

# LI TRIO UPDATE

THE LONG ISLAND CHAPTER OF TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION ▲ October 2008

THE LONG ISLAND TRIO GENERAL MEETINGS ARE HELD ON THE SECOND WEDNESDAY OF EACH MONTH FROM SEPTEMBER TO JUNE  
OUR DECEMBER HOLIDAY PARTY SUBSTITUTES FOR THE DECEMBER MEETING. THE MONTHLY MEETINGS BEGIN AT 7:30 PM AND ARE HELD AT:  
145 COMMUNITY DRIVE, MANHASSET, NY

## Our Next Meeting With Dr. Wayne Waltzer

We are pleased to announce that our guest speaker for LI TRIO's October 15, 2008 meeting will be Dr Wayne Waltzer, Director of the Renal Transplant Service at Stony Brook University Hospital.

Please note that the meeting is being held on 15 October, 2008 which is the third Wednesday evening in October as opposed to the customary second Wednesday evening in October. This change in schedule is due to the Jewish Holiday being observed.

Wayne Waltzer, MD is also a Professor and the Chairman of the Department of Urology at Stony Brook University Hospital.

The Department of Urology was recently ranked among the top 50 best practices for Urology in hospitals in America by U.S. News & World Report (August 2007).

We are looking forward to welcoming Dr. Waltzer as our special guest speaker this month. ▲

## Our September 2008 Monthly Meeting With Two Special Guest Speakers

**L**ong Island TRIO had two special guest speakers at our September 10th meeting.

First, we had a surprise guest at our September meeting. It was none other than renowned transplant surgeon Dr Lewis Teperman! If you are a new TRIO member and don't know much about Dr. Teperman just Google his name and be prepared to spend a few days catching up. From LI TRIO's perspective, Dr. Teperman was instrumental in actually forming the Long Island chapter that is so vibrant today. Our president acknowledged that fact at our meeting and Lew Teperman stated once again that he had a very special place in his heart for Long Island TRIO.

Dr Teperman told us he had several important things to tell us. He reminded our meeting's attendees that transplantation is a "risk-benefit" scenario and there is still a concern that the recipient could contract an illness or virus from the transplanted organ.

We all know that there are more people waiting on the transplant waiting lists than there are organs available for transplant. There are a variety of reasons for this shortage. However, one area of organ donation that has helped increase the number of organs transplanted (relatively speaking) is in the category of donation after "cardiac death"; that is a death declared on the basis of cardiopulmonary criteria (irreversible cessation of circulatory and respiratory function) rather than the neurologic criteria used to declare "brain death" (irreversible loss of all functions of the entire brain, including the brain stem).

As currently practiced, donation after cardiac death inevitably raises more concerns than donation after brain death. In an interview with the New England Journal of Medicine, Sue McDiarmid, a professor of pediatrics and surgery at the University of California, Los Angeles, and the immediate past president of

## UPCOMING EVENTS AT LI TRIO

Please note that our October meeting is being held on October 15, at 7:30 PM.

▲ **October 15:** LI TRIO October Meeting at 7:30 PM-Dr. Waltzer is our special guest speaker.

▲ **November:** National Donor Sabbath

▲ **December 6:** LI TRIO's Annual Holiday Party 7 PM- 11 PM Come join us on Saturday evening for a lovely hot buffet and DJ entertainment.

The party will be held in the beautiful Catering Hall of The Elks Club at 901 Lakeville Road, New Hyde Park. Invitations are being sent under separate cover via U.S. Mail.

## LONG ISLAND TRIO UPDATE

The Newsletter of **The Long Island Chapter of Transplant Recipients International Organization** is published monthly and mailed free to all members. Please send any letters and any other correspondence to:

### LI TRIO

P.O. Box 81, Garden City, NY 11530

Please send all articles, member profiles, stories, anecdotes and other newsletter submissions to:

**Mike Sosna, President**

### LI TRIO

5440 Little Neck Parkway, Suite 4H

Little Neck NY 11362

Tel: 516.902.8111/Fax: 516.482.2599

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## NEWSLETTER STAFF

**Mike Sosna**—Editor

**Laura Laria Roberts**—Original Design

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## LI TRIO GENERAL MEETINGS

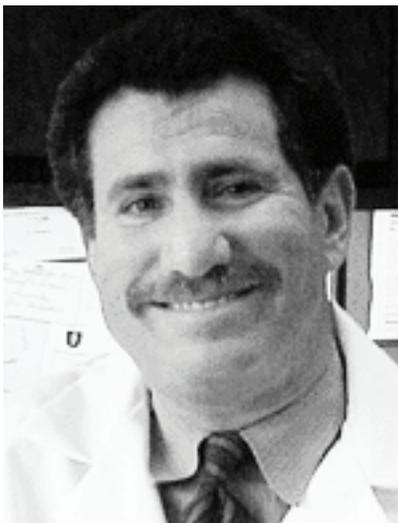
The Long Island TRIO General Meetings are held on the second Wednesday of each month beginning at 7:30PM from September to June. Our December Holiday Party substitutes for the December Meeting. The monthly meetings are held at:

**145 Community Dr., Manhasset, NY**

## LI TRIO MISSION STATEMENT

Long Island TRIO is a non-profit ALL VOLUNTEER organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness.

**JOIN US!**



OPTN/UNOS, said "The perception of some physicians and families is that the end-of-life experience is changed because organ procurement begins immediately after death has occurred. However, many families find great solace in the ability to donate organs under these special circumstances."

If the number of organ donations after cardiac death continues to increase, more patients will be able to receive transplants. At present, however, these donations remain troubling to some and are not as widely accepted as donations after brain death. There have been many conferences that collectively voiced support for donation after cardiac death and this included the Institute of Medicine's conferences. However, there are renewed discussions that are taking place and Dr. Teperman explained that the Pope will likely weigh in on this issue as well. The result is likely to decrease deceased donations and force greater reliance on donation *(continued on Page 3)*

## LI TRIO Board Of Directors

**Ruth Pohl**

**Jo Michaels**

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**Erin Hogan**

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**Frank Feltkamp**

**Tom Bush**

**Walter Ruzek**

**Dave Rodgers**

**George and Sue Tietjen**

**Florence and Jerry Sosna**

**Donald Schwartz**

**Mike Sosna**

## LI TRIO Presented Organ Donation Awareness Night At Shea Stadium-July 22, 2008

We helped enroll over 104 people in the New York State Donate Life Organ Donor Registry while promoting organ donation to over 54,000 fans at Shea Stadium. The following press release for this event was distributed to the media:

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**SHEA STADIUM EVENT DEDICATED TO  
DEMONSTRATING  
THE POWER OF ORGAN DONATION TO  
SAVE LIVES**

*Transplant Recipients, Donor Families and  
Transplant Professionals Take the Field  
to Urge Mets and Phillies Fans to Become  
Champions of Organ Donation*

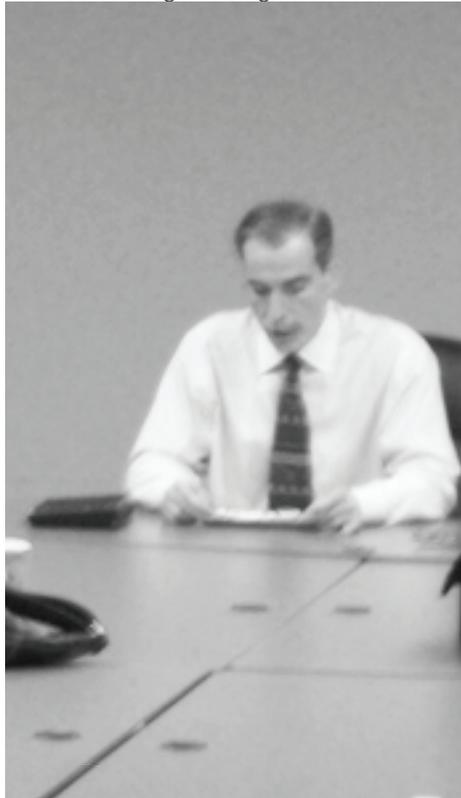
Deerfield, IL, and New York, NY- July 22, 2008 — With nearly 100,000 people across the country in need of a life-saving organ transplant, Astellas Pharma US, Inc. and Long Island TRIO (Transplant Recipients International Organization) are helping take the cause to the field by presenting "Organ Donation Awareness Night at Shea Stadium" during the New York Mets vs. Philadelphia Phillies game on July 22. The event will also honor the thousands of donors and donor families across the United States who have already given the gift of life.

"One organ donor can save up to seven lives, while a tissue donor can improve twelve or more lives including actually restoring eyesight for another person," said Mike Sosna, president of Long Island TRIO- Transplant Recipients International Organization. "Each day, about 77 people nationwide will receive the 'gift of life,' an organ transplant, but sadly 18 others will die waiting for a transplant. We hope that this event will encourage people to say yes to (continued on Page 6)

(continued from Page 2) after brain death and a greater reliance on living organ donation when possible. Currently, All major religions support organ, eye and tissue donation as an act of charity.

Dr. Teperman also discussed a new immunosuppressive drug therapy currently in a study trial (for new recipients) under the direction of Dr. Teperman and his NYU Medical Center's Transplant Program. Several LI TRIO members recently participated in research survey studies concerning this new therapy. This medication is administered intravenously once or twice each month. One advantage is that it is not nephrotoxic and is intended to replace all other immunosuppressant medications taken daily including calciner inhibitors cyclosporine (Neoral) & tacrolimus (Prograf) as well as rapamune and prednisone. Trials for recipients currently on other types of immunosuppressant therapy are scheduled to begin next year. As always, it was a pleasure to see Dr. Teperman and we look forward to spending more time with him at a meeting within the year. LI TRIO thanked Dr. Teperman for the informative discussion and for his continued support of our organization.

Our second guest began a stimulat-



ing discussion about Medicare's drug coverage and advantages and disadvantages of this Medicare benefit.

Robert J Hopkins, BS, MS, MBA represented his specialty pharmacy (Total Care Rx) that deals with immunosuppressant medications and transplant recipients on a daily basis.

Medicare Part D was signed into law in the 2003 "Medicare Modernization Act" and the Part D benefit has been effective since January 2006.

There are many opinions with respect to this benefit and many of the facts surrounding the Part D benefit as the rules exist today. It is beyond the scope of this report to debate the various opinions so here are some facts and each person is of course free to decide how one feels about this benefit and how it effects you, your peers and your family members.

Part D is independent of Transplant Coordination of Benefits.

Part D does pay for medications (with limitations and a coverage gap).

Part D is not subject to 36-month limit post-transplant payment for medications.

The government cannot negotiate the lowest price for medications.

Each plan has a unique formulary (list of approved medications).

Each plan has a unique appeal process.

Only formulary drugs count against what is known as the "donut hole". Part D will not pay for certain drugs and classes of drugs (barbiturates, benzodiazepines, OTC's and others)

In 2009, there is no longer "government backup" since the Insurers are said to have developed experience in the past few years.

In 2009 the coverage limit will increase to \$2700.00.

Kaiser Study 2008:

3.4 million seniors reached the Gap in 2007

Approx 22% stay stuck in the Gap  
Approx 4% go on to catastrophic care  
Almost 15% of enrollees stop medication while in the GAP

LI TRIO very much appreciates Robert's willingness to be a guest speaker at our meeting and thanked him for sharing his time and expertise with us. ▲

## LI TRIO'S ANNUAL HOLIDAY PARTY

Come join us on Saturday evening December 6, 2008 from 7 PM to 11 PM. for a lovely hot buffet and DJ entertainment.

The party will be held in the beautiful Catering Hall of The Elks Club at 901 Lakeville Road, New Hyde Park. Invitations are being sent under separate cover via U.S. Mail.

## 106TH ANNUAL GREENLAWN FIREMEN'S FAIR

NYODN and over 20 LI TRIO Volunteers worked at tables during this four day event during the Labor Day Weekend Holiday and helped over 100 attendees enroll in the Donate Life Registry in order to help save lives! ▲



### HAPPY RE-BIRTHDAYS!

Betty Baumgartner	July 28, 2002	Kidney
Anthony Devivo	July 8, 2007	Liver
Al Ferro	July 28, 1998	Liver
Karin Grossu	July 13, 1999	Kidney/Pancreas
Jennifer Lentini	July 6, 1996	Heart
Henry Prins	July 2, 1992	Liver
Michael Sosna	July 18, 1995	Kidney
James Wiesmann	July 1, 2001	Kidney
Margaret Young	July 28, 1991	Kidney
Richard DeRocher	August 24, 1999	Kidney
Eileen Dimino	August 10, 1996	Kidney
Cheryl Echevarria	August 23, 2005	Kidney
Iris Edelson	August 2, 1995	Liver
Frank Feltkamp	August 15, 1999	Kidney
Mary Ferris	August 14, 2001	Kidney
June R. Herman	August 29, 2005	Kidney
James Jewell	August 13, 1986	Liver
Anne Marie McCartney	August 20, 1988	Liver
George Tietjen	August 23, 2001	Kidney
Neila Farber	September 29, 2007	Kidney
Elise Folk	September 25, 2007	Kidney
Richard Randall	September 3, 2005	Liver
Hugh Collins	September 13, 1990	Liver
Eric Young	September 7, 1979	Kidney
Jim Spence	September 12, 1991	Liver
Arthur Menendez	September 19, 2002	Kidney
Karen Paulick	September 8, 1996	Liver
Robert Gabe	September 15, 1997	Heart
Jarena Bates	October 15, 2007	Kidney
Roberta Baumstein	October 7, 2003	Kidney
Daly Costello	October 6, 1997	Liver
James Dempsey	October 24, 2007	Kidney
Joseph DiMartino	October 17, 1989	Liver
Anthony Fama	October 28, 2001	Liver
Rachel Feldman	October 25, 1994	Liver
Jules Feuer	October 21, 2005	Liver
Daniel Kum	October 1, 2004	Kidney
Charles Lehecka	October 28, 2001	Liver
Mary Lou Murphy	October 17, 1992	Kidney
Josephine Recine	October 1, 2001	Kidney
Dave Rodgers	October 22, 2002	Liver
Jan Schichtel	October 21, 1982	Kidney
Deborah Taylor	October 28, 1999	Kidney
Bob Violino	October 25, 1995	Kidney

## Donor Sabbath

The National Donor Sabbath is an ecumenical celebration of life in which clergy and congregations nationwide emphasize organ and tissue donation, and discuss their faith's doctrine on donation. The National Donor Sabbath is held each year during the second weekend in November but your congregation can observe Donor Sabbath on any weekend in November. Religious leaders and congregations are encouraged to participate in a variety of ways. As is tradition, LI TRIO will be sending out an email with some suggestions.

There are 99,875 men, women and children currently waiting for the Gift of Life in the United States.

There have been 13,814 transplants from January 1, 2008 through June 30, 2008.

There have been 6,988 donors from January 1, 2008 through June 30, 2008.

Source: UNOS

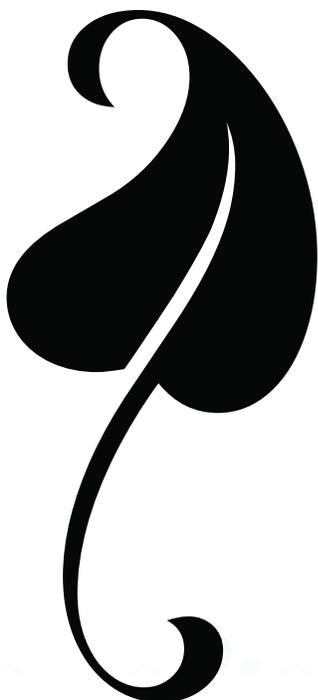
## Recognizing The Brave And Selfless Act of Organ Donation

I'm pleased to report that the House of Representatives has passed the Stephanie Tubbs Jones Gift of Life Congressional Medal Act (H.R. 6950). The next step is for the Senate to pass the companion bill that was introduced by Senator Sherrod Brown as S. 3530. These bills direct the Treasury department to design and produce a commemorative medal that the Department of Health and Human Services will award to organ donors or to a surviving family member. Enactment of this legislation would have no cost to the Federal Government. The medals will be funded by charitable donations and organizations including Long Island TRIO. -Mike Sosna

*LI TRIO's Organ Donation Night At Shea Stadium was a huge success! We hope to see you at next year's event as well.*

**PLEASE CHECK OUT  
WWW.LITRIO.ORG  
FOR OUR LIST OF  
UPCOMING EVENTS.**

The TRIO Singers also performed The National Anthem at the Long Island Ducks baseball game on August 11, 2008. The LI TRIO Singers promote organ donation and show that Transplantation works!



**UPCOMING EVENT AT WINTHROP UNIVERSITY HOSPITAL: GIFT OF LIFE PROGRAM ON 2 NOVEMBER, 2008 FROM 10:15 AM TO 3:00 PM. THIS YEAR'S PROGRAM WILL INCLUDE PRESENTATIONS FROM RENOWNED PHYSICIANS, HEALTHCARE PROFESSIONALS AND FRIENDS OF TRANSPLANT.**

**WE WILL ALSO COMMEMORATE THE 15 YEAR ANNIVERSARY OF THE RAILROAD MASSACRE. ALSO DONOR MOM CLAUDIA GRAMMATICO SHARES HER STORY WITH A SONG SHE WROTE WHICH WILL BE SUNG BY HER NIECE.**

**OTHER DEAR DONORS, AND DONOR FAMILIES WILL ATTEND AND SPEAK AS WELL.**

**THIS GIFT OF LIFE PROGRAM OFFERS CONTINUING EDUCATIONAL UNITS FOR HEALTHCARE PROFESSIONALS WHICH INCLUDE CEU'S AND CME'S AND IS SPONSORED BY NYODN. PLEASE RSVP TO JOY AT 646 291-4400 2514.▲**

## LI TRIO TRIBUTE CARDS AVAILABLE

Florence and Jerry Sosna will send lovely LI TRIO "In Memory of" and "In Honor of" Tribute cards in your name. Please call 516-482-2908 or e-mail [Jerrysosna@aol.com](mailto:Jerrysosna@aol.com)

## In Order To Save Lives: Improved Statistical Tool To Rank Sickest Patients Waiting For Liver Transplants

ScienceDaily (September 2008) — Mayo Clinic researchers have developed an improved statistical model that could help ensure that the sickest patients receive liver transplants first.

Researchers found that including serum sodium concentration in the statistical model now used could reduce by 7 percent the number of patients (as many as 50 people) who die each year while waiting for a liver transplant. Serum sodium levels can be measured with a blood test.

The study was published in the Sept. 4, 2008, issue of the New England Journal of Medicine. ▲

(Continued from Page 3) organ donation."

At the game, representatives from Long Island TRIO will hand out organ donation information and other materials to fans as they enter the stadium, as well as staff donor sign-up stations on each level of the stadium to provide attendees the opportunity to join the New York State Organ and Tissue Donor Registry at the game.

To join the registry, game attendees will complete and sign a short form that includes basic information (i.e. name, address and birth date) indicating that they would like to be listed in the New York State Organ and Tissue Donor Registry maintained by the State Department of Health. Information included on the form will also be shared with federally regulated organ procurement organizations and New York State-licensed tissue banks and hospitals.

The facts\* clearly illustrate the urgent need for more organ donors:

- Nearly 100,000 Americans are on the organ transplant waiting list.
- Every 12 minutes, another name is added to the national transplant waiting list.
- Each day, an average of 18 people die because there are not enough organs to save them.
- 90% of Americans say they support donation, but only 30% know the essential steps to become a donor.

\*Source: Donate Life America, <http://www.donatelife.net/Understanding-Donation/Statistics.php>

#### About Long Island TRIO

The Long Island chapter of Transplant Recipients International Organization (LI TRIO) is a non-profit, all-volunteer organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness. For more information please visit [www.litrio.org](http://www.litrio.org).

#### About Astellas Pharma US, Inc.

Astellas is a recognized leader in transplantation and has been committed to the field of immunology for more than 20 years. Astellas continues to build upon its leadership in transplantation.

## Our Annual Donor Rose Garden Re-dedication Ceremony

Thank you for joining us at Our Annual LI TRIO Donor Rose Garden Ceremony Honoring Donors and Donor Families. We had a wonderful day and it was a pleasure to honor Donor and Donor Families with our special program.

Some of our speakers and invited guests included Senator Kemp Hannon, Assemblyman James Conte, Nassau County Minority Leader Peter J. Schmitt, Judith Jacobs-Nassau County Legislator, Ernesto P. Molmenti, MD-Director of Transplant-North Shore University Hospital, Elaine Berg-President/CEO, NYODN, Winnie Mack-President of Southside Hospital, Gillian Cohen- Liver Recipient, and Kevin Simmons- Donor Brother. We were welcomed by Mike Sosna, President of Long Island TRIO and George Tietjen (Vice President) introduced our distinguished speakers. Long Island TRIO presented roses to each of the Donor Families

at the ceremony and this was one of our ways of saying thank you for the "Gift of Love" and the "Gift of Life". Joy Oppedisano read the names of the Donors as their families came forward to receive a rose. Jo Michaels prepared a written program and Dave Rodgers (Chairperson, Rose Garden Logistics) did a wonderful job with the garden's shrubs, roses and appearance as well as serving lunch with assistance from Dave's son and from Colleen who has been such a big help with TRIO events of late.

The weather was beautiful and we were so pleased to dedicate this day and this event to the Donors and Donor Families. ▲



## LI TRIO MEMBER PROFILE:

2008 U.S. Transplant Games  
Rich DeRocher wins the gold!

The National Kidney Foundation presents the Transplant Games and they are open to all types of organ recipients. They are held every two years at locations around the country. The primary purpose of the games is to promote organ donation by showing the public how successful transplantation can be. In addition to the 12 athletic events for recipients, there are recognition events and programs for donor families and living donors. There is also a 5k run that is open to everyone, and a golf outing for donors and recipients. There are about 50 different teams. Some states have more than one team and some states combine to form a team. I am on Team Liberty, the team that represents the Greater NY. Metropolitan area. I was pleased to be one of the LI TRIO members representing Long Island TRIO at the games.

Now I'll tell you about my experiences at the 2008 Transplant Games. On Saturday July 12th I went to Carnegie-Mellon University to check out the racquetball courts and the track. I met a couple of racquetball players from Team Pittsburg that I had met at previous games. It was great to see them again. One of the best things about the games is meeting people from other teams and seeing the friends you met at previous games. After practicing for a while I headed back to my hotel so that I could get ready for the opening ceremony that evening.

The opening ceremonies are always special. Each team is announced and marches in to the convention center. Our team captain dressed as the Statue of Liberty. She had a crown, a torch, a flowing green gown, a green wig, and green face paint. Team Liberty's 35 athletes followed her into the convention center carrying banners and torches that lit-up.

We also have donor families and living donors that are part of our team. They marched in after all the athletes and they got the biggest ovation of all. The highlight of the opening ceremony was when a 24 year old woman, who had received a liver transplant in Pittsburg when she was 2 years old,

received the opportunity to meet the family of the 18 month old girl who was her donor. They had both been searching for each other and the donor's sister found the recipient on Facebook! Dr Starzl performed the surgery and he, the recipient, and the donor family were all reunited on the stage. The recipient had won a medal at the games and she gave it to her Donor Mom.

Sunday was racquetball day. When I arrived at the courts I found out that there were 4 players in my age group and that we would play a round robin. That meant that I would have to play 3 matches. Each match would be best 2 out of 3 games. My first match was relatively easy, my second match was harder, and my third match was very hard. Even though I knew that I won all 3 matches, I was so tired from playing for 2 1/2 hours that it took awhile for the fact that I had won the gold medal to sink in. It was the first medal that I had won since I started going to the games in 2000. I am going to have it framed and give it to my brother Paul, whose generous gift of a kidney allows me to compete.

Monday was track and field day. I'm not a track and field person. I only started to compete so that I had something to do on the day between racquetball singles and doubles. I also get to spend the day with other members of the team out on the track. My legs were so tired from Sunday's racquetball that I didn't expect to do very well. I was very surprised to get a Bronze Medal in the long jump and to finish 4th in the 100 and 200 meter races. I felt honored when Dr. Starzl presented my medal.

Since they didn't have racquetball doubles this year, I went to watch Team Liberty compete in volleyball, basketball and bowling on Tuesday. I also spent some time trading pins. Each team has their own pin and the goal is to get a pin from each of the other teams. It's a great way to start a conversation and meet people from other teams. I've never received all of the pins because I usually end up giving some of my pins to little kids who really, really want to get them all. This year I think I got them all. That night we had the closing ceremony at the University of Pittsburgh. Awards for the best male and female athletes

and several awards for outstanding efforts at promoting organ donation were given. The Chairman of the NKF announced that the 2010 games would be held in Madison Wisconsin and then we saw the video that will be sent to each of the athletes later this year. As usual, the games were over much too soon.

On Wednesday it was time to go home. While I was waiting for the bus to the airport, I was talking to a woman whose husband had received a double lung transplant. She told me that while she was waiting for a shuttle bus to the closing ceremony, she was talking to a Donor Mom. They were telling each other their transplant stories and when they talked about the dates and locations it became apparent to her that she was speaking with the mother of her husband's donor. Only at the Transplant Games could you meet your donor family while waiting for a shuttle bus!

So if you haven't already been to the games, start planning now. It's an event that you'll never forget and that you have to experience at least once.▲



## WELCOME NEW LI TRIO MEMBERS

Helena McDermott  
Babona Wynn  
Yolanda Malone  
Barbara Gantman  
Gary Fischer  
Rich Fischer  
Steven and Bryan Fischer  
Josephine Recine  
Kevin O'Brien  
Dorothy Collins  
Tara Hoffman  
Audrey Saltzman  
Tonia Finkelstein  
Kathleen Gerlach  
Jean A. Kelly  
Alison Milligan  
Arlene Goldberg  
Fran Oreckinto



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E-Mail Tree—Joe LaBarbera litrio@gmail.com

Corresponding Secretary/Publicity—  
Ruth Pohl 631-884-0482

Website Design/Legislative Initiatives  
& Guest Speakers—Mike Sosna mike@sosproductions.com

Special Projects—Ed Burki 516-620-3700

Rose Garden Ceremony—Jo Michaels 516-798-8411

Rose Garden Logistics—Dave Rodgers 516-449-1421

Data Base Manager—Howard Pohl 631-884-0482

Donor Families & Social Secretary—  
Barbara Musto 516-671-5793

Singers and School Speakers—  
Sue Tietjen and George Tietjen 516-746-0693

The Ways and Means Committee/  
Holiday Party Chairpersons—  
Florence & Jerry Sosna 516-482-2908

Please note that our October meeting is being held on  
October 15, at 7:30 PM.

▲ **October 15:** Elections will be held at our meeting.

VISIT LI TRIO ONLINE: [www.litrio.org](http://www.litrio.org)

E-MAIL LI TRIO: [mike@sosproductions.com](mailto:mike@sosproductions.com)



LI TRIO

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