join together to celebrate and support each other in this exciting and challenging life we lead, hopefully for many years to come!

*--Sincerely, **Jim Gleason**, TRIO President  
(celebrating my 20<sup>th</sup> year  
with this ‘new’ heart)*



## TRIO's Chapter Council Chair Speaks Out, Asks for Feedback

As the new Chair of the Chapter Council, I need your feedback. There was no history to indicate how the Council functioned in the past, so I'm going to take this opportunity to

put a new spin on it. Going forward, in addition to the quarterly highlights, I would like the meetings to revolve around what we need to do as chapter presidents to help new chapters get started and to grow the existing chapters.

On the most recent teleconference, I heard about all the great things that are being done. But I also heard things like: *I'm new at this; Our membership isn't staying around; It's been a struggle finding new members, and What does everyone do at their meetings?* only to share a few of the comments.

Everyone knows that our time is very valuable and limited. The Chapter Presidents' teleconference is just another meeting we need to squeeze into our busy calendars. So, let's make it worthwhile! I think our time can be best utilized discussing new and useful business practices and sharing ideas to help our newer chapters find success.

I would like to get your feedback on this idea. Can we do things differently? Can we find ways to grow TRIO? Let's work on making our new and existing chapters stronger.

Over the coming weeks I would like to hear from ALL of you about your thoughts on this issue. Please take the time to share your ideas with me. I can be reached at 410-558-0451. Or, you can e-mail me at [martm6905@gmail.com](mailto:martm6905@gmail.com).

Together we can help TRIO grow.

--Marty Maren  
Chair, TRIO Chapter Council  
President, TRIO Maryland Chapter

**Congratulations to UNOS!**  
... on the 30<sup>th</sup> anniversary of its  
incorporation: March 21, 2014.

## Educational Summit 2014: It's Coming! Are You?

Our location for this year's big educational and social event is confirmed for L.A., California, hosted at the OPO offices of One Legacy, on Friday and Saturday, September 19-20. As usual, we will have an **open** national board meeting Friday morning before the Summit begins with lunch at noon. Just confirmed: UNOS' new CEO, Brian Shepard, will be the keynote speaker. Several internationally known transplant specialists will host workshops on specific organ transplant topics; names and topics will be announced in the weeks ahead. Expect to see a detailed agenda with hotel information along with a survey of interest to see if you are coming so we can plan accordingly. We plan for about 100 TRIO members and invited guests coming out for ten workshops, two lunches and possible dinners or a baseball game. We hope you can join us for this annual event.

**"YBSW?"** What's involved in a 'summt' event, you ask? Well, just go to the [TRIOweb.org](http://TRIOweb.org) site and under Communications/Resources you can sit in "virtually" on the workshops and presentations from previous summits. It's certainly not like being there and participating in person, but you will get the idea. Did you check out the online educational fun in viewing the very popular 2012 panel discussion on **"Sexual Intimacy Post-transplant"**? That session really engaged the audience and provided insight into the survey results many completed as a foundation for that session. Our audience asked for a repeat of that topic with longer time to explore and share at future events, so that one will definitely be on the agenda.

Mark your calendars for LA, September 19-20, and start saving your \$\$\$ for the trip now.

Scholarship opportunities will depend on pending sponsorships, so are not known at this time.

## Wanted: Your Ideas for Grant Applications or Funding

Each year, TRIO's Fund-Raising and Grants Committee searches for financial resources. With most large companies reducing their support, we need your ideas of where to go for TRIO funding.

If you have an idea, please share it by e-mailing [info@trioweb.org](mailto:info@trioweb.org).

## TRIO Board Elects New Officers

At the annual in-person meeting of the TRIO Board of Directors, held at the Gift of Life Donor Program offices in Philadelphia, PA, on November 16, 2013, TRIO's Board of Directors elected new officers:

- Treasurer: Susan Pincus (Philadelphia)
- Secretary: Steve Okonek (San Francisco)
- Vice-President: Harvey Mysel (Chicago)
- President: Jim Gleason (New Jersey)

Expressions of appreciation for their service were extended to out-going treasurer James Mateiko, secretary Susan Pincus, and long-serving vice-president and former TRIO president Elizabeth Rubin. These outgoing officers will remain on the Board of Directors.

## Public Policy Committee Update

If you haven't already nominated your chapter's Public Policy Chapter Champion, there is still time to get someone on the distribution list for upcoming news in this area of advocacy. Without a name and email for that person, the distribution will still go out to the chapter presidents, but with chapter officers having more than enough to do, that public policy champion can be the liaison between this committee and your members, passing along latest news and calls for action, while at the same time providing feedback to this committee from chapter membership.

Rodger Goodacre, a member of TRIO's national Board of Directors and a member of the TRIO Maryland Chapter, serves as Chair of the Public Policy Committee. Rodger has now been joined by Ted Lawson, board member of the TRIO Manhattan Chapter. Together they are developing plans for 2014 and beyond, following on the recent successful membership engagement focus of the CMS drug issue.

If you would like to serve on this committee, email [info@trioweb.org](mailto:info@trioweb.org).

## TRIO Membership Is Renewable Annually

\$10 of your chapter membership dues goes to TRIO national and are renewable as of January each year. If you have not renewed with your chapter, please do so soon!

If you are a Member-at-Large, your \$20 annual membership can be renewed by printing and mailing the membership form on [TRIOweb.org](http://TRIOweb.org) or from page 8 of this *Lifelines* issue.

## UNOS Recognizes TRIO in the UNOS "UPDATE" Magazine

TRIO continues our long-standing support of UNOS and their work in making our organ transplants possible with close partnership and with many TRIO members serving in various roles, adding the voice of the patient to UNOS' decision-making process at all levels.

In the most recent issue of UNOS' bi-monthly glossy UPDATE magazine, TRIO is mentioned in three separate items.

For the first time in UNOS history, a patient was nominated to be the next vice-president for the organization. That position is the next year's president (followed by being the immediate past president). TRIO's President, Jim Gleason, with ten years of service on UNOS committees and currently a member of the UNOS/OPTN board and its executive committee, was one of two patient nominees for that national election that concluded March 5. Betsy Walsh, a living kidney donor and lawyer was elected and will serve starting in July of this year, becoming the first ever patient to fill that very important office. Photos and bios for both nominees are featured in the current UPDATE issue, mentioning TRIO in Jim's bio, of course.

In the popular news section "**Across the Country**" TRIO's officer election results were mentioned, along with noting that a UNOS past president, Charlie Alexander, was recently named as a new director to the TRIO board.

And, finally, in a sad note, a former UNOS board member, Melissa Doniger, was honored in their "**In Memoriam**" column, noting her passing and her being a liver recipient who volunteered with TRIO.

### UNOS "UPDATE" Content Goes ONLINE!!

UNOS recently shared the following information: "After extensive evaluation, we have decided to transition content from our bi-monthly print member publication, Update, to our online communications vehicles. This decision reflects the growing preference of members to receive and access information online, where content can be delivered more quickly and where currency can be more easily maintained. The March/April issue of Update will be the last printed version. Staff and budget resources previously allocated to Update will be used to enhance UNOS' online presence.

Transplant Pro will serve as our primary means of communicating important information to members on a regular basis. Content valued by Update subscribers will be incorporated into this vehicle and our web sites."

## Transplant DVD Library Grows

Each month we add more great presentations to the Transplant Presentation Library. To date we have sixty titles in this five-year-old program, all listed on the TRIO website under [Resources](#) (← click to view the titles). DVDs are distributed to chapters on a bi-monthly basis. Members-at-Large can call the TRIO office at 800-874-6386 or email [info@trioweb.org](mailto:info@trioweb.org) to request individual DVDs.

The newest titles, just added (to be distributed to chapters shortly) are:

- Program #58: “Communicating with Your Donor Family”
- Program #59: “Brain Death Clinical Cliff Notes
- Program #60: “Infectious Disease and Heart Transplant Patients” (Special note: This title is available for online YouTube viewing as a special new service trial. Just click on the below YouTube image to link to it.)



If you haven't taken one from your chapter's library, check the available titles and ask for one at your next meeting. And don't forget: we invite chapters with special guest presentations to record and submit them for possible addition to this amazing collection.

## Don't Miss an Issue . . .

Obviously, if you are reading this, you have gotten the new electronic *Lifelines* which, for those with registered e-mail addresses, is sent directly to your e-mail box. That means you are also receiving your monthly E-News that keeps you on top of TRIO communications between *Lifelines* issues. If you are reading *Lifelines* from TRIO's web site, that's fine; but you are welcome to get a personalized copy directly by sending your e-mail address to [info@trioweb.org](mailto:info@trioweb.org).

You can also help fellow chapter members who may not be on the list by suggesting they submit their e-mail address or offering them a copy you have printed. Issues of *Lifelines* remain available on the web site archives under Resources.

## iDoctor: Could a Smartphone Be the Future of Medicine?

With the advent of an electronic *Lifelines*, possibilities open up for exciting and innovative ways to offer information to our readers. This link to a YouTube video news report is just one example. Come and watch how a Smartphone may become a revolution in how we experience personal medical care in the near future. Some uses are already approved.

Harvey Mysel, one of our board members, shared another news item describing a patient's cover for their iPhone that would do some of the things cited in the referenced article, available for \$199 and can be ordered now! So, maybe the future is NOW?

If you are reading *Lifelines* on your computer (or smartphone), just click on the link to watch this 8:50 minute video report: [iDoctor NBC News Report](#) or, if you are reading a printed version, go to an internet access device and type in: <http://www.youtube.com/embed/r13uYs7jglg>

## Youth Circle Update

We have a new member of the TRIO Youth Circle leadership team. Joining Josh Morrison and Allie Weese is a young heart recipient, having received her heart in Philadelphia when she was only 7, Melissa Speck is now a young professional working in the Washington, DC, area as a teacher.

Catching up with Josh, we find this altruistic kidney donor working for (and what a perfect fit this is) a very creative group known as the Alliance for (kidney) Paired Donation in Toledo.

Together, this Youth Circle leadership team is working on revitalized plans for this initiative. Along with their inspiring stories already there, you will soon be able to view plans on the Youth Circle section of our TRIOweb.org site.

Do you or does your chapter know of young adult (aged approximately 18 to 30 years old) transplant patients/recipients in need of a support community with similar interests and challenges? Have them register with the Youth Circle for news distribution and to post their inspiring stories by writing to [info@TRIOweb.org](mailto:info@TRIOweb.org)

This growing population of very inspiring survivors each have a powerful story of how well organ transplantation works and with their youthful energy, TRIO wants to empower them in their efforts to 'give back' for those life gifts through the Youth Circle.

## Books, Books and More Books

Having recently hosted a book reading at our local OPO's Transplant Family House for some of the 30 families staying there, it was so much fun to share from the growing library of transplant related books to fit the needs of each family by organ type or life circumstance. With well over 150 titles to draw from on the library shelves behind me (mostly donated by authors for review and since donated to this amazing home away from home for patients), each need could be accommodated with a reach of my hand like magic to each book on a shelf behind us.



Some new titles to explore include Amy Clipson's **The Gift of Love: One Woman's Journey to Save a Life** (a kidney donation story of the triumph of one woman's faith against all odds, and a soul-filling reminder that no matter how hard life gets, it is worth fighting for). For a liver transplant story, try Dan Bonner's **Gifted: an extraordinary journey through illness and liver transplantation**, a humbling and inspirational story of faith, courage, hope, trust and perseverance that will have you cheering and crying; but most of all rejoicing in the message that with the gift of life, anything and everything is possible. For caregivers we offer the inspiring story by MaryAnn Raccosta, **The Survivor, the Hero, The Angel: A Mother's Story - one decade**. This amazing mother and author is featured on an upcoming Transplant Presentation Library DVD program to be released to chapters this coming summer. So read her book and then come listen to her presentation.

Finally, on a very different note, Ed Linz, heart recipient and author of **Life Row**, has turned his talents to an exciting new novel, **Hurling to the Edge**, that while not transplant related, is a fun and thrilling read described on the cover as: "a thriller involving Physics, Religion, Drugs.....and Sex" and based on my recent read, Ed really puts

his heart into fulfilling that ambitious description. I gave it "**5 Stars**" in my Amazon review.

Don't forget: you have access to that library of 150+ titles, many with reviews linked to each, on our TRIOweb.org web site under "Resources."

--Jim Gleason, TRIO President, Web Master, and Book Reviewer

## CMS Drug Issue (continued from Page 1)

Hopefully, YOU used the resources TRIO made available to post your own comments and support to that website, joining the 5,000 others who rose to the challenge.

And the good news is that with all that pressure and outcry, CMS recently agreed to withdraw that controversial "protected class" portion of their plan, taking it back for further study with promises to include affected classes in future discussions. So, yes, **it is a victory and we are celebrating**, but also, we and our partners in those coalitions remain cautious and watchful as CMS develops future designs that would affect yours and my health in areas such as this one would have done. That's what TRIO is all about, standing up for and being the voice of the transplant community.

Thanks for being there for all of us, today and in the future.

## TRIOweb.org Update

Good news! We now have both a site sponsor (Astellas) and an advertising support agreement that will bring this resource again into the revenue-producing side of our financial ledger. Last year was a year of transition, with no ad revenues despite significant earlier successes, so this is an important turnabout for TRIO.

Along with this *Lifelines* being made available directly via our e-distribution lists, for those who choose to not share their e-mail addresses, this and future issues will be posted on the home page for general access.

Note: you can always revisit past issues which have been [archived on the site](#) (← click here) for several years.

## Did you know?

There are **121,768** waiting list candidates!  
Visit [www.unos.org](http://www.unos.org) to see TODAY's number

**UNOS Resources: 888-894-6361**

## Lung Transplant Breakthrough

You can watch a TED talk demonstrating a lung perfusion machine that is changing lung transplantation processes today.



[\(Click here to see the video.\)](#)

## You Can Donate to TRIO Just by Shopping on AmazonSmile (and it costs you nothing additional)

AmazonSmile offers shoppers the opportunity to donate to charitable organizations.

- Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to TRIO when you shop on AmazonSmile.
- AmazonSmile is the same Amazon you know. Same products, same prices, same services.

In addition, if you purchase an eligible item through March 31, 2014, Amazon will donate an extra \$5 to TRIO.

To add TRIO has your charitable organization, follow these easy steps:

1. Visit [www.smile.amazon.com](http://www.smile.amazon.com)
2. Sign in with your regular Amazon account (or create one, if you do not have one)
3. When prompted to choose a charitable organization, type in and select Transplant Recipients International Organization Inc Washington DC

It's just that easy . . . and you are making a contribution to TRIO, at no cost to you.

If you need assistance, contact TRIO at [info@trioweb.org](mailto:info@trioweb.org).

## To Mail a Copy of This Lifelines Issue

Print all pages. Turn page 8 to the outside/back. Fold in half, with page 8 showing. Place a strip of clear tape (at least one inch long) to close the three open sides of the folded piece. If you use regular 20-lb copy paper, use one first class stamp and one twenty-cent stamp. Use your own return address. Or, you can tri-fold the pages and place in a business-sized envelope, with the same postage.

## Are You Interested in Participating?

Are you a woman who has received a kidney, heart, or lung transplant? Have you considered a pregnancy in your future? Were you ever pregnant after your transplant? Have you lost a pregnancy after your transplant?

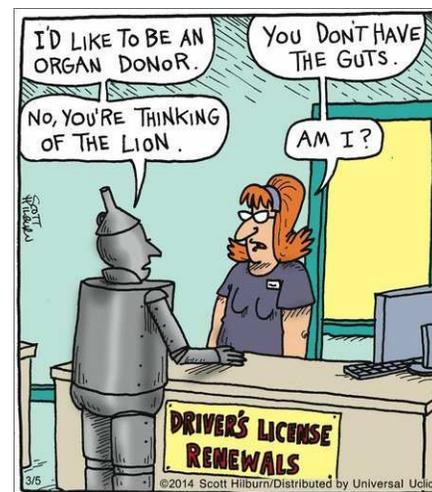
If you answered 'yes' to any of the above, you might consider sharing your decision-making experiences with a nurse researcher who is looking into this. [\(Click here to learn more.\)](#)

## Just FYI: Some Interesting Items You Will Want to Review

(click on the title to go to the article)

- [Promising skin tumor vaccine offers hope for transplant patients](#)
- [Your body does incredible things when you're not awake](#)
- [Building heart tissue that beats: Engineered tissue closely mimics natural heart muscle](#)

## And Now That You've Dealt with All Those Serious Issues, It's Time For a Smile . . . .



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Membership –  NEW or  Renewal: **TRIO membership is renewable as of January 1 each year.**  
Please support TRIO and its important work on behalf of transplant recipients, donors, candidates and their families by joining us in this important endeavor. Thank you for your support of TRIO!

Name of Member: \_\_\_\_\_

Names of other family members: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ ST: \_\_\_\_\_ ZIP: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ email: \_\_\_\_\_

Member is: \_\_\_ Recipient; \_\_\_ Donor; \_\_\_ Candidate; \_\_\_ Family Member; \_\_\_ Other: \_\_\_\_\_

Recipient Profile (Optional): \_\_\_\_\_

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 . . . . . \$ \_\_\_\_\_.**  
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**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](http://www.trioweb.org). OR: consider starting a transplant support group or TRIO chapter in your area (contact [info@trioweb.org](mailto:info@trioweb.org)).

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