

Meet kidney donor and recipient

Lori Interlicchio and Alana Duran at Long
Island TRIO's next General Meeting
Wednesday, April 13 @ 7:00 PM

Volunteer Opportunities at 5:00PM. See page 3.

L O N G I S L A N D T R I O

LONG ISLAND TRIO NEWSLETTER

The Long Island Chapter of Transplant Recipients International Organization

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LI TRIO

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.



APRIL 2016

Transplant Profile – Bobby Seeback

Twenty Years of Giving Back



You would think that it would be hard for **Bobby Seeback** to maintain a positive attitude. After all, he has survived, among other maladies, Hodgkin's disease, the loss of his spleen, appendix, lower lobe of a lung, heart failure, a fractured pelvis, and osteoporosis. But Bobby keeps his spirits up by giving back to others. The primary way he gives back is through his gifts of music; he has recorded albums and teaches guitar on an individual basis and in adult education classes in Massapequa and Farmingdale. His living room holds a small armada of guitars which he uses to support his teaching efforts. Sometimes he will play rhythm guitar while his students take the lead. His interest is to help people and that allows him to keep his resolve in the face of all of his medical issues. Music keeps him positive; it is his gift to

give to others. He bought his first guitar for \$20 at age 15, along with an amplifier and microphone, and it has remained a lifelong passion.



Bobby is a very active participant in **Long Island TRIO's School Speaker Program**. He does about twenty school speaking engagements a year for LI TRIO and many for other groups such as **Live On New York**, and at hospitals, churches, and synagogues. Lying on his death bed for four months before his transplant, Bobby came to realize the seriousness of the organ donation shortage. When he speaks at schools, it is a very intense situation for him; in fact, it is life or death. Students must get the right information, he asserts, to make good decisions about organ donation. When he stayed at Columbia Presbyterian Hospital before his transplant twenty years ago, five people died. Patients knew that someone was about to expire when the alarms went off on the transplant floor, followed by the code words "Arrest Stat" over the PA system. Bobby still shudders even now, when he returns to the transplant floor at New York-Presbyterian Hospital to see his doctor and those words come on the speaker system. It is a reminder to him

that unless something is done, some people needing transplants are going to go without an organ.

Bobby has experienced a lot in his life and not of all of it has been pleasant. He was bullied as a youth because of his height but he has even used those experiences to demonstrate positivity: He has mastered the martial arts, attaining a brown belt in kung fu, a green belt in karate and has been trained in filipino muay thai, a form of kickboxing that includes blows using the elbow and knee. He takes me proudly to another room in his house where a section is devoted to his children's' martial arts trophies.



With Dr. Ronald Drusin NY
Presbyterian Hospital

But music has been his life: He started out singing opera with the Long Island Singers Society and touring the world. They sang all manner of music including spirituals, gospel, and American folk music.

Unfortunately, he lost

his voice with the onset of Hodgkin's disease, and a tumor on his diaphragm and resulting surgeries. On his first CD, with the band Mystic Gypsy, Bobby did not sing because he had severe heart failure and could not breathe. One of his bandmates carried him out of the studio after playing guitar one night. He was very close to death but wanted to finish the album. Twenty years after his transplant, he is ready to give singing another try and thereby celebrate his rebirth through organ donation. He will be dedicating his new song *Angel from Heaven* to his heart donor and performing it at local venues. He hopes that this effort will inspire people and give hope to those who are now waiting for transplants.

He is involved in a messy custody case involving his two children and believes that "there are many things that I can teach my children." The case takes up a huge part of his time as he is serving as his own representative, which he could utilize better in doing more productive things. He shows me a huge scrapbook detailing his medical and life experiences. He did this as a way of leaving something behind because he feared he

would not have a successful outcome. But he is still here. He would like to dedicate himself to making their lives better, as he has done with the countless number of students he has spoken to on behalf of organ donation.



With Dr. Mehmet Oz, transplant
surgeon

As he said, "Life is going to throw a lot of curveballs at you, but it makes you the person you are." He is particularly grateful to his cardiologist Dr.

Ronald Drusin, who responded to a letter Bobby wrote, as toxic

chemotherapy was destroying his heart. Dr. Drusin set up an evaluation for Bobby and got him onto the transplant list where, more than a year later, he underwent a transplant by Dr. Mehmet Oz, now a celebrity but, in 1996, just a competent transplant surgeon. Twenty years can make quite a difference.

Upcoming Events

Saturday, April 2 - The Remember and Rejoice Service hosted by Manhattan TRIO - *21st Annual Ecumenical Service*. St. Patrick's Cathedral, 5th Avenue between 50th and 51st Street, 2:00 - 4:00 PM

Saturday, April 9 - ALF Re-Birthday Celebration for Liver Transplant Patients and their donors - 10:00 AM - 12:00 PM - Breakfast Program - Homewood Suites, Carle Place

Wednesday, April 13 - General Meeting - Steven Knapick, RN, BS, CPT, Senior Transplant Specialist, Interim Director, Stony Brook Medical Center with donor Lori Interlicchio and recipient Alana Duran. Hear the firsthand account about a fascinating gift of life, made possible by technology, social media and caring individuals - 7:00 PM - 145 Community Drive, Manhasset

Wednesday, May 11, 2016 - LI TRIO General Meeting - Speaker to be announced - 7:00 PM - 145 Community Drive, Manhasset

Saturday, May 21 - Liver Life Walk Long Island - One Step. One Walk. One Future to a future without liver disease. Eisenhower Park - Check-In 9:00AM, Opening Ceremony - 10:00AM, Walk Begins 10:20AM - Parking Field 6A

Sunday, May 22 - NKF Long Island Kidney Walk - 100,000 walkers are on the move across the nation! Get in step with us as we move kidney disease, a top ten public health problem! 26 million Americans with kidney disease are counting on us, so we need all the help you can give! - Eisenhower Park - Check-in 9:30AM, Start time 10:30AM

April Re-Birthdays

Fran Addazio	April 11, 2002	Kidney
Gillian Cohen	April 17, 2005	Liver
George Donohue	April 12, 1996	Kidney
Margaret Gonzalez	April 18, 2002	Kidney
Kristen Margolies	April 22, 2010	Bone Marrow
Kristen Margolies	April 8, 2014	Lung
Kate Mayerhofer	April 1, 2010	Kidney
Anne Melican	April 20, 2009	Kidney
Leonor Morton	April 6, 2014	Liver
Iris Pappalardo	April 26, 2012	Kidney
Sandrajane Rios	April 16, 2008	Liver
Mark Sakitt	April 18, 2014	Kidney
Robert Skaretka	April 28, 1991	Heart

May Re-Birthdays

Ralph Greener	May 8, 2008	Kidney
Victor Haymer	May 1, 2014	Kidney
Melvin Kershner	May 21, 2009	Kidney
Leslie Kreisman	May 5, 2000	Kidney
Hopeton Lue	May 30, 2000	Kidney
Brian Maguire	May 10, 1992	Kidney
Richard Prete	May 8, 2008	Liver
Vinny Santalucia	May 27, 2000	Kidney
James P. Schneidmuller	May 23, 1987	Liver
Joe Senatore	May 19, 1999	Heart
Roz Siegel	May 5, 2014	Kidney
Gale Teney	May 23, 2011	Kidney
Ida Tesoriero	May 12, 2005	Kidney

Have You Paid Your Dues?

Long Island TRIO relies on members' dues to support all of its activities. Whether spreading the word about organ donation to high school students, signing up organ donors at fairs and other functions, maintaining the website, publishing the newsletter, supporting the annual Holiday Party, or maintaining the magnificent Rose Garden at Eisenhower Park and the moving ceremony there, LI TRIO needs your support in order to continue its activities. If you receive a green *LI TRIO 2016 Dues Reminder* in the mail, please fill it out and return it, with a check for \$25 (still). **If you cannot afford to pay dues at this time, please check the appropriate box on the card and return it.** In that way, we will know that you are still interested in receiving our correspondence and we can continue to keep you informed of our activities.

Quarter Century Club



The Quarter Century Club is an organization of organ transplant and bone marrow recipients whose transplanted organs have survived and functioned for twenty-five years or more. Currently, the group has more than 125 members. Their activities, which include a dinner-dance, appear to center around the Transplant Games, which take place this year June 10 to 15, 2016, in Cleveland. More information may be obtained at their website <http://quartercenturyclub.org/>, their Facebook page, or by email at gef3rd@gmail.com.

Looking to Volunteer?

Prior to the April 13 General Meeting, LiveOnNY will conduct training on how to conduct organ donation activities. Come for pizza at 5:00 PM then a one-hour training session starting around 5:30. Then stay for a fascinating General Meeting. All are welcome.

Special School Program at Port Jefferson

A school visit to Port Jefferson's Earl L. Vandermeulen High School turned out to be a very special event as two of the participants had a direct connection to the school.



Megan Ryan

Megan Ryan teaches math at the Port Jefferson Middle School. She became part of a donor family, along with her mother **Cathy** and both spoke very movingly about the loss of brother and son Terrance Ryan and his Gift of Life to heart

recipient **Robert Skaretka** (His story and that of the Ryans were featured in the February 2014 issue of the LI TRIO Newsletter.) All of the students had passed through Meg's math class in Middle School and were moved by her mom Cathy's speech, the family's loss and generous gift.



Cathy Ryan, Donor Mom

Jesse Rosen, an extremely popular history teacher at the high school, spoke of his recent donation of a portion of his liver to his mother **Laurie**. On December 17, 2015, Jesse became a hometown hero by becoming a living donor. Thanks to intense preparation, he was out of

the hospital less than a week later; he and his mom continue to do well three months post-operation.



Jesse Rosen

The Rosens' operations took place at New York University Langone Medical Center and **Dr. Lewis W. Teperman**, the Chief of the Transplant Surgery

Division there and their transplant surgeon, was

on hand to inform the students about the procedure and to drive home the need for more people to sign up to be organ donors. Dr. Teperman is a tireless advocate for organ donation and has spoken frequently at Long Island TRIO meetings. He was his usual witty

and wellspoken self. **Dave Rodgers**, who coordinated the double-period session, presented an overview of organ donation and transplants, as well as a examination of the pressing need for donors in New York State.



(left to right): Dave Rodgers, Cathy Ryan, Dr. Teperman, Jesse Rosen, Megan Ryan

Even for those of us in the audience who have heard these presentations many times before, the involvement of local teachers and their families made for a very stirring experience.

LI TRIO Works on Behalf of Recipients and Donors



Mike Sosna with Sen. Kemp Hannon Proclaiming Organ Donation Awareness Day

*Former Long Island TRIO President and current Board of Directors member **Mike Sosna** is a prime activist regarding the issues that are important to LI TRIO members. A report of his recent activities working for members on organ donation issues reveals some of the many ways that LI TRIO serves to improve the lives of recipients, donors, and their supporters.*

Education

• **Dave Rodgers, Brian Papszycki and Mike Sosna**-presentation at North Shore-Northwell Health Manhasset

We presented to a large group of Social Workers at Northwell Health, Manhasset Campus. The program was effective and excellent feedback was received. The social workers had many comments and their discussions showed that there was a great deal of interest in the cause. There were experienced social workers, interns, and students in attendance and there were follow-up questions. I was impressed once again (as was the audience) with Dave's sharing of his story.

Support

• Participated in the North Shore Transplant Center Support Group February meeting and met with individuals (and in some cases their significant others) who are candidates for renal transplantation. We help provide support to future transplant recipients as well as recent transplant recipients. I have attended the meetings and have tried to help share experiences for the past seven months and joined other LI TRIO members including **Margie (Ng-Reilly)**, **Monica (Blum)** and **Mary (Graffeo)**, at scheduled meetings and at scheduled luncheons in providing answers to specific questions as part of peer to peer support....

Advocacy

Legislative initiatives and public policy:

• Meeting in person with Senator Hannon:

Regarding New York Senate S6228 - Met in person with Senator Hannon and confirmed support for providing an official four year extension to Lauren's Law which was set to expire in October. The Senate subsequently passed this legislation.

New York State Assembly A8594 - It is expected that this extension will also be passed in the New York State Assembly. As we speak with members of the Assembly we are pleased to find overwhelming support for the extension at this time. Governor Cuomo will also have to sign this legislation into law. Upstate has **Lauren** and **Jean Shields** effectively and successfully advocating for this legislation.

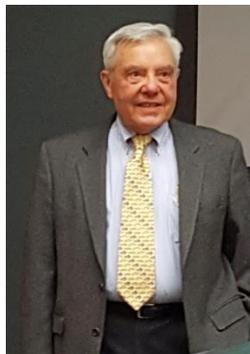
Organ Donation and Transplantation Awareness

• **Set up an official proclamation that addressed Governor Cuomo. It was passed, printed and delivered to Governor Andrew M. Cuomo's office.**

The proclamation request was made by Long Island TRIO and Senator Kemp Hannon officially introduced the proclamation memorializing Governor Andrew M. Cuomo to proclaim February 14, 2016 as Organ Donation Awareness Day in New York State.

As of March 25, 2016 there were 121,309 candidates for transplant, according to the United Network for Organ Sharing (UNOS). In New York State, there were 10,254 candidates awaiting a transplant.

March General Meeting



Lionel Mailloux MD

We were honored to hear two guest speakers at Long Island TRIO's March General Meeting. The principal speaker was **Lionel Mailloux MD**, an esteemed nephrologist associated with Northwell-North Shore University Hospital. Dr.

Mailloux has spoken several times at LI TRIO meetings and is always informative and interesting.

He gave a well-rounded presentation on the characteristics of Chronic Kidney Disease (CKD) and trends regarding kidney transplants. He described the stages of CKD as it progressed as measured by GFR (glomerular filtration rate) and other factors and the resulting treatment that accompanies each stage. The primary course of treatment is dialysis and, ultimately, transplant. Dr. Mailloux cited the persistent problems associated with CKD which include its increasing prevalence, increasing levels of morbidity and mortality, problems with dialysis, lack of referrals for preemptive renal transplantation, and lack of awareness of all available therapies.

Although the number of kidney transplants has increased, as well as the number of deceased donors, there is still a long waiting period – the median waiting time is 3.6 years for those newly wait-listed. Since 1996, the probabilities of survival have steadily improved among recipients of both living and deceased donor kidney transplants with living donor recipients having an advantage over deceased donor recipients.

While early and appropriate management of the disease can delay or limit its progression, care for advanced CKD patients is still not optimal. Kidney transplants are highly successful but overall treatment practices may need more rigorous attention.



Martin W. Clarke Jr.

A highlight of the meeting occurred at its beginning, when **Martin W. Clarke Jr.** shared his experiences of working on behalf of organ donation (Martin's story was featured in the June 2015 edition of the LI TRIO Newsletter.) Martin does so as a tribute to his grandfather **Angelo Stekardis** who was a lung transplant recipient and who passed away in 2014. Martin conducted his activities as part of his Eagle Scout program and enlisted the aid of his fellow

scouts to sign up more than one hundred organ donors. Adorning the front of the conference room was a table brimming with organ donation materials which Martin and his mates used to make their persuasive arguments.



(clockwise from top left):
Kaitlyn Clarke, Martin Clarke with organ donation table, Martin, LI TRIO President Joy Oppedisano, Lionel Mailloux MD



Martin is in process of passing the torch onto his younger sister **Kaitlyn** who is starting to become involved in the quest to increase the number of donors and thereby make organs more available for life-saving transplants. As a symbol of the life-affirming qualities associated with organ donation, the tables where the audience sat were decorated with brilliant red flowers.

LI TRIO Visits Hofstra Northwell Medical School

Members of Long Island TRIO paid their annual visit to the **Hofstra Northwell School of Medicine**. **Dave Rodgers** and **Shelby Caban** educated the first-year medical students on the issues of organ donation and transplantation and then sat in on case studies where the students consider the suitability of candidates for transplants.

Dave is a liver recipient and Shelby a heart recipient and cancer survivor, and, as Dave put it they "*spoke on organ donation and transplantation and The Gift Of Life...* ..Tremendous day of interacting with the future doctors, presenting the steps leading up to transplant, life after transplant, pay it forward for others and the need of more people to sign up to be a donor."

The faculty of Hofstra is very much invested in this yearly exercise with the close participation of **Dr. Samuel Packer**, Chair Emeritus Department of Ophthalmology, Professor of Ophthalmology, Chair, Medical Ethics, Northwell Health, Co-Director, Hofstra University Bioethics Center, **Dr. David Marcus**, Assistant Professor of Emergency Medicine, **Dr. David Bernstein**, Professor of Medicine, and **Dr. Judith Brenner**, Associate Dean for Curricular Integration and Assessment.

As is typical of the Hofstra medical students, the audience was enthusiastic and vitally interested in hearing about Dave and Shelby's experiences.

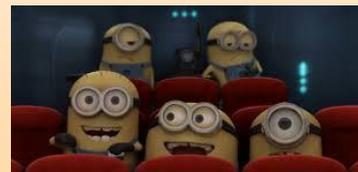


(left to right): David Marcus MD, Dave Rodgers, Judith Brenner MD, Shelby Caban, Samuel Packer MD

February General Meeting Postponed

Due to anticipated bad weather, the February General Meeting of Long Island TRIO was postponed. The meeting was to feature a presentation of ***The Power of Two***, a moving documentary about twin sisters who received double lung transplants. Look for the film to be shown at the September meeting as

Long Island TRIO Goes To the Movies!



President's Corner

"Spring is sprung, the grass is ris.
I wonders where the birdies is.
They say the birds is on the wing.
Ain't that absurd?
I always thought the wing was on the bird."

While frequently attributed to Ogden Nash or ee Cummings the author of this amusing little poem - known as "Spring in the Bronx" - is **Anonymous**. **Anonymous** like the many volunteers who do so much and yet remain in the background while uplifting and saving others. **Anonymous**, like the many volunteers who have been instrumental in starting programs, lending a hand and "giving life."

Many of these volunteers include recipients, donor families, and those touched by transplantation. During the month of April, Donate Life Month, flags are raised by our local transplant centers, events coordinated, educational programs, bicycle rides, 5k walks, ice skating events, and more are conducted. They are all planned to honor those who have contributed to making a difference, saving lives, as well as those who want to make a difference.

So, Happy Spring, Happy Donate Life Month – Let's get busy and Thank You!!!

Please contact me (**Joy Oppedisano**, Pres. LI TRIO 516 232-3151) if you would like to participate in a planned event or are interested on working on an event. In fact, if you are interested in joining a committee and would like to volunteer in any capacity contact me also! You may also want to nominate someone as a board member. If you would like to nominate someone who has contributed to the mission of LI TRIO – please contact our nominating committee (email litrioedb@gmail.com – or telephone: 516 620-5900).

Spring has sprung –

Let's join together and plant the seeds that make life meaningful---and make life possible.

Joy Oppedisano

Does greater scrutiny of transplant centers create disparities for the sickest patients?

Editor's Note: The following article appeared in the January 2016 American Journal of Transplantation. It describes a new study which indicates that transplant centers that receive low scores on performance evaluations tend to remove more patients from the transplant waiting list. We want to hear your comments and opinions about

what needs to be done to alleviate the chronic shortage of available organs for transplantation. Send your thoughts to the editor at litrionews@gmail.com.

A new study indicates that transplant centers that receive low scores on performance evaluations tend to remove more patients from the transplant waiting list. According to US data from the Scientific Registry of Transplant Recipients on 315,796 candidates on the kidney transplant waiting list from 2007 to 2014, the rate of removal was approximately 60% higher for centers that received low performance evaluations compared with all other centers, even after adjusting for candidates' demographic and clinical characteristics.

Transplant rates significantly declined following low performance evaluations, and deaths following waitlist removal were significantly lower among candidates removed at centers with low performance evaluations. This suggests that these centers removed a relatively healthier group of patients.

The results reveal that a consequence of greater scrutiny of transplant center performance may be reduced access to transplantation for the most sick and complicated patients, because centers with poor outcomes become more conservative with their waiting list.

"These findings must be placed in perspective that numerous studies verify that the survival benefit of kidney transplantation extends to patients with multiple risk factors and with use of relatively higher risk donor organs. Thus, any policies that may stifle the growth of transplantation should be carefully examined," said Dr. Jesse Schold, lead author of the *American Journal of Transplantation* study. "At the same time, transplant centers must be vigilant that their processes of care are based on best clinical judgment and available empirical evidence and not irrationally influenced by regulatory oversight.

Ultimately, as a field, we must critically assess whether we can align policies and care practices to best treat patients and provide transplant opportunities for recipients and donor families."

More information: J. D. Schold et al. Association of Candidate Removals From the Kidney Transplant Waiting List and Center Performance Oversight, American Journal of Transplantation (2016).

Letter to the Editor

From LI TRIO member Janet W. – Long Island TRIO was the most supportive outlet we had during all the dialysis and then transplant - due to Jim's doctor Lionel Mailloux who was the best doctor and so calm & concerned during all of our troubled times.... Keep up the good work – You are a comfort to people with need of a transplant.

Chapter Officers

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 Immediate Past President: Dave Rodgers

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