



**Transplant Recipient International Organization
Pittsburgh Chapter
September & October 2012 Newsletter**

TRIO MISSION STATEMENT: TRIO is a non-profit international organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness.

IN CASE YOU MISSED IT

The summer edition of the Pennsylvania Caregiver Magazine, published by TRIB TOTAL MEDIA, featured several TRIO members and their transplant story as well as several articles regarding transplantation. Following is an article illustrating many myths that people have regarding transplantation. This article, written by Gen Lucidi Payne, is reprinted here courtesy of TRIB TOTAL MEDIA.

Transplant Myths vs. Facts

Despite ongoing efforts to dispel the misconceptions and inaccuracies about organ, cornea and tissue donations, many myths still persist.

1. If I am in an accident and medical personnel find my donor card, they won't try to save my life.

The number one priority is to save every life. All life-saving efforts must be exhausted before tests are performed to confirm the absence of brain or brain stem activity and a brain death is declared. In addition, for a traditional organ donation, a person must be in a hospital and on a ventilator at the time of death. Before any transplant decisions are made, CORE (Center for Organ Recovery and Education) discusses the options with the family.

2. My body will be mutilated and disfigured if I would donate.

Donation does not interfere with viewing in an open casket and other funeral arrangements. Donated organs and tissue are removed surgically in the hospital operating room. Doctors maintain dignity and respect for the donor at all times.

3. Only wealthy people receive transplants.

Financial and celebrity status do not determine who receives a transplant. A national computer network, maintained by the United Network for Organ Sharing (UNOS) matches organs according to height, weight and blood type, followed by medical urgency and then time accrued on the waiting list. Most major insurances cover transplants.

4. I cannot choose what I want to donate.

You may specify what organs or tissues to donate on your donor card.

5. I am not the right age for donation.

There is no age limit for organ donation. Organs can be donated from someone as young as a newborn. The general age limit for tissue donation is 80 and cornea donation is 70.

6. If I do not sign a donor card, my organs and tissues won't be donated.

If potential donors are not on the organ donor registry, their legally authorized representative (usually a spouse, relative or close friend) is offered the opportunity to authorize the donation

7. My religion does not support donation.

All major religions either consider donations as an individual decision or support or see it as the final act of love and generosity toward others.

8. Only heart, liver and kidneys can be donated.

Kidneys, liver, heart, lungs, pancreas, intestines and stomach are the organs that can be donated. Corneas, ligaments, tendons, bones and skin are the tissue most often donated. Heart valves and certain arteries also may be donated. Corneas offer the precious gift of sight.

9. Organs go to people who didn't take care of theirs.

Organs go to people who were born with or developed diseases that have caused organ failure. Less than five percent of people awaiting transplant have destroyed their organ through substance abuse and they must achieve and sustain sobriety before they can be listed for transplant.

10. My organs aren't of any value because of my medical illnesses.

Few illnesses or conditions prevent someone from being a donor. At the time of death, CORE reviews medical and social histories to determine suitability. Poor vision, cataracts and glaucoma do not eliminate someone's ability to donate. The ability to donate is determined on a case-by-case basis at the time of death. Although someone may not be able to donate blood, it does not always prevent the individual from donating organs and tissues

11. Families can override a donor's wishes.

For individuals at least 18 years old, a signed donor card or donor designation on the license are recognized as legally binding

For more information or to become a organ, tissue and cornea donor, contact CORE at core.org, donatelife-pa.org or 1-800-DONORS7.

TRIO Leadership Summit 2012: Not Just for “Leaders”

TRIO National held the “2012 Leadership Summit” in Pittsburgh on September 28 and 29. The workshops were held at the Center for Organ Recovery & Education (CORE).

The summit began with an opening luncheon from 12:00 to 1:00 P.M. on Friday. A variety of workshop sessions followed. At 7:00 on Friday evening, a “25th Anniversary Gala Celebration” dinner took place at the Comfort Inn. The keynote speaker was Walter Graham, Executive Director, United Network Organ Sharing (UNOS) CEO, UNOS Foundation. Dr. Starzl was an honoree and was presented with a Lifetime Achievement Award. Walter Graham was also presented with a Lifetime Achievement Award. Saturday began with a continental breakfast at 8:00 A.M. Workshops continued up to the conclusion of the summit at 5:00 P.M.

After the president of TRIO, Jim Gleason, began the summit with his opening remarks, Susan Stuart, President and CEO of the Center for Organ Recovery and Education (CORE) was the first guest speaker. Susan informed everyone of the history of CORE and it's role as an Organ Procurement Organization (OPO). She also made note of some of the new renovations underway and soon to be completed at their facility. A session regarding transplantation and youth had two young recipients, Mary Wu and Allie Weese, share their transplant stories. Mary is from New York City and had her first kidney transplant at UPMC in 1984 at the age of three. She has recently completed a book of her transplant story and is trying to get it published. The book's title is “Confessions of a Kidney Transplant Recipient”. David Cooper, MD, PhD, FRCS, gave a very interesting talk on Xenotransplantation, which is exploring the use of non-human organs for transplants or “cross-species” transplantation. Another session, which was interesting as well as very humorous at times, was titled “Enjoying Sexual Fulfillment Post Transplant”.

Besides members of the Pittsburgh Chapter of TRIO in attendance, other chapters represented were members from the Akron-Canton Chapter, the Greater Cleveland Chapter, Japan Chapter, Long Island Chapter, Nations Capital Area Chapter, Philadelphia Chapter, San Francisco Chapter, Ventura County West Valley Chapter plus Members-at-Large and our Youth Circle.

The President of the Japan Chapter, Yushi Nomura, flew all the way from Tokyo, Japan just to attend the summit! The Japan Chapter of TRIO has over 200 members! Mr. Nomura was presented with a Special Achievement Award at the Gala Celebration Dinner.

Photos and videos are available on the TRIO web site at:
trioweb.org / then go to Communications/Resources / then click on
<http://trioweb.org/storyLeadershipSummit2012.shtml> or click on the links below.

Photos taken by Susan Pincus during the Summit can be viewed at:
<http://share.shutterfly.com/share/received/welcome.sfly?fid=e0e39cbebea35fa5f12f12eb75ef82b5&sid=2FcMmzRylex>

Videos of the Summit are also available for watching. They are being edited and added each day. Go to:
<http://trioweb.org/storyLeadershipSummit2012.shtml>

PROPOSAL TO REVISE THE NATIONAL KIDNEY ALLOCATION SYSTEM YOUR OPINION MATTERS!!!

The Organ Procurement and Transplantation Network (OPTN) was established by Congress and is operated by a private, nonprofit entity. The OPTN is requesting public comment on a proposal to revise the allocation system used for kidney transplants. All public comments received are considered by the OPTN prior to approval of any final policy by the OPTN Board of Directors. The comment period for the proposed kidney allocation system is from 9-21-12 to 12-14-12. As of July 19, 2012, there were 92,696 candidates listed for a kidney or kidney-pancreas transplant. All of these candidates will be affected in some way by the proposed changes.

To read the proposal and submit a comment go to:

<http://optn.transplant.hrsa.gov/policiesAndBylaws/publicComment/proposals.asp>

NEXT TRIO SUPPORT GROUP MEETING

TRIO Support Group Meetings are held on the third Sunday of the month, except in the months of August, due to our picnic, and in the month of December, due to our Holiday Party. The meetings begin at 1:30 PM and alternate between Allegheny General Hospital, Snyder Auditorium and UPMC Montefiore Hospital LHAS Auditorium. Flyers are normally sent out before the meetings as well as being posted on the TRIO website. The next TRIO Support Group Meeting is at UPMC Montefiore, 7 South, LHAS Auditorium on Sunday, October 21 at 1:30 PM. Two guest speakers will be present, Kelly Martin, CRNP, UPMC Center for Liver Diseases, Division of Gastroenterology, Hepatology and Nutrition University of Pittsburgh and Mark Wasko, Regional Account Manager, Giant Eagle Specialty Pharmacy. October 2012 is national liver awareness month and the topic of the meeting is *LIVER HEALTH & WELLNESS – YOUR LIFE!*

HOLIDAY PARTY

The TRIO Holiday Party will be on Saturday, December 1, 2012 at Calabria's Restaurant. Calabria's in Castle Shannon on Rt. 88 near the intersection with Rt. 51. More details of this fun evening will be coming soon.

CURRENT TRIO-PITTSBURGH BOARD OF DIRECTORS

Mary Alice King (President), Rudy Molnar (Vice President), Rich Wegrzyn (Treasurer), Paul Armbruster (Secretary), Chris Armbruster, Anna DiPilato, Shannon Flynn, Kathy Jacobs, Carol Foglia, Tom Meshanko, Jo Anne Schwarz, DeeAnne Seeger and Georgene Thomas.

Due to new changes personally and professionally, Colleen Yost recently resigned from the TRIO Board of Directors. On behalf of the board of directors, "Thank you Colleen, for your dedication and excellent job you performed while being on the board and good luck with your new assignments in the transplant field."

CURRENT TRIO-PITTSBURGH CHAPTER HONORARY BOARD MEMBERS

Dr. Kareem Abu-Elmagd, Dr. Thomas Cacciarelli, Dr. Barbara Carpenter, Dr. Robert Kormos, Dr. George Mazariegos, Dr. Dennis McNamara, Dr. Srinivas Murali, Dr. Obaid Shakil Shaikh, Dr. Ron Shapiro, Dr. Thomas Starzl, Susan Stuart, Dr. Henkie Tan, Dr. Ngoc Thai, Dr. Kusum Tom and Dr. Steven Webber.

TO CONTACT TRIO-PITTSBURGH CHAPTER:

Phone: 412-647-7461 or 1-877-647-3439

Mailing address: UPMC Montefiore, 7 South / Attn. TRIO President / 3459 Fifth Avenue / Pittsburgh, PA 15213
For more information about TRIO Pittsburgh, visit the website at www.trio-pittsburgh.org

ELECTIONS AT THE NOVEMBER ANNUAL MEETING

The offices of President and Secretary are up for election this year. The election will take place at the Annual Meeting, which is also the Support Group Meeting for November. The date is on Sunday, November 18, and the meeting is scheduled for Allegheny General Hospital, Synder Auditorium. If you would like to run for President or Secretary of the Pittsburgh Chapter of TRIO, please contact me at paul_armbruster@yahoo.com or leave a message on the TRIO phone line at 412-647-7461 or 877-647-3439.

HAPPY SEPTEMBER ANNIVERSARIES

Donna J. Bias: Liver recipient: 9-11-94

Patricia Chincheck: Liver recipient: 9-21-97

Norman Dinardo: Heart recipient: 9-2-95

Jack Silverstein: Kidney, pancreas and bone marrow recipient: September 1, 2 - 2002

HAPPY OCTOBER ANNIVERSARIES

Paul Armbruster: Liver recipient: 10-5-02

Jeffrey George: Liver recipient: 10-21-90

Mary M. Gonzalez: Liver recipient: 10-26-00

Paul Jewell: Heart recipient: 10-7-93

John Polcznski: Heart recipient: 10-23-06

Richard Wegrzyn: Heart recipient: 10-23-05

HEART SUPPORT GROUP MEETING

The next scheduled Heart Support Group Meeting is on Saturday, October 20, at Panera Bread on the Boulevard of the Allies. The meeting begins at 12:00 and lasts until 1:30.

For more information, contact Tom Meshanko at: t.meshanko@verizon.net or call 412-351-6704.

WESTERN PA KIDNEY SUPPORT GROUP MEETINGS

South Hills Meeting: Saturday, 10-13-12 10:00 – 12:00 PM at Jefferson Regional Medical Center, James Bibro Pavilion. Contact: Diana Bell: 724-292-9318 or dkbell1981@yahoo.com

Cranberry Support Group Meeting: Sunday, 10-14-12 2:00 – 3:30 PM at Panera Bread, Cranberry Twp.
Contact: Nikki McKenna: 412-216-0144 or mckennanr@gmail.com

Pittsburgh West Support Group Meeting: Sunday, 10-14-12 2:30 – 4:30 PM at King's Restaurant in Oakdale
Contact: Mike Currin: 724-796-1603

Pediatric Contact: Lori Bible 724-981-0368 sbible6@msn.com

For more information about kidney disease and support groups visit www.wpakidneysupport.org

LOCAL SUPPORT GROUPS for LIVER DISEASE

GREATER PITTSBURGH PBC (PRIMARY BILIARY CIRRHOSIS) SUPPORT GROUP

Meets on the 2nd Tuesday of each month at Panera Bread – Waterworks Mall – Fox Chapel
For more information contact Ellen Kerber or email at kerber@kerbers.com

LIVING WITH HEPATITIS SUPPORT GROUP

Meets on the 3rd Thursday of each month at
330 South 9th Street, Main Bldg., Room 182 Pittsburgh, PA 15203
For more information contact Jen Warner at 412-535-2670

WESTMORELAND COUNTY SUPPORT GROUP

Meets every other month on the 3rd Monday (Jan, March, May, July, Sept and Nov) at Hempfield Church of Christ 144 Hugh Black Rd Greensburg, PA 15601

For more information contact Antonia or Mike Redigan at 724-423-5948 or antoniaredigan@hotmail.com

CIRRHOSIS ONLINE SUPPORT GROUP

Online cirrhosis support group at www.mdjunction.com/cirrhosis

For more information go to: AMERICAN LIVER FOUNDATION - WESTERN PENNSYLVANIA CHAPTER at www.liverfoundation.org/chapters/westernpa/

UPCOMING EVENTS:

Sunday, October 21: TRIO Support Group Meeting at UPMC at 1:30 PM

Sunday, November 4: Kidney Walk at the Pittsburgh Zoo & PPG Aquarium

Check in begins at 7:30 A.M. Walk begins at 9:00 A.M.

If you would like to walk with Team Pittsburgh, please contact Colleen Yost at www.colleen@yosts.net or contact Shelly Zomak at www.zomak@comcast.net

Sunday, November 11: Second Chance at Life presents Pittsburgh Celebrity Hockey vs. Dr. Stephen Bailey & the Kosice Icers. Shadyside Academy Ice Rink, 423 Fox Chapel Road, Fox Chapel, PA 15238

Doors Open at 6:30 p.m / Game begins at 7:00 PM / Tickets \$10.00 at the Door / \$8.00 Purchased Pre Game

Email mpaul@secondchanceatlife.org for ticket sale locations or at www.secondchanceatlife.org

Saturday, December 1: TRIO Holiday Party at Calabria's in Castle Shannon

More information to come.

In closing:

“A man sees in the world what he carries in his heart.”

Johann Wolfgang Goethe, from “Faust”

Respectfully submitted by Paul Armbruster, TRIO Pittsburgh Secretary