



NEWSLETTER

Long Island Chapter of Transplant Recipients International Organization

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April 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.

April Is "Donate Life Month"

The Long Island chapter of TRIO is very lucky to have dedicated volunteers making all of the following initiatives possible. We are pleased to team with our coalition partners inclusive of Senators, Members of the Assembly, NYODN, and Transplant Centers as we travel to Albany to help save lives and truly make a difference.

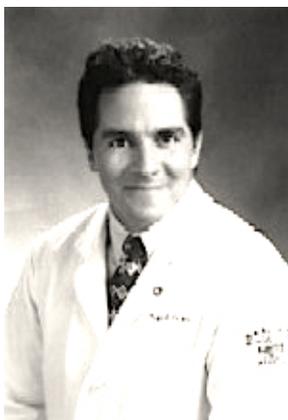
Long Island TRIO is commemorating Organ Donation Awareness Month as we participate in over a dozen events in April, 2010. Our festivities and events will be followed by a 27 April, 2010 trip to Albany, New York where we have scheduled appointments with New York State Senators and Members of the Assembly in their Capitol District offices.

Our chapter will obtain New York State official proclamations that proclaim April 2010 to be forever known as and referred to as "Organ Donation Awareness Month" in New York.

We will be meeting with Assemblymen and Senators who are working with Long Island TRIO and our coalition partners in order to improve the New York State Donor Registry Of Consent. We will also ask for support from Senators who have promised to meet with us as we discuss with them the imperative logistics of New York State accepting "Electronic signatures" as legal consent in order to make an anatomical gift.

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Our March 2010 Meeting With Dr. Jorge Ortiz



On March 10, 2010 we had the pleasure of meeting with Jorge Alberto Ortiz, MD-Chief, Liver Transplantation and Hepatobiliary Surgery Albert Einstein Center for Liver Disease and Transplantation.

Dr. Ortiz specializes in multi-organ transplant including liver, kidney and pancreas and hepatobiliary surgery. Hepatobiliary surgery encompasses disorders of the liver, bile ducts, and gall bladder. Dr. Ortiz has over 10 years of experience in liver transplantation, teaching and research.

As we went around the room to introduce ourselves, one of our newly welcomed members awaiting a transplant informed us that her husband was going to be her donor but a tumor was found on his kidney. Dr. Ortiz shed light on this dilemma by stating that even a donor with a compromised organ should be considered for transplant. (Continued on Page 2 Column 2)

General Member Meeting- April 14, 2010

Our next meeting will held on April 14 at 7:30 PM and we are pleased to present David C Wolf, MD, FACP, FACC, Medical Director of Liver Transplantation, Westchester Medical Center as our special guest speaker. You will find that Dr. Wolf is an exciting speaker who will present an interesting discourse and answer questions at the conclusion of his presentation.

Upcoming Events

April 14, 2010 -General Membership Meeting with special guest speaker David C Wolf, MD- Medical Director of Liver Transplantation, Associate Professor, Department of Internal Medicine, Division of Gastroenterology and Hepatobiliary Diseases, New York Medical College and Westchester Medical Center

April 24 at 10 AM-Transplantation Re-Birthday Party presented by ALF. All Transplant Recipients are welcome to attend. Location: 145 Community Drive

April 27, 2010-Legislative Day- scheduled meetings with New York State Legislators in Albany. Call for info.

April 2010- Donate Life Month- Please refer to several "Donate Life Month" and other special events, Flag Raising Ceremonies and Walks listed in this issue.

Please note that our LI TRIO May meeting will be held on May 26, 2010 at 7:30 PM. We'll see you at our meeting on April 14th!

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This will help our chapter's volunteers who work throughout the year signing up new donors to the Donate Life Registry. We also have a legislative initiative that will ensure that the "Registry choice" is not skipped and that New York State will require all drivers (when renewing their licenses) to either check the box and register in the NYSDL Registry or check a box saying that they defer this decision to their families or a later date. We are also trying to accomplish another important goal; that is for New York State to eliminate the requirement of each person checking off specific body parts to be donated.

Our TRIO chapter has led the charge into the classrooms in hospitals, courts, universities, high schools and physician's offices and our LI TRIO speakers bureau has directly reached over 18,000 students in person in the classrooms to date. Our chapter is also finding support for Legislative Bill Number: A. 292 (Magnarelli) and S.4373 (Oppenheimer) that will require health education regarding organ, eye and tissue donation awareness in every high school in New York State while cooperating with TRIO, the Transplant Community in New York State, and OPO's. These bills call for the requirement of thirty minutes of "Donation Education" in 8th or 9th grade school health classes in high schools. As New York State is asking the donation question of every person applying for a license, it stands to reason that NYS would want its populace to be prepared to make an educated decision. The curriculum and all content and materials will be provided at no cost to all New York State high schools.

We are also meeting with Senators in Albany to help garner support for legislation that will provide a tax check off box on personal income tax return forms for gifts for the Life Pass It On Trust Fund for gifts of organ and tissue donation outreach and research. Legislative Bill Numbers: A. 6190 (Titus) and S.4319 (Adams), and New York State is considering the following incentives as well:

It has been suggested that the registry be expanded to allow altruistic living donors to register and begin the assessment process. A tax credit would be implemented to help offset lost wages for living donors. This would require a change to the tax code. Legislative Bill Number A.214 (Jeffries) provides a leave of absence for employees in private business who are organ or bone marrow donors and insurance reimbursement to employers for wages and salary paid on such leave.

Another bill -Legislative Bill Number A. 4265 (Ortiz) allows a person who donates one or more organs to another individual to receive up to \$10,000 tax deduction for non-reimbursed expenses. New York State is also considering a bill that would provide a funeral benefit or nominal state tax credit for deceased donor families to defray the time and any burial costs that may have been impacted by donation. As an example, Pennsylvania adopted a \$300 funeral credit or offset several years ago, but has never implemented this credit (to date) due to concerns that it may require federal legislation to overcome "National Organ Transplant Act" restrictions.

North Shore LIJ is hosting special events on April 1, 2, 6, 8, April 13 and April 20, 2010. For all dates, specific contact information and phone numbers, please point your browser to www.litrio.org.

April 13- 10 AM-2 PM Plainview, in the Main Lobby.

April 20, 2010 11 AM-2 PM Syosset, in the Lobby.

Our chapter has quite a full schedule of events for "Organ Donation Awareness Month" this April, 2010. We look forward to all of our volunteers making April 2010 a very special "Donate Life Month".

Please join us on April 27, 2010 as we travel to Albany to meet with our Legislators.

-Mike Sosna, President

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His reason for promoting compromised organs for donation is that without them many patients will die waiting for a better option. In the case of the member, he simply said that the doctors might be able to and willing to remove the tumor and transplant the organ. Our new friend (the (new TRIO member) was pleased to hear this and was very interested in finding out more about this possibility.

Dr. Ortiz told us that the Philadelphia waiting list is currently 2/3 of the time people wait on the New York waiting list. He advised anyone waiting for an organ that they can register at more than one center in multiple regions and if one is willing to travel, Orlando, Florida among other regions has a very short waiting time.

In terms of the risks after transplantation, Dr. Ortiz noted that there is a risk of cancer particularly melanoma or post transplant lymphoma (PTL). As many of us know the risks of transplant outweigh the alternative of dialysis for those with chronic kidney failure.

Dr. Ortiz discussed some other issues post transplant such as the BK virus. He mentioned that if the recipient has the BK virus, eventually the organ will experience rejection. He reiterated that the recipient should be tested every few months for the BK virus. When comparing medications that help prevent the rejection of an organ, Dr. Ortiz said that Cellcept presents more short-term complications, while prograf has more long-term complications. He believes that it is best to have a higher dose of cellcept and a lower dose of prograf and prednisone, if prednisone is needed at all.

Dr. Ortiz was a very informative guest speaker and gave hope to those waiting eagerly for a transplant. We thank Dr. Ortiz for being an integral part of our LI TRIO chapter.

-Helena McDermott

From our friends at American Liver Foundation: You're invited to a Transplantation Re-Birthday Party celebrating the Gift Of Life and the miracle of Transplantation!

Date: Saturday, April 24 at 10 in the morning at our regular meeting place in Manhasset- 145 Community Drive. ALF's guest speaker will be Dr. Benjamin Samstein, Surgical Director, NY Presbyterian Hospital/Columbia University Medical Center.

All transplant recipients, friends and family are welcome.

Please RSVP- Tracy Merlau- 212.943.1059.

- Kidney & Urology Foundation's 2010 Long Island Walk the Walk for Kidney Disease & Organ Donor Awareness

On Sunday, April 25, 2010, we invite you, your family, and your friends to join us as we take a stroll around Farmingdale State College, and help to save lives in the process.

Our annual WALK the WALK for Organ and Tissue Donation is a fun and healthy way of raising awareness of the importance of organ and tissue donation and how easy it is to become a donor.

The money you raise will go directly to research, patient services, and public and professional education.

Event Location: Farmingdale State College Farmingdale, NY

Check-In Time 9:30 am- Start Time 11 am

Register: <http://li.kidneywalkthewalk.org/register/>

1.800.633.6628

- Liver Life Walk 2010-Long Island: Sunday, May 16th at Eisenhower Park

Also-New York City: Sunday, June 6th at Battery Park

www.liverfoundation.org/walk

or call 212-943-1059 for more information.

Monday, April 19, 2010-The Paley Center for Media, 25 West 52nd Street

Reception: 6:00 PM • Program: 6:30 PM

There are over 100,000 people on the national transplant wait list, and most wait for kidneys. The organ shortage crisis and recent events surrounding the underground market for organs begs us to explore current practices in organ allocation, incentives for organ donation, and how health care policies evolve.

Kidney & Urology Foundation of America (KUFA) is hosting a timely and compelling seminar, bringing together a diverse panel of thought leaders in the organ donation, transplantation, and health care policy arenas on Monday, April 19th at The Paley Center for Media, 25 West 52nd Street, between 5th and 6th Avenues, New York City.

Please join us for a Reception at 6 PM and Program at 6:30 PM. If you are a kidney or transplant patient, physician, transplant coordinator or other patient care professional, health policy expert or legislator, ethicist, patient advocate, media representative, or an interested member of the community, you won't want to miss this forum on the current state of transplantation in the USA and possible changes to the transplant landscape.

Speakers:

David J. Cohen, M.D., Professor of Clinical Medicine; Medical Director, Renal Transplantation, Columbia University Medical Center, New York, NY; -The current clinical practice of transplantation: organ allocation, the current transplant wait list, and how organ allocation policy evolves.

Nancy Scheper-Hughes, Ph.D., Chancellor's Professor in Medical Anthropology-Historical perspectives on organ shortages, the 'underground' market for kidneys, and current issues in the U.S. regarding the sale of organs.

Alex Tabarrok, Ph.D., Bartley J. Madden Chair in Economics at the Mercatus

Center-The economics of incentive programs to increase organ availability in the US.

Moderator:

Jonathan A. Winston, M.D., Associate Professor of Medicine/Nephrology, Mount Sinai School of Medicine

Registration is free. Light refreshments will be served. RSVP required.

Space is limited. Reservations will be accepted on a first come, first served basis.

To Register By Phone:

Carol Brower-732.866.4444

or Heather Reel-212.629.9770

Happy Re-Birthday to you!

April Re-Birthdays

Fran Addazio	April 11, 2002	Kidney
Evelyn Alvir	April 15, 2004	Kidney
Gillian Cohen	April 17, 2005	Liver
George Donohue	April 12, 1996	Kidney
Alvin J Futterman	April 8, 2005	Kidney
Margaret Gonzalez	April 18, 2002	Kidney
Anne Melican	April 20, 2009	Kidney
Michael Murphy	April 10, 2004	Kidney
Diane Newman	April 2, 2009	Kidney

New Members

Jeff Frame
Peter Z Kupczak
Henry Serrapica
Michael Kahne

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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 Tel: 516.902.8111 / Fax: 516.482.2599

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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Holiday Party Chairpersons	Florence and Jerry Sosna	516-482-2908

Transplant Recipients International Organization



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 Long Island Chapter
 PO Box 81
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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:

- 106,886 Americans are on the organ transplant waiting list as of April 7, 2010.
- Visit www.litrio.org to read all about LI TRIO's Donate Life Month Events.