

TRIO Supports:



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Lifelines

October 2010



Transplant Recipients International Organization, Inc.

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

www.trioweb.org • info@trioweb.org • 1-800-TRIO-386

TRIO Welcomes Board of Director Member Ronald Seagrave



In a unanimous vote of approval, TRIO's Board of Directors appointed Ron Seagrave to the Board. Ron is a liver transplant recipient in 2006, having been listed for six years at a Richmond, VA, facility prior to receiving his transplant at Beth Israel Deaconess Medical Center in Boston, MA.

It is encouraging to note that Ron responded to a request in TRIO's blast email news, requesting members to come forward and serve the transplant community through participation on TRIO's Board of Directors or numerous committees. Ron responded!!!

Ron has been a member of TRIO and has served as a volunteer for Donate Life Virginia since 2004 and for the past six months as a contact point listed on TRIO's website.

Ron's professional military career of 30 years included service as a staff member of the Commander Submarine Squadron Twelve of the United States Navy and as an Electronic Warfare Instructor and later as an Instrumentation Engineer. He has also served as a history and computer science teacher and is a noted historical researcher.

Ron comes to TRIO with an outstanding background as an author of historical non-fiction. He recently published "The Early Artisans and Mechanics of Petersburg, Virginia" and is currently completing work on a book entitled "Jefferson's Isaac: From Monticello to Petersburg." Currently, he serves as president of the non-profit organization Greater Petersburg Historical Society of Virginia.

Ron states that he looks forward to serving TRIO in areas of Veterans Affairs and to dealing
(... continued on page 5)

TRIO Members Show Their Mettle at the US Transplant Games

TRIO members spent an exciting four days at the 2010 US Transplant Games held in Madison, Wisconsin, July 31 – August 3. TRIO, a sponsor of the Games, had an information booth with rally towel giveaways and TRIO pin sales during registration. Members were found throughout the many venues – competing, supporting and having a good time.

Below is some of what was seen and heard.

Susan Pincus (TRIO Philadelphia Chapter) organized the TRIO booth and giveaways to promote its mission, good works and website. **Pam Gleason** (TRIO Philadelphia Chapter) arranged the booth beautifully and **Jim Gleason** (TRIO Philadelphia Chapter), **JT Rhodes** (TRIO Northeast Florida Chapter), and **Susan Pincus** greeted booth guests with giveaways. The TRIO rally towel giveaways could be seen during the Games in athletes' bowling and golf bags and wiping many a sweaty brow.

Anabel Stenzel (TRIO San Francisco Bay Chapter) and **Isabel Stenzel Byrnes** (TRIO San Francisco Bay Chapter), the focus of the inspiring documentary movie "The Power of Two", were exhibitors during registration and **Faith Carlin** (TRIO Philadelphia Chapter) was there for the National Transplantation Pregnancy Registry. **Mary Wu** (TRIO Member at Large) shared her transplant story at the Games' evening Coffee House, where audience members took the microphone to present their inspirational stories.

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Jim and Pam Gleason
at the TRIO booth.



President's Message



J.T. Rhodes

TRIO continues to grow and offer more services for our members. Please help TRIO grow by inviting your friends online and at clinics to join TRIO so that the Voice of the Transplant Community will become stronger. Applications can be found online at www.trioweb.org and most local chapter websites which can be accessed from TRIO national's website.

TRIO had a significant presence at the transplant games with our booth. Just wish TRIO had more money so that we could have given away more rally towels which were a hot item at the games. In less than an hour each day all 500 towels were given away! See Susan Pincus' article on pages 1 and 3 for more on booth and games. For all of you who were at the Games and not included in the 'seen and heard' article this issue, please send games information to TRIO's Managing Services Director Sylvia Leach (sleach@trioweb.org) for possible inclusion on the web or in a future update.

Your local chapter president has received your TRIO pins for all paid members to proudly wear. If you haven't received yours, ask for your pin at the next meeting you attend! The TRIO website continues to be updated with information on transplantation and what the TRIO chapters are doing. A second informational email was sent to members who had registered their email addresses with TRIO. If you did not receive it and want to be on the list, please give our Managing Services Director your email address.

Another important service that TRIO provides to members is having representation on various UNOS committees. It is important that the viewpoint of recipients be shared with UNOS. I serve on the Operations and Safety committee of OPTN/UNOS. It amazes me how hard UNOS is working to improve patient safety in transplantation. I am sure that Ron Taubman, who serves on the Kidney and Pancreas Committee, and Jim Gleason, who serves on the Donor and Patient Affairs Committees, are just as impressed. If you would like to serve on a UNOS committee, contact me, Ron or Jim and we will try to help you get appointed.

We now have a full Board of Directors. Keep your eyes open for other potential board or committee members. We continue to have several openings on various committees and would like your help in filling those important positions.

Financially, TRIO continues to improve and has received a grant toward our Primary Care Physician Project and two grants for continuing our Presentation Library program.

In this issue of *Lifelines* you will find numerous informative articles. Dottie Lessard, an author and two-time recipient, has written an uplifting motivational article. If you would like more articles of this nature or on any other subject just let TRIO know. We are trying our best to serve you but need feedback from members to be sure we are doing what you want. See the article on page 4 about the member services survey and upcoming feedback to members.

Ron Taubman and his committee are working hard to make sure the essay contest for high school students is a success. The board accepted the committee's proposal to start the contest as a prototype in California so that any problems can be corrected before going nationwide.

Hope everyone has a healthy, happy and successful fall.

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

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

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TRIO Members Participate at the US Transplant Games (. . . continued from page 1)

George Franklin (TRIO National Capital Area Chapter) earned a silver medal and **Jack Silverstein** (TRIO Pittsburgh Chapter) a bronze in their respective Men's Team Bowling tournaments. TRIO was well represented at the swimming natatorium with **Mary Rhodes** (TRIO Northeast Florida Chapter) and **Holly Werlein** (TRIO Member at Large) each winning a gold and silver in their events, and **Patricia Bridges** (TRIO National Capital Area Chapter) earning three silvers and a bronze. **Jim Gleason** was also seen participating at the swimming venue and fighting it out the next day with **John Branton** (TRIO Philadelphia Chapter) on the badminton courts, each winning silver and bronze, respectively. **John Branton** and **Steve Okonek** (San Francisco Bay Area Chapter) were seen competing, though not against each other, at the table tennis tournament and **Okonek** was also showing his moves on the basketball court. **Faith Carlin** and **Susan Pincus** were at bowling, track and field and volleyball, with **Pincus** taking home a silver medal with her volleyball team. **JT Rhodes**, sidelined by injuries, was seen cheering everyone on.

Patricia Bridges



John Branton



Steve Okonek



JT Rhodes



Susan Pincus



Faith Carlin

Jack Silverstein, TRIO Pittsburgh Chapter, Receives NKF Transaction Council "Making Lives Better" Award



Introducing Jack Silverstein as the recipient of the "Making Lives Better" award, Ken Howard, Chancellor of NKF, said:

As the only child of Holocaust survivors, our awardee knows all about triumphing over tremendous odds and he wants others to have that same opportunity. Since receiving his life-saving kidney, pancreas and bone marrow transplant eight years ago, he has become a walking billboard for transplantation and organ donation. Everywhere he goes, he wears hats, t-shirts and/or pins promoting organ donation and the Transplant Games. He uses the gear as a conversation starter in waiting rooms, and his outgoing personality and concern for others does the rest as total strangers share their stories and concerns with him.

After he retired, he decided to devote his days to helping others, as a professional volunteer. His personal goal is to touch and make lives better for as many people as possible on every step along their journey to transplantation. At both the local dialysis and transplant centers, he talks one-on-one with those interested in getting on the list and those already transplanted so they can personally connect with someone who is successfully living with a transplant and so he can help prepare them for what lies ahead. He teaches them to become outspoken advocates for their own quality care, and continues this outreach over the phone and through the support group he founded.

Congratulations to Jack on a well-deserved award for his many hours of volunteer work!

-- Article by Susan Pincus, Secretary, TRIO Board of Directors

In Tribute to TRIO Good Friend and Supporter, Anthony De Pasquale

TRIO Manhattan received sad news on May 9, 2010. Anthony De Pasquale, loving husband of the chapter president, Lorraine De Pasquale, had passed away suddenly. We considered him the backbone of our group. He was low key and a man of few words, but yet, no one would deny, that without Anthony, our chapter would not have been a success.

Anthony enjoyed greeting new visitors to our monthly TRIO meetings. He made it a point to listen to their concerns, showed them around and made them feel welcomed. He would make sure that everyone had a seat and knew where the “goodies” were set up. Once Anthony learned your name, he always remembered you and we all felt like we had been friends for a long time.

Every April, for the past 15 years, our Chapter has had a “Remember and Rejoice” service at New York’s St. Patrick’s Cathedral. The purpose of the event is to honor all organ donors for their generous and heroic “Gifts of Life”. At the ceremony, we distribute a booklet with thank you letters from recipients and memorials from the donor families to their deceased loved ones. It was usually Anthony who received the many phone calls from the donor families. He would listen to their stories, commiserate with them for their loss and in general, try to assuage some of their grief. He always said that it was an honor for him to do this. He saw it as his way of indirectly thanking his wife’s donor family.

Every day since his wife’s liver transplant 21 years ago, Anthony had found a way to say “thank you”. He did it from his heart and for “his girl”, Lorraine. He loved to tell people that his forty two years of marriage was the best thing that ever happened to him. Our thoughts and prayers go out to Lorraine.

Sadly, on May 9, we lost a very dear friend!

-- Fran Dillon, Vice President
TRIO Manhattan Chapter

TRIO Receives Grant for Primary Care Physician Initiative

TRIO is pleased to announce that Pfizer has provided a most generous grant to initiate the *Primary Care Physician Program*. Through TRIO members, each visiting with their primary care physician, we will distribute literature and have a brief conversation encouraging primary care physicians to discuss organ donation with their patients.

Additional funding is being sought for this program to provide pre-printed literature (from Donate Life) along with instructional guidelines for member use in talking with their primary care physicians about the need for organ donation. Through more in-depth education of primary care physicians, TRIO members can make a difference in the need for organ donation.

TRIO Services Survey Analysis

The **TRIO National Services Survey** results may be coming to your area soon. As promised, the analysis of the spring survey is almost ready for presentation and is being scheduled by chapters even as you are reading this, with the Akron/Canton chapter first in line to receive this presentation at their November 16th meeting. Check with your local chapter to see if and when this is being offered at your local Chapter meeting.

Overall, the feedback in that survey was very positive in terms of perceived value of the existing TRIO National service offerings, some less so to the individual level (i.e., a member without children didn’t see much value to the scholarships at their level but rated higher in value at the chapter and/or nationwide level). With over fourteen services to rate on three levels of interest, that’s 52 items to rate, just in the specific services area alone, so we thank everyone who took the time to give us their opinions on those services.

In the open response option for new service suggestions there were several common areas to be expanded or added, notably in the mission areas of legislative advocacy, increased National communications to the membership (already addressed partially with the recent addition of the e-mail blast newsletter) and new chapter development/expansion support. To the question about dues, the overwhelming response was to keep it the same as it is today.

For more details be sure to come to your chapter meeting when the full presentation will be offered and your additional ideas solicited even if you missed the survey opportunity itself. We plan to hold a special audio conference to share the results with members-at-large and anyone who couldn’t make it to a chapter meeting presentation. Stay tuned!

UNOS RESOURCES

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

Transplant Book Reviews Available on TRIOWEB

This month we are introducing a new *Lifelines* column featuring recent additions to the Book Review section of the TRIOweb.org site. As this amazing list of books grows to nearly 100 titles, we hope to offer the most recent additions for your consideration in this feature in each *Lifelines* issue. Full book reviews are linked to each title on the web page.

Check out the following:

- **A Sister's Love** by TRIO member, Claudia Rose Novak - a caregiver's story of helping her sister through liver transplant while waiting in Jacksonville, Florida

- **After the Diagnosis: Transcending Chronic Illness** by Julian Seifter, M.D. - insights and advice by a doctor who is *also* a patient, sharing lessons learned both in his kidney practice and his own life as a patient with diabetes

- **Healing Hearts: A Memoir of a Female Heart Surgeon** by Kathy E. Magliato, MD - autobiography of the life and career of a female heart surgeon in a male world of surgeons

- **Before My Heart Stops: A Memoir** by Paul Cardall - born with half a heart, this is the true story of one man's year-long struggle to survive long enough to get a second chance at life with a heart transplant

- **My Child Needs a Transplant, Now What?** by Tandy and James Owen - family sharing of facing their child's liver transplant life challenges with faith and courage

- **Passages In Caregiving: Turning Chaos into Confidence** by Gail Sheehy - bestselling author of *Passages* shares from her personal experience lessons in how to care for a loved one through chronic illness and death

- **Seven Letters that Saved My Life** by Dottie Lessard - inspirational writing by a two-time organ transplant recipient, mother, writer, personal empowerment coach, motivational speaker and professional athlete. (See Dottie's motivational article on page 6 of this issue.)

For a full listing and many complete reviews go to **Book Reviews** under the **Communications** section on www.trioweb.org. A direct link is: <http://trioweb.org/communications/bookreviews/home.shtml>

If you know of other transplant related books not listed, we welcome titles for possible review and addition to this list. Please email that information to our resident book reviewer, GleasonJim@aol.com.

TRIO Presentation Library Grows With Second Year Support Funding

We are pleased to announce that the TRIO Transplant Presentation Library has received two new grants that will support its continued growth for the next 12 months with exciting new topics delivered bi-monthly to your local chapter and available to members-at-large by contacting the National office. With eleven programs already identified (two recently shipped and ten already recorded) this promises to be an even more successful program than the first year! Check the TRIOweb.org site for the updated listings from both years' offerings. Your local chapter submissions for possible inclusion in the library are always welcome, so keep that in mind when you have speakers at those chapter events.

Transplant Movie Listings

Have you discovered the other "hidden treasure" offered on TRIOweb.org, the long and ever growing list of transplant movies? Each title is linked to a document of everything you would want to know about each movie, i.e., title, plot, synopsis, actors, reviews, etc. Go to **Movie Reviews** under the **Communications** section where there are now 86 listings with one-line descriptions of the story, many with star ratings from our movie night event viewings. In future columns we will offer new listings in the same format as the book review listings seen elsewhere in this *Lifelines* issue. Again, if you don't see your own favorite transplant movie listed or come across a new one just coming out, send the title to our movie researcher, Susan Pincus at susan@carbonatorrental.com and she will do the rest.

Ron Seagrave, Board of Directors

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with various education issues and that he hopes to make a positive impact on TRIO's membership development.

Ron and his wife Andrea retired to Dinwiddie, VA, in 2005. Andrea continues to teach.

TRIO looks forward to utilizing Ron's extensive professional, managerial and organizational background in furthering its missions.

TRIO's Next Board Meeting

The addition of Ron Seagrave fills TRIO's Board of Directors to the number of positions specified in the Bylaws. TRIO will hold its next quarterly meeting on Saturday, October 23, at 2:00 p.m., via teleconference. If any TRIO member is interested in attending by teleconference, please contact TRIO's Managing Services Director, Sylvia Leach, at sleach@trioweb.org.

Living the Life You Want for Yourself Despite ANY Obstacle

What makes you excited to get out of bed every morning? The fact that we as transplant recipients have been given a gift to still be breathing and moving should be the very first spark of excitement but a lot of times, it isn't. And that's ok, we are human but we owe it to ourselves, our donors, and our loved ones to do all we can to Live Life Fully each and every day. We can find something to be happy about each day and we must do that because the emotions of feeling good, proud, loved, and needed are the emotions that are going to fuel us to be and do better.

Are you doing exactly what you want to be doing in life? If not, why? What is stopping you from doing it? Once you identify the "roadblocks" you can take steps to get by them. When you break through these you will feel superhuman strength from within that will give you the drive to keep going.

When you truly believe for yourself "You can Do It" there will be nothing and no one that will be able to stop you-not even your health. You may not be able to do your goal perfectly or in perfect time, but you can most certainly do it somehow and someday each day to get you to "your perfect". And what's "perfect" anyway? I just want to keep moving and striving for more-it's what keeps me alive.

It is the failures that make us stronger and more determined. And listen guys, it's ok to *fail* if you are *doing* because there is NO true failure when you are taking action and moving towards your goal. To me, you are heroes, warriors, champions, when you move and do your best giving everything you have to reach something or change something you aren't happy with. Often times it is the journey and what we learn, what we face and overcome that creates the true goal and gift, not the final destination.

I know everyone has it inside them to live the life they want, accomplish the dream they want. You must have the courage to step outside your comfort zone and push forward with a belief in yourself that is stronger than any "statistic, question, or fear". Fear has no power unless you give it power-it is an empty word that you don't have to "fill up". Drain it with determination and a vision of what you will do and accomplish.

I know there are many bumps in this life that we have but I also know the MOUNTAINS that we get to climb and the HILLS we get to charge over make those bumps moments in time that can be dealt with each and every time. NEVER forget all you did to fight for this chance of life--all your hard work and determination. Use that same inner fire that you had while fighting to live to now live the life you deserve.

If you are not taking good care of yourself by exercising and eating right, take a moment after reading this to write down 5 things you are doing

wrong and write 5 things you can do to make a start at changing them-NOW, not tomorrow, not next week-NOW. I want you to write 10 things that you are doing right, that you are proud of yourself for and truly feel the emotion that it gives you. Embrace that emotion and engrain it into your mind. Create a need and want to feel that daily. This will propel you to want more. You must create this for yourself; no one can do it for you. I can tell you all the things you should do to get there but until you decide from within to do everything you can to make it happen, it won't be enough.

I challenge you all to want more today and *live your life like your donor is watching*. I know they will be proud and so will I. I am so honored to be able to share my vision with you and hope I can somehow help you to reach further than ever to accomplish everything you deserve. Remember you were saved for a reason, make sure you are doing all you can to live that reason. *Today, tomorrow, always!*

-- Dottie Lessard, Life Coach, Mom, Athlete
Author of Seven Letters That Saved My Life
Co-Founder of Whole-Body Well-Being
www.dottielessard.com

TRIO Launches Essay Contest as Prototype in California

An essay contest for high school seniors is being launched in the State of California as a first-year prototype project for future national participation. The pilot project is headed by Ron Taubman, former member of TRIO's Board of Directors and past president of the TRIO Ventura County/West Valley Chapter.

Funded by a generous donation from the Transplant for Life organization, headed by Mr. Irv Goldberg, the project will be named in recognition of TFL project co-chairs Jerry Mark and Irving Grant.

Ron states that the project mission is to create a yearly essay program with a monetary award that will promote new ideas to increase the rate of organ and tissue donation. He expects the project to kick-off in October of 2010, with the first deadline for essays to be in the summer of 2011.

Check www.trioweb.org for updates on the project.

How Can TRIO and It's Partnership With United Airlines Help You?

TRIO is most fortunate to be one of only 20 organizations partnering with United Airlines to allow frequent flyer seats for pre- or post- transplant-related travel AT NO COST. To take advantage of this wonderful program, generously provided through United Airlines, call 1-800-TRIO, go to the TRIO website (www.trioweb.org) or email us at info@trioweb.org.

TRIOWEB.ORG Highlights

Today the most active area of our TRIOweb.org web site is in its TRIO Youth Circle area. The growing list of inspiring stories of young people thriving and energetically supporting the TRIO mission with their organ donor awareness activities makes for interesting reading. Once you have discovered this special new initiative, please reach out to transplant youth in your personal and chapter's network to spread the word of its existence to a new audience that TRIO is working hard to support. This youth team is coming up with new support ideas that will be announced on those pages when ready. One exciting idea under consideration is offering virtual support group meetings for youthful recipients who are looking for employment. Imagine the possibilities of that!

Two other web pages of special attention are the chapter activity reports linked from each chapter's name in the Active Chapters list (under **Community** at the top of any web page) and the expanding list of TRIO Transplant Presentation Library topics, now growing into 20+ DVD offerings available to every TRIO chapter member or member-at-large. That program index is linked from the home page story about the library. Check them out today.

Are You Wearing Your TRIO Pin?

If not, ask your Chapter President how to get your pin. TRIO Cloisonne lapel pins were sent to all chapter presidents for each TRIO member of record. The pins were individually labeled with member's name. Member at Large pins were mailed to them individually. Additional pins are available for purchase on TRIO's website.

The lapel pins are presented to each TRIO member as a statement of appreciation for their membership in 2010.

We hope you enjoy wearing the pins as a symbol of TRIO's efforts on behalf of transplant awareness, education and advocacy.



TRIO's Youth Circle Shares Answers to Your Questions.

The TRIO Youth Circle seeks to share experiences of youth around the country. You can learn more about the Youth Circle and read inspiring articles and news items from other youth by going to TRIO's website: (<http://trioweb.org/storyYouth.shtml>).



This month's question is: **How did your transplant affect your fitting in at school?**

Mary Wu's Answer: I had a lot of trouble fitting in at my school because of my transplant. Many of my classmates knew that I was sick and hearing just from word of mouth or gossip about my kidney problems and that I had a kidney transplant. After my second kidney transplant I had major facial hair and weight gain issues, which made me extremely self-conscious and I did not do well with the popular and rather fashionable groups in high school. The mood swings I experienced from my medication did not help matters. My health and taking care of my kidneys always had to be number one, so I could not socialize or participate in extracurricular and especially sports activities. Many of the students teased me or pitied me--which I despised. Looking back, I wish that my classmates had been more educated about organ transplantation and donation. Knowledge and education are the first steps to so many things. (Mary Wu, mwu82@yahoo.com)

Valen Cover's Answer: Being diagnosed with Polycystic Kidney Disease at the age of ten really affected my fitting in at school. Due to my enlarged kidneys, I was not allowed to participate in contact sports in gym class. I had to sit and watch the other kids play, and I hated to stand out and look different, but I had no choice. As youth, all we want is to fit in and have friends.

I wish I had known of the many non-profit organizations and support groups out there willing to help. I was lacking the support of others my age going through the same thing that I was, and their support would have been vital to my confidence and self-esteem. I encourage anyone facing health challenges to volunteer, get involved, share your story, and embrace whatever it is you're fighting! (Valen Cover, pkdwillnotbeatme@yahoo.com)

In future issues of the Youth Circle column we will be discussing topics of interest to our younger transplant community. Let us know what you want to talk about! Contact Valen, Mary or sleach@trioweb.org

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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