



Lifelines

July 2009



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

Mark Jackson Joins TRIO Board of Directors

TRIO is pleased to announce that Mark Jackson, Founder and CEO of Moreson Conferencing, has joined TRIO's national Board of Directors.



Mr. Jackson brings to the Board a solid business background and extensive experience from serving on boards of numerous local, national and international service organizations.

Mr. Jackson, a 17-year veteran of the teleconferencing industry, founded Moreson Conferencing in 1996 as a national and international conference calling network.

Jackson's background includes serving as a Trustee of the Birmingham (AL) Chamber of Commerce where he also serves as a member of the Chamber's Entrepreneurs' Round Table, a board member of the American Lung Association of Alabama, the Alabama Foundation for Agriculture, the University of Alabama at Birmingham School of Business Advisory Board and on the President's Leadership Council, the British American Business Group. He has held board positions with the National Library for the Blind in Stockport, England, and currently serves on the board of the March of Dimes (Alabama Chapter), the Japan-American Society of Alabama, the Russian-American Chamber of Commerce, just to name a few of the service organizations he has served.

Mr. Jackson was born and raised in Birmingham, AL, where he lives today with his wife Allison and their two young sons, Carey and Jordan.

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TRIO Welcomes Newly Formed Southern New Mexico Chapter

What began as an informal transplant support group three years ago in Las Cruces, NM, has now formalized into the TRIO Southern New Mexico Chapter.

At its organizational meeting, the chapter elected Geraldo Aguilar as President, Rudy Ortega as Vice President and Susan Brown, Secretary/Treasurer.

Geraldo is a 'donor dad,' sadly losing his 15-year-old daughter, Sabrina, after an ATV accident. Sabrina had carried an organ donor card since she was 13 years old. Geraldo says, "... We now know she saved five lives and we know her loving, caring spirit lives on." Rudy, a retired government contractor, received a kidney/pancreas transplant in 2003. Despite his devoted involvement in community service, Rudy is now working to acquire another credential: a degree in engineering. Susan received a kidney transplant in 2005 after three years on dialysis. In addition to her many volunteer activities on behalf of organ donor awareness, she has worked diligently with TRIO national to complete the requirements for TRIO chartering.

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TRIO Board of Directors Plan Summer and Fall Meetings

TRIO has scheduled its next quarterly Board of Directors meeting for Saturday, August 8. To continue its efforts to curb costs, the meeting will be held by teleconference. If you would like to attend, please contact Sylvia Leach at sleach@trioweb.org to make arrangements.

The fall Board of Directors meeting is tentatively scheduled to be held in Philadelphia in October. Details will be posted on www.trioweb.org.

President's Message



J.T. Rhodes

Over the years, TRIO has been blessed with many dedicated chapter presidents. Being a chapter president involves a large commitment of time and patience. Hopefully, as a chapter member, you appreciate all that your chapter president and your chapter board of directors do for you.

As a chapter president myself, and in talking to other chapter presidents, it seems there would be something we can all do to alleviate some of the burden that falls on the chapter president. Several times I have tried to get someone else to take over as president of our local chapter, but it quickly comes back to me or there are no volunteers.

It can be a very demanding job at times and the president often wonders why more people don't volunteer to help out when asked. In most organizations it is a general rule that 20% of the people do 100% of the work, but personally I think it is a lower percentage for TRIO.

As president of TRIO, I would like to personally thank all the chapter presidents for the hard work they do. I hope that the chapter members will also thank them personally.

Tom Behra has been president of Akron-Canton TRIO for more than ten years. He helps his members and plans several of the chapter's functions. Tom expresses his members' interests to your national board and maintains a healthy, active chapter.

Linda Cheatham, CPA, has served as president of Nations Capitol Area Chapter for eight years. She has served as Treasurer of TRIO national and continues to serve as Assistant Treasurer. Linda also serves as liaison to the Washington Transplant Roundtable.

Dave Courtney was one of the founders of the Texas Panhandle chapter and keeps this chapter alive. He is also very active in presumed consent issues.

Lorraine DePasquale has been president of our Manhattan chapter for 18 years. She does an excellent job with one of our larger chapters and seems to do a lot of work on all the chapter events. Her dedication and love of TRIO is very strong.

Suzanne Himes, RN, BSN, is serving her fourth year as president of the Greater Cleveland chapter. Suzanne will do anything to help one of her members and often gives me great ideas for TRIO.

Rich Koper is serving his first term as president of our Pittsburgh Chapter and is quickly learning how to be a great chapter president. He looks at chapter issues with an open mind and is willing to make changes to help his chapter.

Steve Okonek, president of the San Francisco Bay Area chapter since 2004, is very active in his support of TRIO. Despite recent medical problems, he has continued to keep his chapter involved in many projects and working with the OPO.

Elizabeth Rubin is the founding president of the Philadelphia Chapter, serving since 1997. She has also served TRIO national in various positions, including past president and currently serves as secretary of the national board. She is now in the process of getting this chapter active again.

Mike Sosna has been president of the Long Island chapter for the past three years. If something needs to be done in this chapter, you can be sure that Mike will see that it is done correctly. Mike also serves TRIO national as Public Policy Committee chair.

Ron Taubman recently resigned, due to medical issues, after serving for four years as president of TRIO Ventura County/West Valley Chapter. He led this chapter to promote many organ donor events and is one of the reasons TRIO national is active with Donate Life Hollywood. Ron also served as vice president of TRIO national and as chair of the successful Symposium that TRIO held last year.

Thank you, chapter presidents. You are the lifeblood of TRIO!

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

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TRIO Announces Transplant Presentation Library

Across the country many TRIO chapters host speaking events on many interesting topics. A new service of TRIO national is being launched as an aid

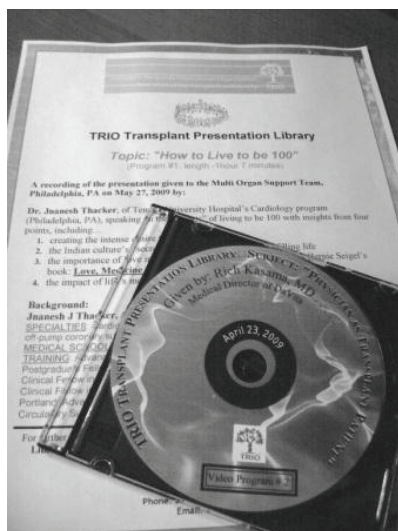
to both chapters and patients in making such presentations available for a wider audience.

Periodically, a DVD will be mailed to each chapter containing an hour-long presentation from recent meetings where noted transplant professionals have shared some topic of interest to our transplant community. It is anticipated TRIO chapters may use these recorded presentations at chapter meetings and/or local events as an educational resource.

Our vision is that each chapter will eventually build a Transplant Presentation Library where individual programs on DVD can also be loaned out to patients interested in the topics contained in this library for personal in-home viewing.

Currently there are five programs scheduled for release over the coming months. A central index will be maintained on TRIO's website so all members can know what is available from their local chapters. While these presentations in most cases may not have been professionally recorded, they still offer a valuable resource that can be shared in many venues. The recording quality of each program continues to improve as we gain more experience in the process of capturing these presentations. While this is currently being undertaken on a limited budget, it is hoped that with financial grant support this program will expand and grow in both the quantity and quality of the recordings over time.

Chapters are invited to record and submit their own local presentations for inclusion in this central Library. Contact the national office for details such as a release form for speakers and technical information on how to submit recorded presentations.



Current Legislative Activity Affecting the Transplant Community

A bill has been introduced in the Senate and the House of Representatives to prohibit preexisting condition exclusions in group health plans and health insurance coverage in the group and individual markets. This includes organ transplantation.

The bill, entitled "Preexisting Condition Patient Protection Act of 2009" was introduced in the Senate (S. 623), sponsored by Senator John Rockefeller (D-WV) on March 17. The Senate bill has five cosponsors and has been referred to the Committee on Health, Education, Labor, and Pensions. At the same time, Congressman Joe Courtney (D-CT) introduced the companion House bill (H.R. 1558) with 61 cosponsors. On May 14, 2009, the House Bill was referred to the House Subcommittee on Health, Employment, Labor, and Pensions.

H.R.2776, Title: "To amend the Family and Medical Leave Act of 1993 and title 5, United States Code, to allow leave for individuals who provide living organ donations," was introduced in the House of Representatives on June 9. The bill is sponsored by Rep Ruben Hinojosa, (D-TX). The bill has five cosponsors and has been referred to the Committee on Education and Labor, and also to the Committees on Oversight and Government Reform, and House Administration. No companion bill has been introduced in the Senate at this time.

No further legislative activity has been reported in reference to the "Immunosuppressive Bill" (Senator Durbin: S.565, Representative Camp: H.R.1458) since our report to you in April *Lifelines*. These bills are currently in committee.

Linda Cheatham, TRIO's liaison to the Washington Transplant Roundtable, reports that the Roundtable has sent letters to three different groups of senators and representatives who serve on various health and finance committees.

To read the text of the Roundtable letter, go to www.trioweb.org, click on "Communications" and go to the "Legislation" topic.

To read the full text of the bills and learn the current status of the proposed legislation, go to www.thomas.gov or to www.govtrack.us.

Oral Care is Crucial to Promoting Good Health in Transplant Patients

Transplant patients have so many details to remember, but dental care should not be forgotten. According to two recent articles from the National Institute of Dental and Craniofacial Research and the University of Southern California School of Dentistry, the care of teeth is essential to the long term security of a transplant graft. Just by being an organ transplant patient you are at risk of developing serious mouth problems. Your medical condition and side effects from your transplant medications can also damage your oral health and complicate your dental care.

A complete dental check-up should be part of every pre-transplant evaluation. It is absolutely essential for your mouth to be as healthy as possible before your transplant procedure so that you will not be as susceptible to the side effects of your transplant medicines. Cavities, periodontal (gum) disease and any other mouth problems should be treated before the transplant. Notwithstanding a transplant, it is also important for your general health to keep your mouth free of dental disease.

After the transplant, anti-rejection medications that suppress the immune system also make it more likely for you to develop infections, including ones in your mouth. Dr. Hessam Nowzari, director of the University of Southern California School of Dentistry's Advanced Periodontics Program, says that their research has shown that "active viral infection is frequently associated with severe clinical complications including transplant failure." In particular, the "human cytomegalovirus (HCMV) infection is specifically associated with renal transplant failure." Potential problems in the mouth include: dry mouth – "cotton mouth" caused by a lack of saliva in the mouth, which can increase the risk for tooth decay; mouth ulcers – sores in the soft lining of the mouth, which can make chewing, speaking or swallowing painful; infections – including gum disease that can hurt the tissues holding the teeth in place, or thrush, which is a fungus infection that appears as white patches in the mouth; gingival overgrowth – enlarged gums that cover part of the teeth; and tumors – mouth cancers, especially in those patients who have smoked. With adult patients, dentists

concentrate on halting the progression of gum disease and treating all other dental infections. With children, treatment is often different because of the different set of issues that they face.

The systemic problems of critically ill children facing transplant can cause numerous infections, including those listed above. Such problems can also affect the development of the teeth of youngsters. According to Jose Polido, a USC School of Dentistry faculty member who also heads the Division of Dentistry at Children's Hospital, both baby teeth and permanent teeth are susceptible to such problems as generalized enamel hypoplasia and hypomineralization – poor formation and mineralization of the enamel.

Parents of medically compromised children can do their part in preventing many dental problems by providing healthy food choices and curbing the intake of sugary foods; making sure their children brush and floss their teeth regularly; seeking out dentists who specialize in periodontology, pediatric dentistry and with experience in hospital dentistry; and talking to healthcare professionals regularly. Once a child is diagnosed with an oral infection, if prior to transplant, dentists tend to take a more aggressive approach that can involve removing baby teeth to control the spread of infection and prevent damage to the permanent teeth. This, in turn, will help set them up for a successful transplant.

It is clear that good oral health is important for all children and adults, but those waiting for a second chance at life need to take special care to assure that their teeth do not cause additional issues: oral care is clearly key to a successful organ transplant!

A fact sheet, *Organ Transplantation and Your Mouth*, from The National Institute of Dental and Craniofacial Research (NIDCR), one of the Federal National Institutes of Health, alerts patients to their increased risk for oral health problems. The fact sheet also provides practical information to help patients take an active role in keeping their mouth healthy before and after transplantation.

To view the publication or order free copies, visit <http://www.nidcr.nih.gov/> and click on "Oral Health," or call 1-866-232-4528 to speak to an information specialist.

TRIO Greater Cleveland Chapter Celebrates Twenty Years of Giving Back

Twenty years have rendered thousands of medical advancements and marvels in the field of organ transplantation. Add to that list of accomplishments, the establishment of the Greater Cleveland Chapter of TRIO. Greater Cleveland TRIO turns 20 years *young* this year!

TRIO Greater Cleveland Chapter was the second TRIO chapter established in the United States. The chapter is still growing, improving and changing but has established several wonderful traditions:

- Donor Sabbath Observance held every November as a time of reflection and honor;
- The fall educational seminar to help new and not-so-new recipients;
- Annual meeting and elections, which we also use as an opportunity to honor transplant support professions. This year, we will be honoring the transplant social workers.

In April, the Greater Cleveland Chapter partnered with the local OPO, LifeBanc, to host a "Monster Celebration of Life" during national Donate Life Month. The Lake Erie Monsters hockey team pulled off a victory which capped off a fun-filled event. The goal of the evening was to raise awareness with the people who attended the event about the need to become registered organ and tissue donors.



One of the highlights of the night was a "broom" ball hockey game where two teams from the transplant games Team Ohio, played each other. Media attention, including a remote broadcast from the ice by one of the local news

stations, demonstrated that fun and life continue after transplantation.



In August, we will host our 6th Annual Night at the Races, which is our main fundraiser of the year. The event features live racing, lovely buffet and lots of excitement. We also have side boards, chance raffle for donated items, and this year, a special raffle with the prize of watching a Monsters hockey game from a loge.

Coming up later in the fall, TRIO will hold our third movie night at which recipients, donors, and transplant coordinators watch a movie where transplantation is a main point of the story and have a discussion afterwards. This always generates a lot of conversation and sharing among those who attend. This year, the movie will be *Seven Pounds* starring Will Smith.

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The chapter hosts a fall educational seminar at which recipients exchange information and hear professional speakers.

New Lung Transplant Research Program Announced

-- Reported by Ana Stenzel

I would like to introduce to you a new Lung Transplant Research Ambassador Program. The mission of this critical program is to increase awareness, support and involvement in lung transplant research through outreach and patient advocacy. Through our dedicated lung transplant recipient volunteers from all over North America, we hope to collaborate with distinguished lung transplant centers to educate patients about the availability of clinical trials in lung transplant medicine. By making patients aware of the clinical trials available at their center, we hope to increase patient participation and therefore further medical advancements in the field. Examples of current ongoing research studies at our local lung transplant centers include studies on the genetics of graft dysfunction, inhaled cyclosporine, a new anti-T lymphocyte immune globulin, and CMV infections.

As a person who has lived with cystic fibrosis and has had two lung transplants, I have experienced the roller coaster ride of the lung transplant journey. I experienced first hand how chronic rejection of the lung, which manifests itself as bronchiolitis obliterans syndrome (BOS), as a mysterious, relentless evil, unresponsive to a limited number of risky treatments. BOS creates significant barriers to quality of life and longevity in lung transplant recipients, compared to other solid organ transplants. Currently the life expectancy of lung transplant recipients is 50% survival in 5 years, much shorter than other solid organ transplants. This number has not changed since I was first transplanted in 2000, while the long term survival for kidney, heart and liver recipients has. Such is the critical need for lung transplant research to understand BOS and other complications.

As part of the new Lung Transplant Research Ambassador Program, fourteen volunteer Ambassadors from around the USA and Canada attended training in San Francisco in April 2009 to launch this program. We brainstormed ways in which we can increase awareness about research opportunities in lung transplant medicine through speaking at support groups, mentoring patients who are recently transplanted, and spreading the word online. We welcome others who may be interested in volunteering in this effort. If you are interested, please see: <http://lungtransplantresearch.ning.com/profile/AnaStenzel>

The Lung Transplant Research Ambassador Program is sponsored by APT Pharmaceuticals, makers of inhaled cyclosporine, which is the only phase III clinical trial currently going on exclusively for lung transplant recipients. This trial is open to adult lung transplantation recipients who have been transplanted in the last 60 days. For more information about inhaled cyclosporine, please see: www.cycliststudy.com.

Clinical trials are not exclusive to those with lung transplants. I encourage anyone with a transplant to inquire about research opportunities for their organ. If you are like me and often feel frustrated that there are more unanswered questions in your transplant clinic than there are answered ones, I believe one way to help find those answers is to get involved in clinical studies. Talk to your coordinator or doctor about what studies are going on at your center and how you can get involved. Learn about the studies, and the risks and benefits; decide for yourself with your doctor's guidance if participating in a clinical trial or study could help you or others. Some people are worried about being a "guinea pig." Well, to be honest, as transplant recipients, we are already guinea pigs! For more information on transplant research opportunities available at your transplant center, see: www.clinicaltrials.gov.

I have participated in several clinical trials and observed the long challenging road of getting new medications from the lab bench to the patient's medicine cabinet. It is the efforts of many. We can do our part by participating in clinical trials and research studies. We have the power to prolong life with transplantation by getting involved in research studies and giving back.

The author, Ana Stenzel, is the Co-Author of "The Power of Two: A Twin Triumph over Cystic Fibrosis" (www.stenzeltwins.com).

She can be contacted by email at: anana1872@yahoo.com.

NOTE: TRIO does not agree with, disagree with, nor participate in this study in any way. By publication of this information, TRIO is not recommending participation. Information is for evaluation by each individual and in consultation with their medical team. The decision to participate in any study is at the discretion of the individual.

UNOS' *Transplant Living* Site Offers Resources and Information

Did you know that the estimated average first-year billed charges for a heart transplant totaled \$658,800; for a kidney, \$246,400; for a lung, \$399,500; for a liver, \$519,600 (and that's in **2007** dollars!)? You can learn the cost detail information on UNOS' 'Transplant Living' website: www.transplantliving.org. (Click on Before Transplant and go to "Financing a Transplant" and then click on "Costs".)

Under "Financing a Transplant" you can also locate excellent commentary and information on *Social Services, Funding Sources, Care Following a Transplant, Financial Resources Directory, and Financial Q&A*.

At Before Transplant, you can read about *Organ Allocation, Getting on the List, Selecting a Hospital, and Preparing for a Transplant*.

At During the Transplant, you can learn about how each type of transplant is performed, by organ.

At After the Transplant, you can learn more about the post-transplant process, including topics such as *Medications, Pregnancy, and Staying Healthy*.

On the 'Transplant Living' website, UNOS also offers sections about Pediatric, Living Donation, and Community.

Please visit UNOS at www.unos.org. From there you can click on 'Transplant Living.'

102,008

on the waiting list
as of June 22, 2009

-- www.unos.org

TRIO Southern New Mexico Chapter

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The chapter started with 13 members and is expecting an additional six members this month. The chapter meets at 6:30 p.m. on the second Thursday of the month at Mountain View Hospital in Las Cruces.

The group is very active in the Las Cruces community, conducting and participating in numerous donor awareness activities and is currently working with the city of Las Cruces to establish a 'Memorial Walkway' in a park on the Rio Grande River, to honor organ donors. The chapter works closely with their OPO, New Mexico Donor Services in Albuquerque.

Welcome, TRIO Southern New Mexico Chapter!

Board Member Mark Jackson

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According to TRIO board member Jim Gleason, "With Mark's extensive experience working with so many different organizations, we anticipate his strong leadership and support in helping TRIO to increase its role of support in being the "Voice of the Transplant Community."

To learn how you, too, can serve TRIO's mission, contact Jim Gleason, Chair of the TRIO national Nominating Committee to discuss your interest. Jim's email address is: GleasonJim@aol.com.

TRIO Greater Cleveland Chapter

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Wrapping up the old and welcoming the New Year takes place at the After Holidays Party. As the pace slows in January, the chapter gets together for a true time of catching up and celebrating another year of life and the hopes of continued health.

Over the past twenty years, we have made many, many friends, sadly said good-bye to a few and welcomed new recipients into our membership. Our commitment to the mission of Transplant Recipients International Organization is stronger than ever as we continue to grow and evolve. We welcome new challenges and opportunities to reach out to all those individuals and families whose lives have been touched by transplantation.

Cheers to the next 20 years of the Greater Cleveland Chapter of TRIO!

-- Colleen Jarvis

Vice President, TRIO Greater Cleveland Chapter

USDA Offers Food Safety Information for Transplant Recipients

The United States Department of Agriculture's Food Safety and Inspection Service offers a booklet about the importance of food safety for transplant recipients. The booklet "is designed to provide practical guidance on how to reduce your risk of foodborne illness." The booklet offers detailed discussions, information and charts about critical and diverse topics, such as causes of foodborne illness; symptoms of illness; handling, preparing and consuming foods; and eating out.

The 24-page booklet, entitled "Be Food Safe," can be read or downloaded at: www.fsis.usda.gov/pdf/food_safety_for_transplant_recipients.pdf

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. OR: consider starting a transplant support group or TRIO chapter in your area (contact info@trioweb.org).

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