



# NEWSLETTER

Long Island Chapter of Transplant Recipients International Organization

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**September 2010**

*Our General Meetings are held on the second Wednesday of each month from September to June. Our holiday party in December substitutes for the December meeting. The meetings begin at 7:30 PM and are held at*

*145 Community Dr., Manhasset, NY.*

## LI TRIO Meeting: September 15, 2010 at 7:30 PM With Lewis W. Teperman M.D.

Dr. Lewis Teperman, Associate Professor of Surgery has created an internationally recognized transplant program at NYU Langone Medical Center. The program offers unparalleled quality in its patient care, training, and research programs and Dr. Teperman is the Director of Transplantation.

We are pleased to announce that Dr. Teperman will be our guest speaker at our special meeting on September 15, 2010 at 7:30 PM. The meeting is being held on the third Wednesday of the month (as opposed to the second Wednesday of the month) due to the Jewish Holiday. Please note the special date, 15 September, 2010.

## The LI TRIO Singers Hit A Homerun for Organ Donation Awareness on August 15, 2010.

The LI TRIO Singers performed the National Anthem on the field at the New York Mets game, and our volunteers worked at tables in order to help enroll fans in the New York State Donate Life Registry.

## 2010 Transplant Games

More than a thousand athletes went for the gold in Madison, and they all had something in common: they're all transplant recipients. They all received life-saving operations, thanks to the generosity of others.

## Long Island TRIO Donor Rose Garden Re-dedication Ceremony

I'm pleased to announce the re-dedication of our "Donor Rose Garden" in Eisenhower Park.

*When:*

Long Island TRIO's most cherished event will be held on September 25, 2010 12 Noon-2 PM.

*Where:*

Please join LI TRIO and The New York Donor Network in honoring and thanking Donors and Donor Families as we re-dedicate our "LI TRIO Donor Rose Garden" to Donors and Donor Families in a ceremony being held on Saturday, September 25, 2010 at 12 Noon.

The "Donor Rose Garden" is located in Eisenhower Park, East Meadow, NY in Nassau County- adjacent to the Women's Sports Pavilion-Parking Field 6/6A.

Donors and Donor families are indeed our heroes and we hope you will join us.

Very truly yours,

*Mike Sosna, President LI TRIO*



## Upcoming Events

*September 15, 2010 - 7:30 PM-General Membership Monthly Meeting with special guest speaker Dr. Lewis Teperman, Director of Transplant -NYU Langone Medical Center*

*September 25, 2010 at 12 Noon-Our 2010 Donor Rose Garden Re-dedication Ceremony in Eisenhower Park/ Parking field 6/6A.*

*October 13, 2010 7:30 PM- LI TRIO General Membership Monthly Meeting.*

*December 3, 2010: Save The Date!*  
LI TRIO will be inviting you to our Holiday Party.

*Please note that our LI TRIO September meeting will be held on the third Wednesday of the month as opposed to the second Wednesday of the month. Please note the special date, 15 September, 2010.*

## San Diego Couple Final Link In Kidney Transplant Chain

*By Janet Lavelle, UNION-TRIBUNE*

For Rita and Oscar Ayub, the National Kidney Registry came up with a lifesaving shortcut. It helps find donors for people who need a kidney, but only if they have a partner willing to give an organ to a stranger.

Rita Ayub never resigned herself to the idea that her husband, Oscar, would have to wait years for a kidney transplant because her organ wasn't a good match. (Continued on Page 3 Column 3)

## Parents Give Doctors Double The Thanks For Kidney Exchange That Saved Twin Boys' Lives

Source: *New York Daily News*

By Erik Badia



Mom Evette Leavy, sons Alan and Brian, and their dad, Brian De Vale - have reason to smile after the parents donated kidneys to their boys.

A Long Island couple who donated kidneys to their twins expressed gratitude to a team of doctors who gave the boys a second chance at life.

"They saved both our sons' lives," Brian De Vale said during an emotional reunion at New York-Presbyterian Weill Cornell Medical Center yesterday.

The 14-year-old boys had been suffering from a degenerative kidney disease and received organ transplants - one last month and the other last year.

"Thank you," the parents said repeatedly. "Thank you."

The parents were informed last year that the boys needed transplants as their kidneys began to break down from a rare disease called focal segmental glomerulosclerosis.

After being ruled out as a potential donor because of her risk of diabetes, mom Evette Leavy changed her eating habits, lost 15 pounds and was able to donate one of her kidneys to their son Brian in July. The dad donated a kidney to son Alan.

"I trusted them with my children and I trusted them with my life," Leavy said.

The boys were equally grateful.

"We just want to say thank you," Alan Leavy told his parents and the miracle medical team.

Brian, who is now winding down his regimen of anti-rejection medication, said he's almost fully recovered.

"I feel better now," he said. "Before I would just sleep all day."

The doctors said the twins will now lead normal lives with the need for only periodic monitoring.

Note: You can also check out the press conference and multimedia video report on our chapter's webiste at [www.litrio.org](http://www.litrio.org).

## Spain Is The World Leader In Organ Transplants

Source: *Indo-Asian News Service*

*Spain conducted over 4,000 transplants in 2009, making it the world leader in the field of organ transplants.*

This has been declared in the 2010 edition of the EU's newsletter Transplant, which will be released later this month. "Transplant activity in Spain, which retains its world leadership in this field, continues to grow in a sustained manner, basically thanks to donations from family members of elderly people who have died," the report said.

### September Re-Birthdays

Hugh Collins	September 13, 1988	Liver
Alice Dillon	September 5, 2007	Kidney
Neila Farber	September 29, 2007	Kidney
Elise Folk	September 25, 2007	Kidney
Robert Gabe	September 15, 1997	Heart
Kathleen Gerlach	September 8, 2005	Kidney
Judith Gluck	September 3, 2002	Kidney
Gary Levy	September 12, 2008	Liver
Vito Losito	September 21, 2007	Liver
Helena McDermott	September 18, 2008	Kidney
Arthur Menendez	September 19, 2002	Kidney
Kevin O'Brien	September 3, 2009	Kidney
Jack S Panes	September 17, 2008	Kidney
Karen Paulick	September 8, 1996	Liver
Richard Randall	September 3, 2005	Liver
Barry Rose	September 12, 1995	Kidney
James Spence	September 12, 1991	Liver
Eric Young	September 7, 1979	Kidney

### August Re-Birthdays

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 30, 2005	Kidney
Linda Jannace	August 12, 2009	Kidney
James Jewell	August 13, 1986	Liver
Godeliva Pagan	August 22, 1999	Liver
Janine Rempe	August 14, 2008	Heart
Chris Russo	August 13, 1997	Kidney
Joan Sabal	August 31, 2005	Kidney
George Tietjen	August 23, 2001	Kidney
Luis Torres-Ayala	August 18, 2008	Liver

### July Re-Birthdays

Beth Chapman	July 11, 2008	Pancreas/ Kidney
Dr Waled Chowdhury MD	July 21, 2008	Kidney
Anthony Devivo	July 8, 2007	Liver
Anthony DiMaria	July 19, 2007	Heart
Jeffrey Fenn	July 9, 2004	Kidney
Albert Ferro	July 28, 1998	Liver
Karin Grossu	July 13, 2001	Kidney/ Pancreas
Michael Keane	July 18, 2007	Liver
Laura Laria	July 6, 2006	Kidney
Jenifer Lentini	July 6, 1996	Heart
Henry Prins	July 2, 1992	Liver
Ben Silberstein	July 23, 1994	Liver
Michael Sosna	July 18, 1995	Kidney
James Weismann	July 1, 2001	Kidney
Margaret Young	July 28, 1991	Kidney

## LI TRIO MEMBER PROFILE

### My Transplant Odyssey at North Shore/LIJ

by *Mary T. Graffeo*

My story begins in August, 2007, when my nephrologist of 17 years told me he was retiring because of ill health, and gave my care to one of the young doctors in his practice. When this doctor saw my creatinine of 4.1, he handed me a list of three vascular surgeon's names and told me to have a fistula put in ASAP – and, goodbye.

Needless to say, I was stunned by this news and, after a few days of thinking about it, I decided to get a second opinion. I called several doctor friends for a recommendation, and two of them gave me the name of Dr. Lionel Mailloux. At my first meeting with Dr. Mailloux, I knew that he was the right nephrologist for me. Therefore, I transferred to his practice, and he did all the tests to see exactly what my numbers were. Then, Dr. Mailloux told me that I was a perfect candidate for transplant. He proceeded to manage my medications and diet so that I could stay healthy enough to remain off dialysis while I searched for a donor. It is because of Dr. Mailloux that I was healthy enough for a good transplant.

An aside here is that, owing to the fact that my father was the first kidney dialysis patient on the first hemodialysis machine on Long Island, I had an inordinate, paralyzing fear of dialysis. I had watched him deal with the horrors of the various “shunts” in his left arm (which turned his arm black), and the difficult – and unscheduled – long dialysis treatments. It was then that I decided that dialysis would never be a part of my life. And, with Dr. Mailloux's help, it never was. Thank God for Dr. Mailloux!

On August 26, 2008, I arrived at the North Shore/LIJ Transplant Team offices for evaluation for a Kidney Transplant.

Meeting Dr. Ernesto Molmenti and the whole Transplant Team was very exciting for me. For the previous two years, I had been searching for a live donor, while watching my steadily rising creatinine.

Thanks to my nephrologist, Dr. Lionel Mailloux, I was still healthy enough to stay off dialysis, my worst fear.

The moment I arrived at the Transplant headquarters, I knew that I was in the right place - it felt like home! Dr. Madhu Bhas-karan, the Team Nephrologist, Celenia Mane, the Business Manager, Joan Cappello, the Social Worker, Kristin Barry and Pat DeFlorio, the Transplant Coordinators, the wonderful Team secretary Barbara Cascone - everyone was extremely knowledgeable, and I learned more in that one meeting than I had in the previous two years, with all my considerable research.

Everything was handled so professionally and easily that I didn't have to do anything but be examined and answer the doctors' and nurses' questions, to fill in my medical history. I was told that I had to have a number of tests, which took place in no time.

When all the test results were in, the team and I discussed my donor, my sister, Valerie Heslar. Soon after, I brought Valerie to meet the team. She was tested and found to be a good match for me, but for the fact that she was 35 pounds overweight. The Team Dietician, Rachel Berman, and our Transplant Coordinator, Kristin Barry, worked with Valerie so that she could lose the extra weight (which she did), with a special, healthy diet. Valerie finished all her tests, and was cleared for surgery.

Thus, on February 23, 2009, Valerie and I entered North Shore University Hospital together, and the transplant was done at 7:30 AM that day. I remember joyously hopping up on the operating table, with complete confidence in Dr. Molmenti. My sister's surgery was performed by Dr. Louis Kavousi, using his own new technique, and Valerie has only a small scar to mark the occasion of her donation to me.

My care in the hospital was superb. The nurses, Mariama Madhu in particular, were wonderfully kind, helpful, and knowledgeable. Even the food was great! I left the hospital only two days later and HAVE NOT HAD ONE PROBLEM SINCE!!!

How thankful I am for this fabulous Transplant Team, and my sister, Valerie, for giving me back my life! I can now eat anything I want to and go wherever I please - I recently travelled to Alaska and Phoenix, Arizona, and have a cruise coming up in December, to the Caribbean, and one in July, to Europe. I am researching and writing my third book. My fondest wish is to be able to help others like myself, go through the Transplant Experience, which has made me a new, and, I hope, better person. >>

*(Continued from Page 1 Column 3- San Diego)*

Fortunately for the San Diego couple, the National Kidney Registry came up with a life-saving shortcut. It helps find donors for people who need a kidney, but only if they have a partner willing to give an organ to a stranger.

The Ayubs became part of an unprecedented chain of 21 kidney transplants at 11 hospitals across the country that began in January and ended Wednesday at Sharp Memorial Hospital in San Diego.

Oscar Ayub and an unnamed woman from Yucca Valley were the final recipients, thanks to donors including Rita Ayub.

The transplant chain relied on donations involving 21 donors and 21 recipients in seven states. Each person in need of a kidney had a donor partner — a relative, friend, co-worker or possibly a stranger — whose kidney was not a match for them.

The National Kidney Registry, founded in 2007, runs patients' medical information through a sophisticated computer analysis, matching donors with recipients. The New York nonprofit has become the largest such paired-exchange kidney transplant program in the United States.

The registry now has 2,000 donors in its system with plans to expand, said executive director Thomas Mollo. “We've done 178 transplants,” he said. The 21-transplant chain began Jan. 20 in New York with a donor whose kidney was given to a patient at the same Bronx hospital. The chain continued to criss-cross the country — including nine surgeries on Tuesday and Wednesday before finally ending in San Diego.

*Read the full article on our chapter's website at [www.litrio.org](http://www.litrio.org).*

*The Newsletter of The Long Island Chapter of Transplant Recipients International Organization is 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:*

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**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.*

**NEWSLETTER STAFF**

Mike Sosna—Editor

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**Transplant Recipients International Organization**



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 Long Island Chapter  
 PO Box 81  
 Garden City, NY 11530

**New Members**

**Robert and Melissa Patterson**  
**Robert and Lisa Peace**  
**Carmine and Lorraine Bellucci**

**LI TRIO Tribute Cards**

*Florence Sosna has LI TRIO Donation Tribute Cards “In Memory Of” or “In Honor Of” a loved one.*

*You can contact her at 516-482-2908. At your request, Florence will customize, address and mail the card to your party in honor of a loved one and/or special occasion or in memory of a loved one.*

**Transplant List Stats:**

- 108,412 Americans are on the organ transplant waiting list as of August 31, 2010.
- Visit [www.litrio.org](http://www.litrio.org) to read more human interest stories and articles related to Transplantation.