



TRIO NEWSLETTER

Long Island Chapter of Transplant Recipients International Organization

P.O. Box 81 Garden City, NY 11530 516-942-4940

Website: www.litrio.org E-Mail: mike@sosproductions.com

Special Issue: July /August 2009

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.

Organ Donation Awareness Night" at CitiField-August 19, 2009

- In order to promote the importance of organ donation and saving lives, Long Island TRIO is presenting "Organ Donation Awareness Night" at CitiField on August 19, 2009 at 7 PM. The Long Island TRIO Singers are performing the National Anthem at the Atlanta Braves Vs. New York Mets baseball game and we hope you will join us. Please call Ruth Pohl at 631.884.0482 to purchase tickets for this event. Ruth will mail the tickets to your home. There will be an on-field ceremony before the game and a Long Island TRIO Public Service Announcement played on the huge scoreboard at CitiField during the game. We are showing that Transplantation works and helping fans enroll in New York State's "Donate Life Registry" in order to help save lives.

LI TRIO Meeting with special guest Dr. Wolf

On June 10, LI TRIO welcomed Dr. David C. Wolf, Medical Director of Liver Transplantation at Westchester Medical Center and Professor of Clinical Medicine at New York Medical College. Dr. Wolf gave a straightforward and visually engaging power point presentation about the step by step journey from liver disease to liver transplantation.

Dr. Wolf's goal throughout the presentation and in practice is to have patients understand the realities of liver disease and transplantation from start to finish, so they can move forward with realistic expectations. He started his presentation with an equation (H=R-E) Happiness= Reality - Expectations. Dr. Wolf expressed that he is there to provide the scientific facts about liver transplantation therefore alleviating any unrealistic expectations, so if the patient does follow through with the process they can be happy with the result.

Dr. Wolf then shared some facts of liver transplantation starting with what it is, who would be a candidate for it and the causes of liver disease and ultimately liver failure. He then discussed the signs a patient exhibits when they are ready for a transplant and in some cases why a transplant may be denied. Dr. Wolf stated that three questions need to be asked in order to determine if a patient will be considered for a liver transplant, they are as follows: Does the patient need a liver transplant? Does the patient want a liver transplant? Can the patient tolerate a liver transplant? He then touched upon "listing", the time frame the patient has and the survival rates after one year and five years.

Although the term survival rate may turn some patients off Dr. Wolf is serious about giving his patients all the facts about liver transplantation. The good news is that the five year survival rate from 1983 to 2009 has increased by about 60%. As a kidney transplant recipient I found Dr. Wolf's expertise to be valuable and I gained knowledge

about liver transplantation. It was, however, relative to all transplant patients in the nature of the questions that are asked of a patient before they are considered for any type of organ transplant. Dr. Wolf also took the time to discuss the medications prescribed after transplantation which is a commonality among heart, liver, kidney, and pancreas recipients alike.

Dr. Wolf impressed us with his knowledge and dedication to the subject of liver transplantation. If you are seeking more information with regard to liver transplantation, please review LITRIO's website. We thank Dr. Wolf for sharing his wealth of knowledge.

Upcoming Events

- Long Island TRIO presents: "Organ Donation Awareness Night" at CitiField.- August 19, 2009 The Long Island TRIO Singers are performing the National Anthem at this Atlanta Braves Vs. New York Mets baseball game at 7 PM.
- The LI TRIO Singers are also performing the National Anthem at the Ducks Game on August 31, 2009. 516-942-4940.
- General Membership Meeting with special guest Lewis Teperman MD- Director of Transplant, NYU Langone Medical Center. Please try to attend this important meeting on September 9, 2009.
- LI TRIO and NYODN invite you to a very special Re-dedication of our Donor Rose Garden on September 26, 2009 at 12 Noon.

LI TRIO Member Profile

Helena McDermott

Ten Months Old

My kidney that is... I myself am 32 years old. My kidney transplant was on September 18, 2008 and I have never felt as good as I do today. I feel invincible; "there is nothing I can't do!" Well, that is the phrase that runs through my mind now that I have my new kidney strategically placed in my lower abdomen.

Last March, I didn't have a spring in my step like I have today. Actually the winter of 2008 was the worst ever. I would come home from teaching and take a two hour nap. Ok, for anyone in the teaching field a nap is not that unheard of, but two hours! I went to the doctor for a routine urine test and days later I was told I had acute renal failure. What does that even mean, I thought, but it didn't sound so good.

A kidney biopsy was in order to determine what state my kidneys were in, and of course I wasn't looking forward to this. I had two of these before; due to my diagnosis of IGA nephropathy at four years old and HSP sometime in high school. Aside from taking some medication and missing almost every class picture in elementary school, the IGA didn't greatly affect my life. Now with the biopsy results, it became apparent that it was going to affect me.

As my doctors tried to delay the progression of kidney failure, I began a cycle of prednisone. But, by the end of June my nephrologist said we needed to have a kidney to kidney talk. He told me that the best option was to have a kidney transplant. A Kidney Transplant that sounded scary especially to someone that has a history of fainting when getting blood drawn.

And so the process began. First I went to the Westchester seminar about transplantation. I was accompanied by my parents, sister and husband. As we sat listening to the presentation, I couldn't believe the number of people in the audience. The group spanned in age, gender, and race. It was a crash course in transplantation, with every step of the way neatly packaged into a power point presentation. Doctors, nurses and recipients spoke and when we left, we all felt a little more knowledgeable about the subject.

After the seminar I called the Rogosin Institute at NY Presbyterian Cornell Weill, for a pre-transplant evaluation. This was all happening so fast, but my options came down to transplantation or relying on dialysis to filter my ailing organ. I decided to go full speed ahead with the option of transplantation. It didn't hurt that I had unconditional love and support from my husband, parents and sister.

So the appointment was made for the pre-transplant evaluation. The voice on the other end asked me if I had anyone that would like to be a kidney donor. Hmmm, that was a question I didn't imagine being asked in my lifetime. How do you ask someone to give you their kidney? It's not like I just need to borrow it either, I'm asking to keep it! So in not so many words I told my parents, my sister and husband what I was asked and in not so many words they were all willing to spare a kidney.

So I called back and told the voice that I had four willing donors. Now they would need to call to discuss their history with the Institute. My father was told he was not eligible because he was taking heart medication from his heart attack. Instead of being relieved at the idea of not having surgery he was livid and said he would take the kidney out himself. *This is highly not recommended. I can't or won't is not his vocabulary and luckily he passed this trait down to my sister and I.

As my three willing donors got the first tests, I thought who can I take a kidney from? My mother? What hasn't she done for me already? My baby sister? Who already juggles a thriving career, a budding relationship and very packed social calendar. Or my husband? Who had just lost his father to cancer in May 2008 and now this! The question however was not up to me. We soon found out that my husband was not a match, because his blood type was not compatible with mine. He was upset, but optimistic that everything would work out. Now it was down to my mom and sister. Deep down we all hoped that my sister did not have to be the donor. She was the baby and even though she was 25, that feeling of protecting her never really disappears.

My sister and mom would now begin tests to make sure they were healthy enough for the procedure. It was around the beginning of August and I did not yet get a call about either one of them being a donor. It was then when I started to get a bit nervous. I had heard the hardest part about the entire trans-

plantation procedure was getting the donor. What if neither of them were a match? What if they really didn't want to do it? Now I was beginning to understand what people meant when they said getting a donor was the hardest part.

The whole family went to my cousin's wedding in August and other family members offered to be tested, which was reassuring. Then the next day my mother called and told me she was a match, great news I thought, but then she told me that during the testing they found something. She was diagnosed with breast cancer. It was surreal, my father in-law had died in May, I needed a transplant and now my mother had breast cancer.

My sister called me shortly after and told me she was a match and would be happy to give me her kidney. It was bittersweet. I was happy, there was a match. My sister stepped up to the plate in a time when our family was at rock bottom. My mom now worried about having cancer and her two daughters that would now be in adjoining rooms where a kidney would be transferred from one daughter to another.

My mother had the cancer removed and is now finishing her last treatment of chemo, so it does not reoccur. My sister and I had our surgery in September and are both feeling really great. My sister recovered for two weeks after her surgery and still feels it was no big deal. She jokes that she'd rather have the surgery everyday than get on an airplane.

As for me I feel great. I enjoy telling people how good I feel and can honestly say I have never felt this good in my entire life. Having the transplant was like a rebirth. In the first few months of my reenergized life I catered to the kidney, got it checked and didn't go into large groups of people. Now with it being six months, two weeks, and five days my kidney is right at home. Of course I take my medications every 12 hours but aside from that I am living life with no limits. Who cares about the economy when you have a new kidney and a body and mind that screams "anything is possible!"

LI TRIO's Website

Please visit our chapter's website for current information and legislative initiatives- www.litrio.org.

Happy Re-Birthday to you! New Members

July and August Re-Birthdays

Betty Baumgartner	July 28, 2002	Kidney
Beth Chapman	July 11, 2008	Pancreas/ Kidney
Waled Chowdhury MD	July 21, 2008	Kidney
Anthony DeVivo	July 8, 2007	Liver
Albert Ferro	July 28, 1998	Liver
Karin Grossu	July 13, 1999	Pancreas/ Kidney
Michael Keane	July 18, 2007	Liver
Jennifer Lentini	July 6, 1996	Heart
Kevin O'Brien	July 1, 2005	Kidney
Henry Prins	July 2, 1992	Liver
Laura Laria Roberts	July 6, 2006	Kidney
Ben Silberstein	July 23, 1994	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 Herman	August 2005	Kidney
James Jewell	August 13, 1986	Liver
Anne Marie McCartney	August 20, 1988	Liver
Janine Rempe	August 14, 2008	Heart
George Tietjen	August 23, 2001	Kidney

Anthony and Connie DiMaria

Pamela Fregeau Anto Ayinikal

Ralph and Annamarie Greener

Vito Losito Barry Reiter

Indra C Daniels MD Terry Clemte

Machine Saves Patients Awaiting Liver Transplant

Temporarily Takes Over Liver Functions

Mallika Marshall, MD

The Extracorporeal Liver Assist Device is in clinical trials.

Doctors say 33-year-old Dariusz Reszuta is lucky to be alive. Three months ago his liver started to fail without warning. He slipped into a coma and doctors couldn't figure out why.

Reszuta desperately needed a transplant.

A donor liver was found in another state but it wouldn't arrive in time to save him.

Luckily Doctor Lewis Teperman of [NYU Langone Medical Center](#) was testing an experimental machine called the [Extracorporeal Liver Assist Device](#), one of just six in the country that can temporarily take over liver function.

Dariusz was hooked up to it and for eight hours, his blood traveled through the filtration system. What makes the device unique is that the filters contain human liver cells that cleanse toxins from the body and produce vital proteins.

"We were able to keep him alive in the operating room on this machine waiting for

the organ," Teperman explained.

The transplant was a success and today Reszuta is doing fine. "I feel lucky I was

able to be on the machine. It saved my life," he said.

The machine has been used on about 70 Americans. In some patients, the device allowed the damaged liver to heal itself and they didn't even need a transplant.

Dr. Teperman says if future testing is successful, and the FDA approves the machine, it could save thousands of lives every year.

Yankee homered on same night she received a heart transplant!

Alyssa Esposito's life has been something straight out of a movie. Stories like these are usually reserved for the fantasy of the big screen, not reality. Especially for a girl like Esposito, 18, who, less than a month ago, was toiling on a heart-transplant list, unsure when or if a donor would ever arrive. Her mother, Laura, said she was at death's door.

All those planets actually aligned on May 15, when Esposito embarked on her own Hollywood journey. She gave Yankee outfielder Brett Gardner a bracelet that morning, saying it would help him hit a home run. A few hours later, Gardner, perhaps the least likely candidate on the team to actually fulfill the prophecy, used his speed to turn a blooper down the left-field line into an inside-the-park homer.

In the dugout, he remembered Alyssa and the lucky bracelet.

"To hit an inside-the-park home run," Gardner said, "a lot has to go wrong defensively."

That night, Esposito learned they had found her a donor. She was finally receiving a new heart. She underwent a successful surgery the next day and has been healthy ever since. When she came to, her father, Tony, told her Gardner hit a home run. Since then, whenever the Yankees are losing, the Espositos make sure Alyssa turns the game on. She's a good luck charm!

Read the full story at our organization's website at 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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Help with Immunosuppressant co-payments

Patient Services Incorporated, 800-366-7741 www.uneedpsi.org offers a program to help organ transplant recipients afford co-payments for immunosuppressant medications.

LI TRIO Tribute Cards

Florence Sosna has LI TRIO Donation 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 Candidates-102,820

Transplants January- April 2009- 9,347

Donors January - April 2009-4,744

Source: UNOS- July 2009