



# Lifelines

October 2009



**Transplant Recipients International Organization, Inc.**

2100 M St., NW, #170-353; Washington, DC 20037-1233  
[www.trioweb.org](http://www.trioweb.org) • [info@trioweb.org](mailto:info@trioweb.org) • 1-800-TRIO-386

## Three New Members Join TRIO's Board of Directors



**Carl Anderson**

"Papa Carl," as he is known to his many friends and constituents around New Jersey, is President of the "Jam for Life Foundation," ([www.jamforlifefoundation.com](http://www.jamforlifefoundation.com)) which he formed in 2006 to serve the transplant community through music and the arts and to raise funds to benefit organ and tissue donor awareness.

Carl has a long career in behavioral health and education. He worked as Coordinator of addiction programs (for both youth and adults) and as Director of Outpatient Services at Carrier Clinic, a psychiatric and addiction treatment center.

Carl, a liver recipient and kidney recipient, lives in Ewing, NJ, with his wife Jean.

Upon joining TRIO's Board, Carl said: "I believe my extensive experience in areas of education and behavioral healthcare can provide valuable insights in serving TRIO."

**Susan Pincus**



Susan is an owner and operator of a family business servicing restaurants, taverns and food service organizations in Pennsylvania, New Jersey and Delaware. She is an avid photographer, Transplant Games athlete, Phillies fan and community volunteer.

After almost a lifetime of diabetes and insulin shots, Susan received a healthy kidney and pancreas in October 1998. She has taken on leadership roles in various community organizations including Liaisons for Life (a Gift of Life Donor Program volunteer group), Donors Are Heroes, M.O.S.T. (Multi-Organ Support Team), Transplant Movie Night (as lead researcher), and her condominium's homeowners' association, among others.

Susan serves as a member of TRIO's Scholarship Committee and is helping to re-invigorate the Philadelphia TRIO chapter.

### **TRIO's Board of Directors to Meet in Philadelphia, Oct. 24**

Any member of TRIO who is interested in attending this annual meeting should contact TRIO's national office at 1-800-TRIO386 or email: [sleach@trioweb.org](mailto:sleach@trioweb.org).



**Elizabeth Shore**

Beginning her career as a Sickle Cell Social Worker, Elizabeth next moved into the position of Heart Failure and Transplant Clinical Social Worker at Hahnemann University Hospital in Philadelphia.

After serving as a Bone Marrow Transplant Social Worker at Temple University Hospital, Liz worked as Outpatient Clinical Social Worker in the Heart Failure, Transplant Support Program at the Hospital of the University of Pennsylvania and now serves as Social Worker in the Advanced Heart Failure and Cardiac Transplant Center at Thomas Jefferson University Hospital in Philadelphia.

In joining TRIO's Board, Liz said: "I hope to share 15 years of transplant experience in patient advocacy and legislative awareness."

Liz lives in Wallingford, PA, with her 11-year-old son David, who loves baseball and plays the violin.

### **UNOS Issues H1N1 News**

To learn the latest information from UNOS, go to [www.trioweb.org](http://www.trioweb.org) and under RX News, click on "9/2/09 OPTN/UNOS releases guidance regarding H1N1 and Implications for Transplantation."

## President's Message



**J.T. Rhodes**

We are very pleased to welcome three new members to TRIO's Board of Directors. As you see from reading the articles about them on the front page, Carl, Susan and Liz are all very active in the transplant community. This brings our Board to ten members. We still have open seats and encourage any TRIO member to suggest names to our Nominating Committee for consideration. Thanks to the Chair of the Nominating Committee, Jim Gleason, for his work in finding such qualified candidates.

TRIO's annual meeting and next Board of Directors meeting will be held in Philadelphia on Saturday, October 24. The Gift of Life Donor Program has generously offered their conference room for our meeting. If you would like further details, please contact our TRIO national office at 1-800-TRIO386 or email us at [info@trioweb.org](mailto:info@trioweb.org).

The Chapter Presidents' teleconference is usually held a week or two after the Board of Directors' meeting. We will notify our Chapter Presidents as soon as a date and time is set. As a Chapter President myself, I know that one of the main concerns we all have is how to get more members to attend meetings and become more involved in sharing the workload that usually falls on the President and a small core of chapter members. Some good ideas were shared by the Chapter Presidents on their last teleconference. If you (either as a Chapter President or a member of TRIO) have any ideas or answers to these concerns, please let me know.

An issue of great importance to all of us right now is the health care plans being discussed. I know that many of our members are actively involved in various political parties. While I doubt that TRIO will have a large majority on the same side of the proposed health care changes, maybe there is common ground for some of the proposals. I am asking you to take your time to write or email me ([jtrhodescpa@msn.com](mailto:jtrhodescpa@msn.com)) and the Chair of our Public Policy Committee, Mike Sosna ([mike@sosproductions.com](mailto:mike@sosproductions.com)), and tell us what you like and dislike about health care reform. We want to know what our members think! Please let your voice be heard on these important matters and please communicate with your legislators! You can get complete contact information to write or email your local and national representatives by going to [www.congress.org](http://www.congress.org) and entering your zip code.

Please visit our website ([www.trioweb.org](http://www.trioweb.org)) for information about TRIO and its position on certain issues concerning transplant recipients.

--J.T. Rhodes, President, TRIO Board of Directors  
(President, TRIO Northeast Florida Chapter, 10 years)

**103,868**  
on the waiting list  
as of September 23, 2009  
[www.unos.org](http://www.unos.org)

**Editor's Note:** When we went to press with the October 2008 issue of *Lifelines*, one year ago, the UNOS website stated there were **100,089** on the waiting list. Please check the UNOS website for the current number, at any time.

*Lifelines* is published quarterly by Transplant Recipients International Organization, Inc., 2100 M St., NW, #170-353, Washington, DC 20037, 800-874-6386, [www.trioweb.org](http://www.trioweb.org).

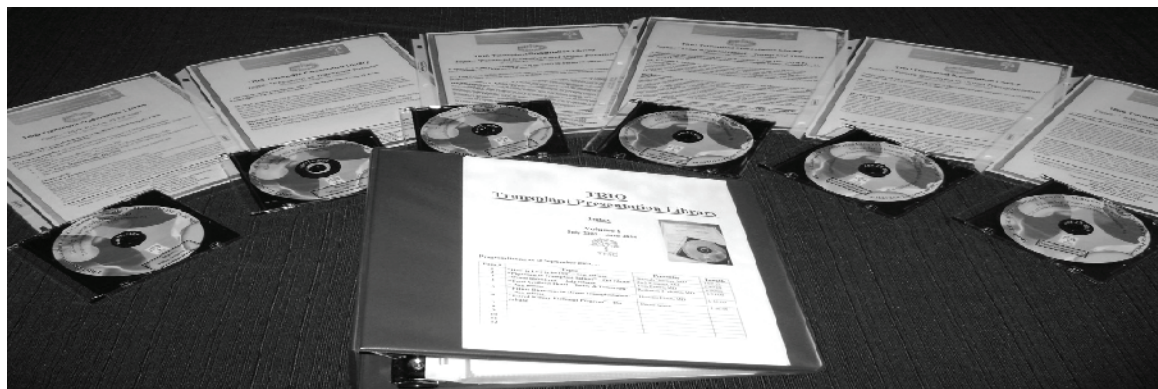
*Lifelines* is published by the Newsletter Sub-committee of the Communications Committee. The Newsletter Subcommittee consists of Pat Beeman, J. T. Rhodes, Elizabeth Rubin, and Dr. Tom Peters, Advisor. Editor: Sylvia Leach.

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## TRIO's Transplant Presentation Library Grows

Following the July launch of the new transplant presentation library featuring monthly additions of local chapter DVD video shows on transplant related topics, there have been five more presentations added to the growing program.

Your TRIO chapter president received the second DVD (and announcement flyer) in August and the 3<sup>rd</sup> and 4<sup>th</sup> releases in September. Programs 5 and 6 will be mailed in time for November use. In most cases, these videos are NOT professionally done and are less than broadcast quality. Quality is increasing with experience gained and, thereby, improving over time. They are intended for both group audience use at chapter meetings or public education events, as well as by individual members who may “sign out” individual shows for home use on their TV or computer. Chapters are encouraged to support the program by recording



local speaking events and to submit them for possible use in this program that benefits you and patients all across the country as another TRIO benefit.

### As of September, the TRIO Transplant Presentation Library offers the following topics:

- “How to Live to be 100” – Jnanesh Thacker, MD
- “Physician as Transplant Patient”  
– Rich Kasama, MD
- “Donor Incentives” – Tom Peters, MD
- “Total Artificial Heart – Today and Tomorrow”  
– Rohinton J. Morris, MD
- “Future Directions in Organ Transplantation”  
– Howard Eisen, MD
- “Kidney Paired Exchange Program”  
– Diane James, BSN

## TRIOweb.org Updates

### Photo Op

Did you see the lead photo on the home page of the TRIOweb.org site recently? Would you like to see your own chapter featured in that same way? TRIO is all about people and we would like to receive your chapter photos for adding that “member personal touch” to the web site, so whether you already have one from some recent (or distant) event, or can take a new one for us now, just send that photo in jpeg (.jpg) format to [info@trioweb.org](mailto:info@trioweb.org) for possible future use. Remember, your news is our news, so submit local event news and photos whenever possible.

### Fall Cleanup

The web site has undergone a “fall cleanup” that makes it easier to find stories of interest by using “lead-ins” as links to full page stories that provide the full detail. Hopefully the sections focused on [TRIO National](#) and [TRIO Chapter News](#) as well as [RX News](#) and [Patient News of TRIO Interest](#) and [Transplant World News](#) will provide you an easy way to keep up with the ever changing world of TRIO and transplant. With so many recent generic drugs coming on the

market which in turn impacts your co-pays and prescription decisions, that news may be very valuable in terms of your real dollars in these tight economic times. With these and other articles, we continue to promote web [Calls for Action](#) to help you and other members channel their efforts where it can really make a difference, helping to fulfill our mission of being the “Voice of the Transplant Community.”

Transplant Recipients International Organization:  
Your voice of the transplant community. 

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Home | About TRIO | Members | Communications | Media | Community | Links | Bulletin Boards

Welcome to TRIO



This is your voice of the transplant community.

**Support TRIO:**

- Donate to TRIO by shopping online: Click here and identify your 'cause' as Transplant Recipients International. A portion of each purchase you make is donated to TRIO! It's an easy way to GIVE! It costs you nothing in addition to your purchase.
- Support TRIO financially through general donations or memorial contributions. [Click here to Download a](#)

## Multiple Listing for an Organ Transplant “Out-of-Region” (A Personal Perspective)

I am a kidney/pancreas transplant recipient. My transplanted kidney (2001) failed on March 15, 2009, and I am back on dialysis. My transplanted pancreas is functioning quite well with an HA1C level of 5.4 to 5.9 on a consistent basis.

My basic concern is that the longer I remain on dialysis, the higher the expectancy that my pancreas will also fail. I live in Los Angeles, CA, where the average wait time for a standard criteria kidney is between 5 and 9 years. Being a Type 1 Diabetic for 46 years (before receiving my kidney/pancreas transplant in 2001), my life expectancy on dialysis is between 3 and 5 years, if I am lucky. I need to find a kidney in the shortest amount of time and yet follow and observe the rules and regulations established by the United Network of Organ Sharing (UNOS), therefore, I have decided to “multi-list”.

Be aware that it is against federal law to buy or sell an organ in the United States, punishable by severe fines and jail time. So, unless you decide to go outside of the United States and take the risks of buying an organ, you had best learn the “ins and outs” that UNOS allows by *Multiple Listing*.

*Multiple Listing* is defined by UNOS as: “Multiple listing involves listing at two or more transplant centers. Since candidates at centers local to the donor hospital are usually considered ahead of those who are more distant, multiple listing may increase your chances of receiving a local organ offer”.\*

My first objective was to get listed by a transplant center so that I could be placed on the UNOS ‘waiting list’. I suggest that a good starting point is to visit the UNOS web site at [www.unos.org](http://www.unos.org) and look up the wait time statistics for transplant centers out of the region in which you currently reside. There are 11 separate regions in the United States. Decide which transplant center, outside your region, would best meet your needs, considering wait time and location.

Upon identifying these transplant centers, do the following:

- Inform your nephrologist that you will be multi-listing at out-of-region transplant centers and that he will have to complete a separate referral form for each center that will be sent or faxed to his attention.
- Call each transplant center and ask to speak to the individual in charge of new transplant requests. Remember to write down their name and contact number. Give them your basic information and then ask questions, such as: will they accept out-of-region candidates; how many visits comprise their evaluation process (usually three separate visits); and what type of insurance coverage is needed to cover the medical expenses. They will most likely ask you some questions to pre-screen you. Be absolutely honest in responding to their questions as it will save you time

and money later should it be determined that you are not a viable candidate for their transplant program.

- Realize that multi-listing will cost you money. You will have to pay for your own travel, living, food and day-to-day costs. Remember, after you receive your transplant, you will have to reside close to the transplant center for at least 4 to 6 weeks, or even longer. Most transplant centers require, at the first evaluation, that you also bring the person who will be your caregiver after the transplant. Most insurance companies (except HMOs) will pay for your out-of-region pre-transplant testing, as it will save them money later when you stop dialysis (approximate cost for dialysis per year is \$80,000.00).

- You will have to prove to the transplant social worker that you have the financial ability to pay for your travel, living expenses and medications. The good news is that Medicare, along with any supplemental insurance, is one of the best types of coverage you can have and is usually accepted around the country. If all you have is Medicare, then you may be liable for the deductibles—and that can become a large cost factor. Therefore, if you cannot afford to travel to another region for a transplant, do not waste your or the transplant center staff’s time.

Be prepared for numerous forms to be completed both before your first evaluation appointment and while at the center. A word of advice: if you decide to multi-list, start compiling your medical records, i.e., hospital records; physician records; and any immunization records. All of the transplant centers will require a dental clearance; therefore, if you have not seen a dentist in 6 months, you should do so to determine if there are any problems and get them fixed. Once you have all of these records, make copies of them, as it is quite a job to compile all of these records.

This article is just a personal overview of the process of being multi-listed.

The UNOS Executive Committee plans to review the multi-listing process sometime in 2010.

If anyone needs information in their multiple-listing efforts, e-mail [info@trioweb.org](mailto:info@trioweb.org).

—Submitted by Ron Taubman, President,  
TRIO Ventura County/West Valley Chapter

\***Source:** UNOS pamphlet titled “*Talking about Transplantation; Question and Answers for Transplant Candidates about Multiple Listing and Waiting Time Transfer*”.

**Editor’s Note:** The above is provided as a ‘personal opinion’ by one individual and is not meant to be taken as advice.

For additional information on multiple listing and copies of the UNOS pamphlet referenced above, visit [www.unos.org](http://www.unos.org).

# Be Prepared for Each Stage of Your Transplant Experience

Transplant Experience can help you take an active role in your long-term health by providing you with continuous information and encouragement pre-transplant, during your first year post-transplant, and beyond—so you can be ready for what's ahead.

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- ② Go to [TransplantExperience.com](http://TransplantExperience.com)



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Transplant Experience has been recognized by the National Health Information Awards<sup>SM</sup>—a program honoring the best consumer health information programs and materials.

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EXPERIENCE**  
Sharing. Informing. Inspiring.

## TRIO Supports “TRIO Twins” in Book Tour to Japan

The TRIO Board recently approved a motion to join in supporting the upcoming “Power of Two” tour as a Community Partner, joining other organizations in promoting this effort by Ana Stenzel and Isa Byrnes, TRIO members and co-authors of the autobiography with that title. At a time when the winds of change are opening up avenues of opportunity for many who have been denied life saving organ transplants in Japan due to social norms and outdated legal blockages, these now famous twin sisters, born with cystic fibrosis and forecasted for a very short life span, are carrying the message of hope. Both sisters have survived to receive double lung transplants and now dedicate much of their professional lives to promoting organ donation and with their Japanese heritage, what better place to go and bring attention to transplant success than this highly touted book signing and presentation filled tour.

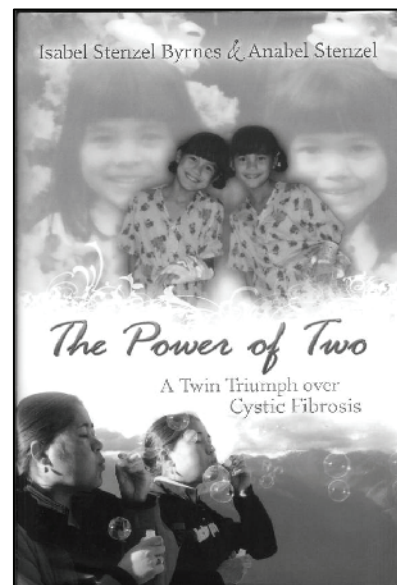
This fall, the Japanese version of the twins’ memoir will be published as “Mirakuru Tsuinzi!: Nanbyou wo norikoeta Futago no Kizuna” (“Miracle Twins! Twins Overcoming Illness Together”) by Iwanami Shoten Publishing. To support the Japanese launch of the book, they will embark upon a speaking tour in October that will share their story and attitudes towards illness and organ transplantation with an industrialized nation that has only had about 100 brain dead deceased donor transplants performed since 1997, the promise that “Mirakuru Tsuinzi!” can influence public conversation about organ transplantation in Japan has already excited Japanese transplant advocates who are taking a lead role in planning the twins’ tour.

The goal of the twins’ speaking tour is to engage in open discussion that can influence public opinion and potentially change hearts and minds around key issues presented in their book. In addition, as discussed below, the Japanese tour provides an opportunity for the twins, as well as sponsors and community partners, to promote organ donation and transplantation, and cystic fibrosis awareness, to people around the world. J.T. Rhodes, President of TRIO’s Board of Directors, has signed on as a member of the project advisory board.

To add to the project, highly acclaimed Academy Award nominated documentary film, television, and new media producer, Marc Smolowitz will be leading U.S. efforts to provide comprehensive, broadcast quality coverage of all aspects of the twins’ Japanese tour. The project plan includes the development of a robust website and new media content portal that will unleash this project’s incredible potential to impact the lives of people affected by organ transplantation, cystic fibrosis and related important causes around the world.

Meet the twins and see the video introduction to their project at <http://www.thepoweroftwomovie.com/>

-- James Gleason, Treasurer, TRIO Board of Directors  
and TRIO Webmaster



## TRIO Members Participate in World Transplant Games in Australia

The World Transplant Games were held this year on the Gold Coast, Queensland, Australia. Team USA had 82 recipients competing, many of them TRIO Members. Team USA placed third in overall official standing, winning 122 medals, with 46 of them, Gold Medals.

The weather was perfect and the events were super!

While the H1N1 virus was a concern, none of the 2,400 people attending the games contracted the virus due to precautions by the Games organizers.

The next Games will be held in 2011 in Goteborg, Sweden.

--Carol Fitzsimons shows off her gold medal for swimming.



--Don Ehnnot, who won 4 gold medals (in road-race, sprints and discus throw), is pictured here with his new friend while on a tour of the Currumbin Wildlife Sanctuary.



--J.T. Rhodes and his sister, Jeanne Prince (who won 2 bronze medals), competing in cycling events.



## Nutritious Behavior Contributes to a Successful Transplant

Nutrition is an integral part of a successful transplant. There are certain general rules of nutrition that we should all know: namely, a well balanced diet consisting of proteins, complex carbohydrates, fruits and vegetables, along with exercise and an adequate amount of sleep a night. But, transplantation brings another set of details to consider. According to Carlene Bowen, a registered dietitian (RD) for the transplant program at Jefferson University Hospital in Philadelphia, the underlying disease affecting individual transplant candidates can cause other problems, making it even more critical for patients to pay attention to their nutrition.

For the pre-transplant candidate, three issues can affect some or all patients: weight management, diabetes and hypertension. Ms. Bowen says that a BMI of 35 or less is suggested for transplant candidates because obesity pre-transplant can increase the risk of infection and/or poor wound healing and ultimate graft loss. Those with weight issues tend also to be more susceptible to diabetes. In addition, overweight patients whose diets contain an excess of sodium may suffer from hypertension and fluid retention, which can be problematic for all transplant patients. In stressing weight management, patients should be taught how to be well nourished, not just to be within healthy weight limits. This is where a dietitian can teach a patient how to get the right balance of calories, protein and other nutrients for him/her. According to Ms. Bowen, current recommendations say that liver candidates, who used to be limited in their protein intake, must now be given enough protein to be able to prevent further malnutrition and wasting of lean body mass. Dietary protein is only limited in patients with severe hepatic encephalopathy and those who are considered to be protein sensitive.

Once patients receive their transplants, new complications may arise because of the immunosuppressants and other medications that are prescribed to protect the graft. Transplant recipients need to be informed of the side effects of all their medications, which can affect the way their 'new' bodies metabolize the food they eat. Since most of the immunosuppressants cause similar side effects, transplant recipients are usually instructed to keep to a regular diet that is low in fat, sodium, and is rich in whole grains, fruits and vegetables. One of the biggest issues for transplant recipients immediately post-transplant is weight gain. Prednisone, one of the standard post-transplant medications, tends to boost the appetite, which may cause significant weight gain if patients are not careful. This may not be a problem for some liver recipients, who may have lost weight pre-transplant, but most patients are instructed to pay attention to portion sizes, while still focusing on the quality of their calories. Although more protein is permitted post-transplant, patients are told to avoid frying, and they are also told to watch food labels for saturated fat and

cholesterol. In addition, it is critical for post-transplant patients to take precautions to avoid food-borne illnesses by washing fruits and vegetables, making sure to store food at proper temperatures and avoiding raw or undercooked meat and meat products. Ms. Bowen recommends that post-transplant patients try to keep their BMI less than 30 simply through a healthy diet of food and multivitamins. She also recommends some form of regular physical activity as soon as patients are feeling strong enough. Patients who develop such problems as diabetes or high blood pressure may have to add additional medications if diet and exercise do not alleviate these problems.

Long-term, transplant recipients must continue to observe the general rules of healthful eating. Regular blood tests and check ups are also recommended to keep alert for certain chronic illnesses or issues such as hyperlipidemia, hypertension and osteoporosis. Immunosuppressive medications, which are key to the survival of the transplant, contribute to the development of these and other chronic illnesses. It is clear that a healthy diet can help transplant recipients remain healthy, but sometimes even the most conscientious eater cannot avoid the long-term effects of the transplant, and may ultimately be forced to turn to additional medications to alleviate subsequent issues.

-- Elizabeth Rubin, Secretary, TRIO Board of Directors

### TRIO to Accept Print and Web Advertising

In keeping up with the times and following the examples set by other non-profits in these tough economic times, TRIO's Board has approved acceptance of limited advertising in its communications resources: the *LifeLines* newsletter and the TRIOweb.org web site. With recent cut backs in many traditional donation support sources, this new revenue will allow TRIO to maintain strength in carrying out its critical mission of service to the transplant community. For details on TRIO advertising opportunities, go to <http://TRIOweb.org> or call the national office directly.

#### Are You Taking Full Advantage of What TRIO and United Airlines Can Do For YOU?

TRIO is most fortunate to be one of only 20 organizations partnering with United Airlines to allow frequent flyer seats for transplant-related travel AT NO COST. Do you or someone you know need to travel for pre- or post-transplant related medical visits? Does a transplant recipient or living donor need to travel with a care-giver? PLEASE take advantage of this wonderful program, generously provided by United Airlines! Call 1-800-TRIO386, go to TRIO's website [www.trioweb.org](http://www.trioweb.org) or email us at [info@trioweb.org](mailto:info@trioweb.org)

Membership – NEW and 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](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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