



TRIO NEWSLETTER

Long Island Chapter of Transplant Recipients International Organization

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March 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.

Long Island TRIO member and friend Maryann Steinbock received the Gift Of Life during one of this winter's snow storms.

Snowstorm liver transplant is a miracle for Long Island woman

By Samuel Goldsmith Daily News Staff
Writer- March 2, 2010



Liver transplant recipient Maryann Steinbock sits alongside members of the NYPD and Nassau County police force and her medical team from Montefiore Medical Center.

Maryann (Mack) Steinbock's doctor called late Thursday night to tell his patient her year of waiting was over. A liver was finally available - but there were daunting logistical problems before the operation could occur.

The liver was in Buffalo, the patient was in Nassau County, the doctors were in the Bronx, and more than 20 inches of snow were piling up outside.

"We were very concerned," said Dr. Milan Kinkhabwala, head of the liver transplant program at Montefiore Medical Center in the Bronx. "We only had a 12-hour window to operate and it was going to be very close."

"When I got the call, I couldn't believe it," said Steinbock, 59. "I live all the way out in Atlantic Beach, and I had to get to the hospital, and there was all this snow."

Hospital officials in the Bronx got on the phone with the NYPD, who coordinated with Nassau cops and the highway patrol to give Steinbock and her husband a seamless trip across three counties to Montefiore.

"It was like being in a movie," Steinbock said. "All of a sudden, the police come, and there were these cute motorcycle guys. Everybody stopped traffic and there was even a helicopter."

"The drive normally takes an hour," said her husband, Corey Steinbock, 67. "This time it took 35 minutes. I clocked it." Nassau cop Rob Prince was tasked with driving the police SUV with Steinbock inside.

She was very calm," Prince said. "We were a little nervous trying to get there, so she started talking about the Mets to calm us down."

The liver was flown in by plane and helicopter, after getting an escort from state troopers, and arrived at the hospital just before Steinbock did. With time winding down, doctors went to work.

"Once we had everything in place the surgery went very well," Kinkhabwala said. "She's doing very well and should be going home later this week."

Corey Steinbock said the quick improvement in his wife's health is remarkable.

"Last week she was pale and all shriveled up. She looked like a ghost," he said. "Now she's like a blossoming flower."

Maryann Steinbock plans to buy tickets for all of her rescuers to accompany her to the Mets' Opening Day at Citi Field. After that, she'll start planning a larger than usual Passover dinner.

"You're all coming for Pesach," she said to the officers at Montefiore yesterday.

"And this summer I want to ride the cute officer's motorcycle."

Long Island TRIO sends Maryann congratulations and all of our best wishes for a speedy recovery.

Upcoming Events

March 10, 2010

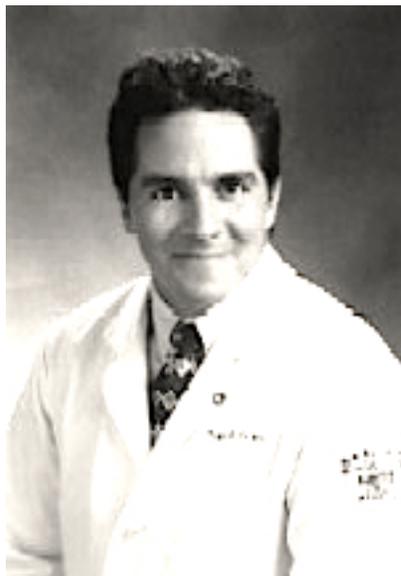
General Membership Meeting with special guest Jorge Ortiz, MD- Chief, Liver Transplantation at Albert Einstein Center.

July 30, 2010-August 4, 2010

U.S. Transplant Games-Madison Wisconsin

Point your browser to www.litrio.org for more information about upcoming events.

March 10, 2010 General Membership Meeting With Guest Speaker- Jorge Ortiz, MD



*Jorge Alberto Ortiz, MD-Chief, Liver Transplantation and Hepatobiliary Surgery
Albert Einstein Center for Liver Disease and Transplantation*

Jorge Alberto Ortiz, MD is the Chief of Liver Transplant Surgery with over 10 years of experience in liver transplantation and research. He specializes in multi-organ transplant including liver, kidney and pancreas and hepatobiliary surgery.

Dr. Ortiz earned his medical degree from Albany Medical College in New York. His postdoctoral training includes a surgical residency from North Shore University Hospital and a fellowship in organ transplantation at Jackson Memorial Hospital at the University of Miami Medical Center. After completing his fellowship, Dr. Ortiz was an Assistant Professor and Director of Kidney Transplantation at the University of California Irvine Medical Center. He was also the Director of Clinical Operations Abdominal Transplant Program at Texas Transplant Institute in San Antonio, Texas.

Active in clinical research, Dr. Ortiz has recently served as an investigator in a study of the safety and efficacy of alefacept in de novo kidney transplant recipients, and as the primary investigator in several other clinical trials, including a study of the utility of Cylex immune status testing in kidney transplant recipients after alemtuzumab induction; a study of the utility of mycophenolate mofetil as maintenance immunosuppression in liver transplant recipients with non-autoimmune liver disease; an observational study of the safety, effectiveness, tolerability and compliance of immunosuppressive regimens using mycophenolic acid in de novo renal transplant patients; a study of belatacept-based corticosteroid-free regimens in renal transplant; and a phase 2 trial of the safety and efficacy of coadministered CP-690 550 and mycophenolate mofetil/mycophenolate sodium in de novo kidney allograft recipients. The results of his completed studies in which he has served as an investigator have been published extensively in peer-reviewed journals.

Dr. Ortiz has authored and co-authored chapters in several medical textbooks, including *Surgical Complications: Diagnosis and Treatment*; *Vascular Surgery: Principles and Practice*, Third Edition; and the *Practical Manual of Abdominal Organ Transplantation*.

Drug to Help Transplants Wins Support

By Jennifer Corbett Dooren- wsj.com

A U.S. federal advisory panel recommended approval of Bristol-Myers Squibb Co.'s organ-transplant drug belatacept for use in patients undergoing kidney transplants.

The panel of medical experts voted 13 to five on a question that asked if the proposed drug should be approved by the

U.S. Food and Drug Administration to keep transplant patients from rejecting their new kidneys. The FDA isn't required to follow its panel's advice but usually does. Belatacept would be used with other drugs to suppress patients' immune systems in order to keep them from rejecting transplanted kidneys.

Panel members said additional studies are needed, however, to look at long-term safety and effectiveness of the product. Most panel members said such studies could be conducted after the drug is approved but a few suggested the FDA wait for longer-term data before approving the product.

In documents prepared for the meeting, the FDA said patients receiving belatacept two years after undergoing kidney transplants had "numerically better outcomes" than patients who received an older drug, cyclosporine. The agency said patients receiving belatacept had better-functioning kidneys, improved blood pressure and lower rates of diabetes.

But the agency said it was concerned with two serious side effects seen in clinical studies, one being post-transplant lymphoproliferative disorder—a type of lymphoma associated with organ-transplant patients—and a brain infection known as progressive multifocal leukoencephalopathy, or PML, that was seen in one patient in the kidney studies and another patient in an ongoing liver-transplant study. PML is usually fatal.

Bristol-Myers Squibb said the PML case seen in the kidney study was in a "more intensive" regimen of belatacept, and is proposing to use a lower dose of the drug. The company also said the risks of post-transplant lymphoproliferative disorder can be minimized by using a lower dose of the drug.

Happy Re-Birthday to you!

March Re-Birthdays

Joseph Behar
Kidney- March 2, 2005

Gerald Blessinger
Liver- March 6, 1992

Ed Burki
Kidney Pancreas- March 28, 2000

Rosalie Collura
Heart-March 28, 1992

Gerard Eichhorn
Kidney- March 6, 1991

Richard Johnson
Liver- March 6, 2003

Irene Kolodny
Kidney- March 9, 2006

Al Lange
Kidney- March 6, 2007

Milton Marcus
Liver- March 2, 2004

Michael Marscovetera
Kidney- March 22, 2005

Faith Samowitz
Heart- March 10, 2009

Robert Seeback
Heart- March 17, 1996

Steven Taibbi
Heart-March 27, 2001

Kathy Vliet
Kidney (P) March 30, 2006

On Long Island in New York, a few wonderful gifts were exchanged and then subsequently acknowledged on Valentine's Day this year.

Long Island TRIO board member Ed Burki attended a wonderful press conference spotlighting these three very special stories about giving The Gift Of Life.

Moms proud of 'Kid'-neys

By Liz Sadler and Rita Delfiner

He went behind his mom's back to save her life.

Anthony Ciambrone's 71-year-old mom, Betty, was stricken with kidney disease after a bout with high blood pressure.

When the North Merrick, LI, woman was told that she needed a transplant, Anthony, 42, volunteered.

"I kind of went behind her back and spoke to the doctors," said the Elmont school custodian.

"There's a very long wait list and I was basically told she really didn't have that much time to wait.

"It really wasn't a hard decision."

Tests revealed that his kidney was a match, and the transplant surgery took place last June.

"I don't know how to thank him for the rest of my life," said Betty Ciambrone, who no longer has to go through a grueling dialysis routine.

"Last winter, I couldn't even walk in the snow. This year, I went out and shoveled three times," she added.

Betty was among three sets of miracle moms and selfless sons who spoke yes-

terday at North Shore University Hospital's Transplant Center in Manhasset, where the surgeries were performed last year.

Dr. Ernesto Molmenti, the doctor who performed all three transplants, said that "the best way to celebrate this Valentine's Day is to see these three beautiful mothers with their three handsome sons who volunteered to give a kidney to them to make their lives so beautiful."

He said parents generally initially turn thumbs-down on accepting a kidney from an adult child and "we have to give a message that it's all right for children to give a kidney to their parents, that it's perfectly normal to live with one kidney."

For NYPD Sgt. Nicole Dean, 45, of Jamaica, Queens, a Police Academy instructor, the shocking news that she had kidney disease and needed a transplant came in August 2008 during a routine physical.

Her whole family volunteered to help out, but she chose her oldest son, Dominick, 24, a salesman at a Long Island car dealership.

"I would never expect in a million years that . . . I would give him life and raise him and now he has given me a better quality of life," said Dean, who had the transplant in March and now feels "great."

Kathleen Geiger, 55, of Northport, had a kidney transplant a decade ago, but was in desperate need of a new one last year. Dennis, 28, of Manhattan, the eldest of her three sons and a research analyst at a hedge fund, said he had the "privilege" to be the donor.

The transplant took place in June -- two months before Dennis was set to walk down the aisle -- but the Geigers were able to dance together at his wedding.

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.

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Mike Sosna—Editor

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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:

- 106,232 Americans are on the organ transplant waiting list as of March 4, 2010.
- There were 26,096 transplants between January 2009 and November 2009.
- There were 13,348 donors between January 2009 and November 2009.
- Visit www.litrio.org to read all about LI TRIO's Valentine's Day 2010 press conference with Senator Kemp Hannon.