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Lifelines

October 2011



Transplant Recipients International Organization, Inc.

2100 M St., NW, #170-353; Washington, DC 20037-1233

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TRIO's 25th Anniversary: Looking Back and Planning for the Future

What an exciting time to be a TRIO member! With celebrating 25 years of service behind us in 2012, this is also a time to look ahead to the next 25 years. This past quarter century of amazing progress and change in medicine and transplantation (which has allowed many of us to be alive to serve and celebrate) is but the beginning, if not for some of our aging selves, certainly for our families and friends who will benefit from all that has been learned in caring for us these many years. Some long-term transplant doctors candidly admit that those early years were ones of trial and error, often conservatively using dosages that today are effective at lesser amounts resulting in fewer side effects and longer lives, not to mention having new drugs that provide alternatives when an earlier one shows signs of kidney or liver damage. Even heart biopsies are being augmented with simple blood draws that indicate risk levels so invasive biopsy procedures are done only when needed.

A national committee is planning not only ways for chapters to celebrate – especially our Pittsburgh chapter which, as TRIO's founding chapter, is celebrating their own 25th year – but also inviting all TRIO members and families to come back to Pittsburgh where it all began for a big event in the 2012. While the date is uncertain at this time, we do expect to plan a weekend event. So far it looks like a Friday gathering with board meeting, workshops, gala dinner and entertainment event with several honorees. Saturday will kick off with a big outside walk/run gathering similar to the cycling events of the early 90's TRIO conferences and will be followed by more workshops and luncheon. Those who choose to stay over into Sunday can gather for a farewell breakfast social event before returning home to continue their re-energized TRIO service and support for the next 25 years.



There will be many ways that you and your chapter can become engaged both in the planning and in attending the "BIG event." In the coming months, through your *Lifelines* newsletter and your member E-news, you will hear much more about this. Today, if your chapter has a long history, reach out to those early members who did so much to 'grow' your chapter even though it may not be as active today. Already we are finding enthusiastic response to that outreach, even if that is for the surviving family members of members who have died during the course of those past 25 years. You know who they are. Reach out and ask if they would like to attend or be involved in collecting that early TRIO history that they helped create with their own years of active service.

For more information as it develops, your local "25th anniversary chapter champion" will be your resident source (along with *Lifelines*, E-News and website announcements) for details as we firm up planning in the weeks and months ahead.

So set aside some funding and some vacation time for this very special TRIO event. We are anticipating an attendance close to 200, so you don't want to be left out.

President's Message



Jim Gleason

“One TRIO”

As we approach 2012 and the exciting TRIO milestone of 25 years serving the transplant community, we are revisiting our short and long range plan for our future together. Under the leadership of Will Oler, a TRIO member with a long successful career in corporate America facilitating strategic planning teams, the goal of “One TRIO” is to create a straight forward, realistic plan that can be truly implemented with follow-up actions to take TRIO into its next quarter century as the voice of the transplant community. Between individual chapter president calls for input and the membership services survey conducted last year, your input is serving as a foundation for this forward-looking process. (See trioweb.org/futureplan.shtml for action.)

A key element of our planning will aim to unify our organization around the theme of “One TRIO.” In some chapters there has evolved a mindset of there being two levels of TRIO membership and a splitting of electing to pay annual dues. While the total dues amount is set by the local chapter, \$10 of that goes to support the many services that are delivered by our national organization, the umbrella structure over all TRIO chapters. This has led to some local chapter members opting to “not pay the \$10 national dues” and become just a local TRIO chapter member. The effectiveness of any organization is in its member service delivery and in its number of members putting strength in its mission of advocacy, especially as it relates to carrying that “voice” to the state and national legislatures. Today our stated paid membership, known through local chapters forwarding those \$10 paid member names is about 800+ but that is only an unknown percentage (maybe 50%?) of the real total TRIO members when we see chapters of 50+ members submitting only 30 or so

names to the national roster. “One TRIO” is aimed at eliminating that disparity, carrying the message that a TRIO member is a TRIO member, not a local vs. national member. Certainly the chapter is the part of that “One TRIO” that the majority of members will identify with and offer their services through, but as you saw in that TRIO National Services Survey, there are many important and valuable services that are delivered to both members AND the larger transplant and general communities on your behalf through the umbrella of TRIO national resources.

As this planning process moves forward, you will see this unified focus as a critical element in strengthening TRIO’s effectiveness in our working together to carry out our TRIO mission and vision. I personally invite you to reach out to me by phone or email with any questions or concerns regarding this “One TRIO” concept. In service through TRIO, together we can make a difference, changing the world for recipients, candidates and families, and empowering you, the individual, with the resources that thousands of members add to your efforts and gifts of service.

Check with your chapter today to be sure you are fully counted as a TRIO member. If you aren’t receiving this *Lifelines* issue directly to your home address, that’s a sign we don’t know you as a TRIO member. Note: Members-at-large pay \$20 dues directly to the national office and are thus already part of this “One TRIO.” Be sure your 2011 dues have been submitted.

PS: Be sure to read all the other exciting TRIO news throughout this issue. If you are not receiving the monthly TRIO E-News in your e-mail, send your email address to INFO@trioweb.org to be added. Meanwhile, you can see the latest E-News issue on the TRIO website (www.trioweb.org) under News from National.

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

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TRIO Committee Progress/Opportunities: *Beyond membership to full engagement*

It is great to see more and more TRIO members getting involved in committee work at the national level. We join TRIO to help make a difference. In supporting TRIO's extensive committee work with your skills and time, you are touching many more since committee work reaches nation-wide.

Where can you find those opportunities? On the TRIOweb.org website home page with its link to the recently updated committees and their current members.

Not sure where you might fit? Contact Sylvia in our national office and she will help guide you to where you would best serve and be most effective. Or, you can reach out to a committee chairperson directly as listed in that online committee document.

TRIO committees are where excitement is home to new ideas and fulfilling actions, working with some very special, dedicated and talented people. Your involvement would be occasional phone conference calls from the comfort of your home, participating in interesting discussions and maybe taking on individual assignments as part of an overall team effort. Your views and suggestions are the driving force behind effective committee outcomes. Those who speak from personal experience explain that this work provides purpose and fulfillment to their lives after transplant. That's why most members join TRIO, to make a difference, putting that new life extension to good use.

See where you can find an opportunity to share that gift. Read what committees are doing in the articles throughout this issue: planning TRIO's future, creating an exciting TRIO 25th anniversary, creating new revenue sources to support our TRIO mission, etc. Check out that web listing and sign up to participate in that action, whether locally or at the national level.

That's what TRIO membership is all about. Come join a committee!

Do You Have United Airlines Frequent Flyer Miles?

Did you know that TRIO provides United Airlines tickets to those needing to travel for pre- or post-transplant visits? Round trip tickets are provided only to assist those who can not afford to travel. This can only be done if we receive your donated miles. To read about this program, go to TRIOweb.org and click on "Resources" or call Sylvia Leach at TRIO.

To donate miles, call United at 800-421-4655 or go to www.united.com > About United > Committed to the community or if a UAL frequent flyer, click on MileagePlus and Use Miles.

Transplant Recipients International Organization News

September 2011

TRIO E-NEWS

Are you getting yours?

If you aren't keeping up with TRIO news between these quarterly *Lifelines* issues, you are not in our national membership database with an e-mail address. Send that e-mail address to INFO@TRIOweb.org and you will begin to receive these colorful and informative "email blasts" each month. Many articles in the E-News are linked to even more information on the TRIO website. TRIO E-News mailings are personally addressed, short, easy to read, colorful connections to current TRIO news.

If you want to see what these E-News blasts are about, go to the link under TRIO National News on the website home page. If you are intrigued by what you see and read there, send your email address to TRIO national, so you can personally receive these E-News blasts.

TRIO Virtual Chapter: Organizing to Serve MALs

"But what about ME?" For a TRIO member-at-large (MAL) that question is being answered with the developing organization of a "virtual chapter." The Virtual Chapter will offer local chapter-like support for our members who are not local to a TRIO support group. MAL co-leaders Lou Reardon and Will Oler are proposing to the board to allow an officer structure similar to that found in current local chapters in support of this MAL group. The plan is to use video and audio technology to overcome the distance challenge faced by MAL TRIO members.

MALs are now receiving their own TRIO Virtual Chapter (VC) E-News. More support will be coming in the near future in response to survey feedback that identified such needs for this membership audience.

As a reminder: MALs need to maintain their membership with annual dues of \$20 sent to the TRIO national office. If you have not yet done so for 2011, mail it in now to continue receiving the benefits of being a TRIO member. And don't forget, MALs can write to INFO@TRIOweb.org to get your DVD of any program listed in the Presentation Library on the TRIO website.

Public Policy: Drug Extension Introduced Again

Mike Sosna, TRIO public policy chair, shared news that the bill seeking to extend Medicare drug coverage for kidney recipients beyond the current 3-year limits has been re-introduced again after 12 years of struggling to get this legislation passed. Senate bill S.1454 was introduced July 29th, and the corresponding House bill H.R. 2969 was introduced on Monday, September 19, with 18 co-sponsors. This is known to be a cost effective alternative to a patient going on dialysis when they lose their graft because they can't afford their meds when that 36-month support stops. It's a tough time to get financial support for anything at the federal level, even for a proposal that would save money in the long term. While some feel that the currently enacted health care bill would provide the same support come 2014, there is still concern that there is no guarantee that the current legislation would include the expensive immune-suppressant meds in the drug formulary when that day comes, so support for this bill is encouraged.

This is another "chapter champion" role being nominated for each chapter, to communicate information and calls for local action in support of this and other important transplant legislation. Are you that person? Talk to your chapter president if your chapter hasn't already named someone to this important role.

TRIOweb.org Update

When is the last time you visited? We're talking about the TRIO website with its constantly changing face and facts. Don't worry if you feel something is missing when you go there, it's just our latest streamlining in response to your suggestions. Transplant stories and news have moved to their own pages, with each category linked from the home page.

As part of the TRIO 25th anniversary, we are looking into a total redesign to bring our very resource-rich web presence into today's more modern "look and feel." Meanwhile, we invite you and your chapter to submit your stories and photos to make this resource even more TRIO member-driven in its content. Look at the chapter listing and click through a chapter name to see their current activity report for exciting ideas and the bigger picture of what TRIO is doing around the country.

What would you add about your local activities as a resource or inspiration to others?

2012 Open Enrollment for Medicare Begins Earlier, Ends Earlier

Every year, people with Medicare get to explore new choices and pick the plans that work best for them. This year, the Open Enrollment period is starting early – on October 15 – and ending sooner – December 7. You will begin to see health plans start their marketing and advertising activities in just a few weeks and it may make you feel overwhelmed with information and promises. Every person with Medicare will have to choose a "Part D" plan to help them pay for prescription drugs. And people who have chosen to enroll in a "Part C" Medicare Advantage plan for their basic health care services have the option of staying in that plan, choosing a different plan, or going back to the Original Medicare program. These are important choices that should be made with extreme care.

For this year, the average premiums for a Medicare Part D plan will be the same in 2012 as in 2011. The average premium for Part C plans is going down by 4 percent. That's great news for people on Medicare who have a fixed income. As in previous years, people with Medicare will continue to have a variety of Medicare Advantage plan choices. Consumers in every part of the country will have a wide variety of Part D plan choices in 2012, including many deductible-free plans and plans with some form of generic gap coverage.

As always, check with your transplant center along with your other health care providers to be sure you select a plan that is accepted, and do not hesitate to ask your social worker/financial coordinator for guidance.

In short, there'll be a wide range of health and drug plan options available across the country, including Original Medicare. People can turn to www.medicare.gov, call the 1-800-MEDICARE hotline, or consult with a local State Health Insurance Assistance Program (SHIP) for help. We want to make sure people can identify and enroll in the coverage option that suits their needs in 2012.

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

(Information taken from
CENTERS FOR MEDICARE & MEDICAID SERVICES)

The TRIO Board of Directors held its quarterly meeting by teleconference on August 13. The next Board of Directors meeting will be held on Saturday, November 19. For details, see the announcement on TRIOWEB.org.

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

Transplant Presentation Library Have You Seen One Yet?

Funded for a third year, TRIO's collection of DVD recorded presentations, sent to local chapters every other month (2 shows per shipment), is waiting for you NOW!

Looking for information about skin issues post-transplant or Mohs surgery to treat skin cancers from an expert? Watch Dr. Chris Miller talk and illustrate with actual patient photos the dangers and treatments that will convince you of the serious nature of caring for what we often overlook. This is just one of the latest topics listed along with 28 others on the library's web page. As a TRIO member, you are entitled to take any of these home for private viewing. MAL's can contact TRIO's office and Sylvia will get the DVD to you.

Ask at your local chapter meeting for access to this library. In the weeks ahead, each chapter is being invited to nominate a "chapter champion" (maybe you would be interested in taking on that role?) to pass along news about the latest releases and to funnel your chapter feedback to improve this exciting program as we move ahead.

Where do these programs come from? Your chapter is invited to record their local presentations to submit for consideration to be included in this growing library. If you see something of interest, ask if it is being recorded.

TRIO Chapters Participate in Quarterly Teleconference

TRIO chapter presidents or their representatives participated in a teleconference on September 13. The teleconference was hosted by J.T. Rhodes, Chair of the Chapter Council.

Jim Gleason, TRIO President, gave an overview of TRIO's action-oriented programs to support the chapters. Afterwards, each chapter shared a report of their most recent activities.

Participating were: Akron-Canton (Mary Fread), Long Island (Mike Sosna), NEFlorida (JT Rhodes), Philadelphia (Jim Gleason), Pittsburgh (Mary Alice King), Southern New Mexico (Susan Brown), Ventura County/West Valley (Ron Taubman, Henry David, Jerry Jackson). Also attending were Will Oler, Chair of the Strategic Planning Committee and Sylvia Leach, Manager of TRIO.



TRIO Youth Circle Grows

Following in TRIO Youth Circle founder's Donatella Rose Parade float rider, Valen Cover, this year you will see one of our current Youth Circle leaders, Mary Wu, as a float rider. Mary is sponsored to ride on the float as a representative of UKRO thanks to Ron Taubman's outreach to TRIO looking for a good candidate.



Our young members may be few in number, but they are active. Between Bill Coon's book, "SWIM," and budding author Mary Wu's "Confessions of a Kidney Transplant Recipient," they are busy getting the word out in print. Julie is busy organizing a local Cleveland young recipient's support group, Mary is in the NYC news as part of the big press event launching their donor registry and speaking at local driver registration offices, while Bill is busy with book signings around the Chicago area.

As local chapters look to engage the younger recipients to balance an aging membership, use the talents and stories of this leadership group as highlighted on the Youth Circle web pages, to attract and sign up new members. Keep in mind that many of these potential younger chapter members may be challenged with coming up with the dues of TRIO membership, but those issues should never be a barrier to full membership.

Recently TRIO was asked if we could find any young (19 year-old) female liver recipients in the NJ area to provide some support (via a local transplant social worker) for a liver candidate of similar age/gender. Using the Youth Circle resources TRIO was able to engage four such successful liver recipients that matched those criteria to help with this outreach. That's what TRIO Youth Circle is all about! Contact the TRIO Youth Circle through email at TRIOYouthCircle@trioweb.org.

Look in a future issue of *Lifelines* for a story about another TRIO member's passion for offering post-transplant support for young people with pulmonary hypertension and/or lung/heart transplants. Rhonda, mother of a 7 year-old heart recipient, founded camp Dragonfly to offer such kids the summer camp experience that they are barred from in traditional camps. Recently, TRIO President Jim Gleason and his wife Pam enjoyed an inspiring visit to the camp in session. It's a youth story of exciting success and passion for a cause dear to TRIO's mission.

Are You “at Risk” to Develop Diabetes?

According to the National Kidney Foundation, 15 to 20% of all transplant recipients are at risk for developing diabetes. Risk factors for diabetes are being overweight, not getting enough exercise, taking immunosuppressant medications, family history of diabetes, being of Afro American or Hispanic ethnicity and being 65 years or older.

Since I had two of the risk factors, my nephrologist referred me to a diabetic dietician. The consultation was helpful but very generic. With my hip, knee, foot and kidney doctors all encouraging me to lose weight, I made it my primary new year’s resolution. During the first five months, I lost 22 pounds--mainly by eating smaller portions of food. My weight stayed the same for the next month.

I noticed that the YMCA where I worked out offered a pre-diabetes prevention course at a cost of \$80. The course lasted 16 weeks with 16 hourly meetings and the truth from the scales that the leader brought each week. The course required me to record a detailed food log with calories and fat totaled each day, the amount of time spent exercising and, of course, my weight. The course leader recommended using the website www.myfitnesspal.com to locate information about fat content and calories. That daily journal was a pain to keep but was a real eye-opener about my eating habits. The registered dietician would review my journal and write comments each week. At the weekly meetings, the group discussed successes and problems and discussed the materials handed out. The hand-outs were various hints on what to do in certain situations, how to stay positive, and how to cope with stress.

After 16 weeks in the program, I lost an additional 29 pounds, for a total of 51 pounds in approximately 9 months. It was well worth the money. I will now go to monthly maintenance meetings that are included in the original cost of the program. The program has been so successful that the YMCA is partnering with local hospitals and health care providers. To learn more, I suggest you go to <http://www.ymca.net/diabetes-prevention/>.

Ask if your local YMCA is offering this program. It’s well worth the cost and trouble!

—J.T. Rhodes, *Kidney Recipient*
(President, TRIO Northeast Florida Chapter; Chair of the Chapter Council; Past President, TRIO BoD)

TRIO Recommended Reading: Books of Interest

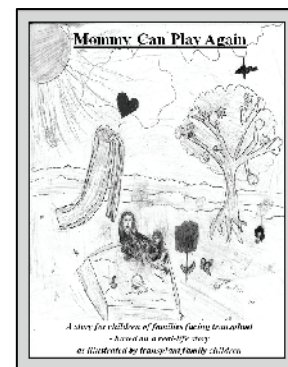
Two great reading recommendations from the TRIO database of over 100 transplant books for you this issue:

(1) **Unexpected Blessings: Finding Hope and Healing in the Face of Illness** by Roxanne Black, founder of Friends’ Health Connection which seeks to help connect patients of similar conditions for support. This national award-recognized author has turned her personal health challenges into a mission of support with her foundation since 1988. In this easy-reading book you will find many chapters of inspiring stories and survival skills, often with humor and built upon her personal experience of dealing with Lupus from the age of 15 and multiple kidney transplants. This reading will help anyone find the “unexpected blessings” that surround us each and every day.

(2) **Love Brought Me Back: A Journey of Loss and Gain** by Natalie Cole is another source of inspiration as we learn from the inside view of this celebrity’s life struggles that lead her to a successful recovery and kidney transplant. As a well-recognized entertainer and now advocate for organ donation, her story is a roller coaster ride as indicated by the title that will both entertain and inspire in its reading.

Mommy Can Play Again

is something very different. Recently released, this book for young children is based on a double lung recipient mother’s life story as told through the colorful artwork of young children. It is aimed at children of a family facing a transplant within the family, not that child receiving a transplant.



This book was a project of the TRIO Philadelphia Chapter and is offered free online. To get your copy, go to chapter news on the TRIO website for easy downloading to print or view on your home PC. A limited supply of printed copies of this 36-page book will be available for the asking. Write to info@trioweb.org for ordering information while supplies remain.

Check out that 100+ book review database under Resources on the TRIO website.

TRIO Primary Care Physician Program: An Outreach to Engage Primary Care Physicians in Donor Awareness

Here's another way you can participate directly in TRIO's mission of raising awareness about organ donation. This funded program will offer individual members the resources to engage their own family physician with the question: "Doctor, do you talk to your patients about organ donation?" Based on that doctor's reply, a short and simple (prepared) response will lead to enlisting their office in both having that conversation with patients and allowing TRIO to send them supporting brochures and posters.

This is another area where chapters are being invited to name chapter champions to carry the message and process to local members. Maybe "*This one's for you?*" as that famous commercial said.

Note: many organizations have tried to get that message to the local family doctor, but without recordable success. CORE, the Pittsburgh area OPO, with a strong letter of TRIO support, just received a major HRSA grant to try something similar in their region. The TRIO Pittsburgh chapter will not be using the TRIO PCP program so as to keep CORE's program result metrics as a true measure of that CORE local process.

We think our simple grass roots approach will succeed where others have failed, but that will be up to YOU, our TRIO member.

To volunteer to participate in the PCP Program planning and reporting process, contact TRIO through email at info@trioweb.org.

TRIO Mourns the Loss of Lorraine DePasquale, President of the Manhattan Chapter

Lorraine founded the TRIO Manhattan Chapter in 1990

after she underwent a successful liver transplant and wanted to do something to show her gratitude. She spent nearly 20 years volunteering countless hours to provide resources to transplant recipients, donors, and their families and caregivers.

She started an annual event at St. Patrick's Cathedral called Celebration of Life to honor donor families' selflessness and the lives of those who had died. More than 2,000 people attended the event in April of this year.

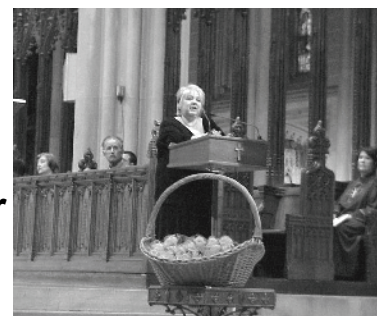
Lorraine became a leading spirit for organ donor families and recipients. "She was widely recognized, highly respected and admired by all in the transplant community," said TRIO Manhattan Vice President Fran Dillon.

Fellow TRIO members admired Lorraine for the compassion she showed while giving support, advice and direction to people in need.

Her friend and fellow TRIO member, Claudia Grammatico, said: "Lorraine's kindness, passion for life, and dedication to the transplant community and donor families is how she will be remembered." To read Claudia's personal tribute to Lorraine, go to trioweb.org/Lorraine.shtml

Lorraine's husband, Anthony, whom she married when she was 20 and he was 21, died in 2010. They were childhood sweethearts.

(Excerpted in part from the NY Daily News, Jill Klein, Daily Newswriter)



Did you know?

**There are 112,221
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

The UNOS patient services staff is available to help you Monday – Friday,
8:30 a.m. – 5:00 p.m. (Eastern Time)

WANTED: TRIO Chapter Champions!

Do you have an interest in championing a specific cause within the transplant community?

Throughout the pages of this newsletter, you will find areas within TRIO that need your assistance. Take that special interest you have and put your dedication to work in any of these areas.

Become a Chapter Champion or join a TRIO committee. To review the opportunities available to you, go to www.trioweb.org and click on "About" to read about TRIO committee opportunities.

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 \$ _____.
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).

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