

Wednesday, February 10
Long Island TRIO at the Movies!

Join us for a showing and discussion of *The Power of Two*, the story of twin sisters' double lung transplants.

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.



FEBRUARY 2016

Transplant Profile: Shelley Fyman

Oh Brother (or Sister), Can You Spare a Kidney?

Shelley Fyman wants you to know she needs and wants a kidney. After all, going through dialysis is not a picnic for anyone, and when your blood pressure can rise or fall drastically during the procedure, putting oneself through that three times a week can really make one want to find a more viable alternative. She has children and grandchildren to visit, and community service to pursue, and a new kidney would go far toward her attainment of those goals.



Shelley Fyman

Shelley's forty-year struggle with diabetes led, as it so often does, to kidney disease. She has been on dialysis for five years already and the procedure can only sustain oneself healthily for possibly ten years. Her three-times a week schedule takes up a huge amount of time and energy. Shelley feels she was never properly educated about kidney disease, didn't

understand the implications of the disease, and felt for awhile that it wasn't real.

Certainly, she has tried to find someone to donate a kidney on her behalf. Her three grown children are medically unable to donate. A cousin, who was very willing to take the plunge, was also medically unable due to open heart surgery. Other relatives have managed to look the other way when the subject of kidney donation arose. Several people have spread the word about Shelley's need, but few have stepped up to donate the Gift of Life.

Shelley has had a few medical setbacks over the years but she has forged ahead. A two-week trip to Indiana to visit her daughter turned into two years, when she began dialysis in 2012.

As indicated, dialysis is not always easy for Shelley. Her BP can drop suddenly to 70 or up to 200 for no reason. The low BP can cause her feelings of nausea or bad leg cramps. As all dialysis patients know, one's mobility is limited, with an arm cuff on one arm and needles in the other. Shelley attempts to compensate for those periods of inactivity by reading her Kindle, talking on the phone, or watching television. But no outsiders, potential germ-carriers, may enter. She is fortunate to have her dialysis center located a few blocks away, but she has to drive even that short distance because of the fatigue she

endures following treatment. In fact, she has hired an aide to drive her home after dialysis; the aide also prepares a post-dialysis meal for Shelley, and assures her medications are taken correctly.



Shelley's difficulties have extended to getting onto an active transplant waiting list. She has attempted to wend her way through the process at her New York hospital but she cannot seem to make her way onto the active list. Every time she submits paperwork to satisfy one requirement, her transplant coordinator will come back with a comment such as "let's just get three more things." Although her cardiac surgeon has pronounced her fit to undergo a transplant, she cannot seem to obtain clearance. The center will, for example, continually request a report from a doctor who was on call during one of Shelley's admittances, despite the fact that the doctor never saw Shelley and has notified the center several times of that fact. She says she "is in a quandary" and doesn't know how to handle it. She has been unable to find other resources which might assist her, such as a dialysis group at her hospital, and she was instead pointed toward a psychiatrist for questions about her mental state when she asked about such a group. The transplant coordinator position has changed frequently at her hospital, which doesn't help Shelley's situation. Her three children are spread out in different parts of the country and, for various reasons, would not be able to act as caretakers if she were to be listed in those geographical regions for easier access to a cadaver kidney.

While her thrice-weekly, four-hours-a-day dialysis sessions and other doctors' appointments take up the bulk of Shelley's time, she has pursued other interests over the years: She enjoys writing and has used her writing skills in a variety of contexts. She taught literacy for years to immigrants and others at the Jamaica Public Library until mobility and parking issues forced her to give up that position. She also took foreign students studying temporarily at a Manhattan college into her large Fresh Meadows apartment and guided them in their first weeks after entering the United States. Even when her health

kept her in Indiana for two years, she still made time to run a book study club for Korean visitors. She has edited two books for a published author and is currently working on a third.

Shelley still has a lot left to give to her family, especially her grandchildren, and her community. All she needs is a kidney.

So Shelley Fyman has certainly done for others and is now looking for someone to do unto her, by donating a kidney. As she put it so well in an address to her congregation in 2013:

The solution is another kidney. A new kidney, OK, maybe not new. Slightly used would be OK too. A side helping of pancreas would be nice, but I'm not greedy. Just a live-donor-lightly-used kidney, like one of the pair you were born with.

She encourages all dialysis patients to be aggressive advocates on their own behalf and maintain their positive activities loud and clear.

Upcoming Events

Wednesday, February 10, 2016 – LONG ISLAND TRIO AT THE MOVIES – Join us we watch *The Power of Two*, the story of twin sisters who underwent double lung transplants, to be followed by a discussion – 7:00 PM – 145 Community Drive, Manhasset – **Special Guest Speaker – See box on next page**

Wednesday, March 9, 2016 – LI TRIO General Meeting – Lionel U. Mailloux MD, Internal Medicine and Nephrology, North Shore University Hospital and Glen Cove Hospital – 7:00 PM – 145 Community Drive, Manhasset – **Special Guest Speaker – See box on next page**



The 13th annual Donate Life float in the January 1, 2016 Rose Parade taught us to "Treasure Life's Journey," the theme of this year's float. The float featured 52 men and 44 women whose own journeys have been touched by the incredible gift of organ donation and transplantation.

February Re-Birthdays

Leroy Boison	February 7, 2013	Heart
Robert Carroll	February 1, 2006	Liver
Carl Caruso	February 18, 1998	Kidney
Keith Dobish	February 21, 2001	Kidney
Mary Graffeo	February 23, 2009	Kidney
Joanne Kellner	February 6, 2014	Kidney
Grace LaBarbera	February 26, 1991	Liver
Mak Steinbock	February 26, 2010	Liver
Larry Swasey	February 6, 1988	Heart

March Re-Birthdays

Gerald Blessinger	March 6, 1992	Liver
Romina Sanchez Burgos	March 7, 1988	Liver
Ed Burki	March 28, 2000	Kidney
Rosalie Collura	March 28, 1992	Heart
Gerard Eichhorn	March 6, 1991	Kidney
Marge Fiore	March 1, 2012	Heart
Carol Heins	March 17, 2008	Kidney/Pancreas
Alan Leavy	March 2009	Kidney
Robert Seeback	March 17, 1996	Heart
Lauren Shields	March 19, 2009	Heart
Steven Taibbi	March 27, 2001	Heart
Kyriakos Tsempelis	March 24, 2009	Kidney

Have You Moved?

Changed your email address? Changed your phone number? Added a cell phone number? Had a transplant?



We would love to keep in touch with you but we need your help in staying current. If there have been any changes in your situation such as the above, please get in touch with us by email at litrionews@gmail.com or by calling the hotline at (516) 620-5900.

Suffolk County General Meeting

Long Island TRIO conducted its second meeting at Stony Brook University Hospital on November 21, 2015. Our organization is attempting to spread its wings further east by reaching out to transplant recipients, candidates, families, and supporters in Suffolk County. Stony Brook University Hospital has been the gracious host for our meetings. **Dave Rodgers** submitted the following report:

The Suffolk County fall meeting was on Saturday November 21 with 33 attendees plus staff from the Stony Brook Transplant team and Karen Cummings of LiveOnNY. Dave Rodgers gave an overview to the audience discussing LI TRIO's role in promoting advocacy, awareness, education and support of organ donation and transplantation. Dave also shared LI TRIO activities like the Rose Garden, meetings in Suffolk and Nassau, the Holiday Party, Newsletter, Website, and legislative issues. **Jeff Fenn** gave an overview of the LI TRIO School Speaker program.

Margaret Valsechi gave a presentation from the point of view of a donor mom and what the Gift of Life can do.

Our guest speaker was Frank Winter from CMS NY (Center for Medicare & Medicaid Services). His subject was *How to Manage Medicare in 2015 – 2016*. Topics included:

- Insurance options
- Health plan highlights
- Enrollment Plan coverages and penalties
- Immunosuppressive drug coverage
- Four parts of Medicare and enrollment
- End stage renal disease
- Advantages plans
- Medicare Rx plans coverage and cost.

Frank then opened it up for question and answers. He noted that each individual situation could be different, so responses were generalized. Frank left his contact information if someone had additional questions.

Special Guest Speakers

Long Island TRIO's February and March General Meetings will include very special guest speakers. In February, before the movie, **Ernesto Molmenti**, Vice Chairman of Surgery, Director of Transplantation, Professor of Surgery and Medicine, Hofstra North Shore-LIJ, will provide opening remarks. The March meeting will include a presentation by teenager **Martin W. Clarke Jr.**, organ donation advocate and trainer of others who wish to promote the Gift of Life. Martin was the subject of the June 2015 LI TRIO Newsletter's Transplant Profile.

LI TRIO at Borough of Manhattan Community College

Professor **Sophia Aidiniou** from the Borough of Manhattan Community College's Health Education Department has teamed up with the LiveOnNY and Long Island TRIO organizations in order to educate the Borough of Manhattan Community College (BMCC) students through peer education to increase enrollment in the New York State organ donor registry. Students volunteer 10-15 hours of their time to learn how and why organ donor awareness is important. Ever November since 2013, we have raised the awareness of thousands of students. One organ donor can save up to eight lives. One tissue donor can save or improve the lives of up to 50 people.

Dave Rodgers



(left to right) Dave Rodgers - LI TRIO, Jennifer Lentini - heart recipient, Professor Sophia Aidiniou – BMCC, Dr. Ernest Patti - Sr. Attending Physician of Emergency Medicine, St. Barnabas Hospital, Bronx NY

School Speaker Program Resumes

Long Island TRIO's School Education Program is a highly successful activity where thousands of high school students get to hear from transplant recipients and their supporters about the benefits of organ donation. The program has concentrated on Nassau County schools in the past but has more recently expanded into Suffolk County as well. **Jeff Fenn**, the school program coordinator, recently addressed the cadre of speakers who provide living examples of the benefits of organ transplantation:

We have been blessed and given a very special "gift". Telling our stories and making others aware of the impact that it's had on our lives is so important.

I just want to take this opportunity to thank you for all your help with the LI TRIO School Education Program. We continue to reach thousands of students each year and hopefully make an impact on them. We have spoken to over 3,000 students so far this year. There is no way that we could accomplish so much without your help.



Mel Lerner speaks to Syosset High School students

For those of you celebrating Christmas, I want to wish you and your families a very Merry Christmas and time with friends and family.

And to all, wishing you and your families a

Happy and Healthy New Year.

Here's to 2016 may it be a great and healthy year for all. May it be a better year than the one before.

Letters to the Editor



Walter Ruzek is the hard-working treasurer and serves on the Board of Directors of Long Island TRIO. He had the following kind words regarding the December 2015 LI TRIO Newsletter:

Hi Howie
We just received the newsletter and I want to let you know how wonderful it is. It's really packed

with stories and items that I'm sure our members will appreciate. The photos really enable a visualization of the stories. Great review of The Tin Woman.

If you wish to share any comments about the Newsletter or thoughts for future articles, please contact the editor at litrionews@gmail.com.

As of January 25, 2016 there were 121,670 candidates for transplant, according to the United Network for Organ Sharing (UNOS). In New York State, there were 10,289 candidates awaiting a transplant.

One Year Since UNOS Changed Kidney Allocation Rules

Editor's note: The methods by which kidneys are distributed to those awaiting a transplant were changed about one year ago by the United Network for Organ Sharing (UNOS). An Associated Press Medical Writer, Lauran Neergaard submitted the following article which appeared in several news outlets, assessing the effects of the new allocation regulations:

WASHINGTON (AP) — A shake-up of the nation's kidney transplant system means more organs are getting to patients once thought nearly impossible to match, according to early tracking of the new rules.

It's been a year since the United Network for Organ Sharing changed rules for the transplant waiting list, aiming to decrease disparities and squeeze the most benefit from a scarce resource: kidneys from deceased donors. Now data from UNOS shows that the changes are helping certain patients, including giving those expected to live the longest a better shot at the fittest kidneys.

The hope is to "really level the playing field," said Dr. Mark Aeder, a transplant surgeon at University Hospitals Case Medical Center in Cleveland who is chairman of the UNOS' kidney committee.

In Abingdon, Virginia, 8-year-old Marshall Jones was one of the lucky first recipients. A birth defect severely damaged his kidneys and a failed transplant when he was younger left his immune system abnormally primed to reject kidneys from 99 percent of donors.

Then last January, after four years of searching, organ officials found a possible match, hours away by plane but available under the new policy — and it worked.

"We don't use the word lightly, but this was really a miracle kidney for him," said Dr. Victoria Norwood, Marshall's doctor and the pediatric nephrology chief at the University of Virginia.

There's a huge gap between who needs a new kidney and who gets one. More than 101,000 people are on the national waiting list, while only about 17,000 kidney transplants are performed each year. Roughly 11,000 of them are with kidneys donated from someone who just died; the rest occur when a patient is able to find a living donor.

The wait for a deceased donor kidney varies widely around the country, and in 2014, more than 4,500 people died before their turn.

The new kidney allocation system can't alleviate the overall organ shortage. "The only thing to shorten total wait time for everybody is more organ donors," Aeder said.

Instead, the policy altered how deceased-donor kidneys are distributed, shifting priorities so that how long you've been on the waiting list isn't the main factor. Among the changes:

—fewer transplants are occurring in which the kidney is predicted to outlive the recipient. Now, the kidneys expected to last the longest — as calculated by donor age and medical history — are offered first to the patients expected to survive the longest. That's called longevity matching. Before the change, 14 percent of the longest-lasting kidneys went to recipients age 65 or older. That dropped to 5 percent as the new policy kicked in, according to UNOS monitoring.

—the less time spent on dialysis, the better patients fare after a transplant. Yet where you live still plays a big role in how quickly you're put on the transplant list, with minorities and those in rural and poorer areas spending more time on dialysis first. The new policy gives people credit for that dialysis time, moving them up the waiting list, and boosted transplants among long-time dialysis users, UNOS found. In turn, transplants inched up among African-Americans, who spend disproportionately more time on dialysis.

—then there are those hardest-to-match patients such as Marshall, about 8,000 of them now on the waiting list. The new policy gives them special priority for organs that can be shipped to a wider area of the country than other kidneys, broadening the search for a super-rare match.

As a result, the percentage of transplants among those patients has risen nearly fivefold, UNOS senior research scientist Darren Stewart said.

UNOS is tracking the changes closely to look for unintended problems because more transplants for one group can mean fewer for another. For example, adults younger than age 50 are getting more kidneys since the rule change, but older patients still account for about half of transplants.

Another question is how the new policy will work long term as a backlog of the special-case patients starts to clear.

"All of a sudden you got a floodgate that opens because you gave these people a big advantage and you're shipping kidneys across the country to them," said Dr. John Roberts, transplant chief at the University of California, San Francisco, one of the largest kidney programs. He praised the rule change but said it may need some fine-tuning.

For example, the new policy also offers wider access to the kidneys expected to last the shortest amount of time, because the oldest or sickest patients might choose one for a quicker transplant rather than gambling that a fitter one will become available. But, "we don't have a great way to predict what's coming for a patient" to help them decide, Roberts said. Discards of those less-fit kidneys temporarily increased a bit as the new policy began.

Stay tuned. Transplant centers are learning to handle the logistical hurdles of shipping more kidneys around the country, potentially opening additional avenues to alleviate geographic disparities, Aeder said. "There's much more to come."

December General Meeting



Dr. Lewis Teperman,
NYU Langone
Medical Center

Our guest speaker at Long Island TRIO's General Meeting was **Dr. Lewis W. Teperman**. He is the Division Chief of Transplant Surgery and an Associate Professor in the Department of Surgery at New York University's Langone Medical Center. Dr. Teperman has presented several times at LI TRIO and is always an informative and entertaining source of transplant information and news.

He started by reporting on the most extensive face transplant done to date, at NYU in August 2015. The surgery extended over two days and took twenty-six hours.



NYU's Face Transplant Team

Dr. Teperman's emphasis at this meeting was the disparity between waiting times for organs in different parts of the country and what could be done about it. He noted that, despite the best efforts of New York organ donation organizations, the number of organs available to New York hospitals for transplants was still low and not nearly high enough to accommodate those waiting for a transplant.

Dr. Teperman cited the map of organ distribution as the source of the disparity of allocations, and noted the poor design of Donation Service Areas (DSAs) which determine how organs are donated geographically. He proposed to reduce the number of DSAs from the current eleven to four, to make organs more available to those in greatest need.



Dr. Teperman expressed regret at losing his LI TRIO umbrella from a previous meeting but received a tote bag this time with the promise of a new umbrella at his next appearance (with President Joy Oppedisano).

As usual, Dr. Teperman engaged his audience by encouraging interaction and expertly answering all questions directed toward him.

LI TRIO Visits Lindenhurst High School

Long Island TRIO school speakers **Allison Pohl McRae** and **Ruth Pohl, Dave Rodgers**, and **Bobby Seeback** delivered presentations on the benefits of organ donation and transplantation to health classes at Lindenhurst High School on December 3, 2015. Dave presented the facts and statistics concerning organ donation and transplants and an overview of the need for educating the public, while identifying two local high school heroes who became organ donors. Bobby related his almost 20 years with a second chance because of the gift of life bestowed on him through organ donation and how he has paid it forward with the birth of his twin boys. Ruth walked through the steps of her journey noting the challenge for her family as a mother and wife. Then Ruth spoke of the reward of her transplant, some twelve years later watching her daughter Allison get married, and now expecting her first grandchild.



(from left): George Smalley-health teacher, Allison Pohl, Ruth Pohl-transplant recipient, Linda Flannery-Assistant Principal, Dave Rodgers-recipient at Lindenhurst High School

Her daughter Allison, a Lindenhurst High School graduate, then presented the point of view of the daughter wanting to do anything and everything to save her mother's life. Allison gave a detailed sequence of events, sharing

the emotion and drama of her mother's rollercoaster ride, including her own testing to be the donor. Allison summarized the ordeal of her mother's journey finally saved by the generosity of a 20-year old young lady, the same age as Allison at the time, whose untimely death led to the donation of her liver to Ruth. The students, health teachers and the Assistant Principal thanked them for sharing their knowledge, compassion and their personal stories.

January General Meeting

The General Meeting of January 13, 2016, marked the first meeting of the new year and was a change of pace from the more typical meeting, where a transplant medical specialist is the guest speaker. For this meeting, the topic was tissue donation and the gift of sight. The featured presenters were **Gary Harris**, the Director of the Donor Center for LiveOnNY, and **Amanda Vesey-Askey**, Hospital and Community Liaison for the Eye-Bank for Sight Restoration. Both presented fascinating information about subjects that the membership does not usually hear about.



Gary Harris, LiveOnNY

Millions of recipients benefit from tissue donation, which may include corneas or entire eyes, skin, or heart valves. Because so many of the medical considerations which make organ donation difficult are not present in tissue donation, the latter is much more commonplace. One tissue donor can help up to a hundred recipients. Skin may

repair severe burns, hernia repair, breast reconstruction, and is taken from non-visible areas. Heart valves may replace defective valves and help those suffering from congenital heart failure. Bone donations may allow for a pain-free life and prevent future amputations. Mr. Harris' unit within LiveOnNY serves as donor coordinators, taking hospital referrals, approaching and screening potential donors, and then placing the donations with recipients. Tissues are evaluated for infection and/or cancer, suitability determined by age and medical criteria; the goal is to restore the body to its natural state. Tissues are stored in quarantine and donation should take place within 12 to 24 hours.

Ms. Vesey-Askey reviewed the various eye diseases for which eye and cornea donations are appropriate, including injuries and infections, Peter's Anomaly

(opaque vision at birth), keratoconus, and Fuch's dystrophy. The first corneal transplant took place in 1905; there are now 1000-1300 cornea transplants per year, and 60,000 individuals have now had vision restored.



Amanda Vesey-Askey, Eye Bank of New York

President's Corner

February is notably the month of worldwide heart awareness and Valentine's Day.

Valentine's Day, February 14, is a day that we remember those we love.

Many are showered with chocolates, flowers, gems and cherub adorned heart shaped cards. It is also National Donor Day. The Health Resources & Services Administration has designated this day, where love abounds, as a day of reflection and awareness of those that gave the gift of life, as well as those waiting.

So as we celebrate our love of those who are special it is indeed another opportune time to include those who have given life and their families, as well as those waiting for transplants. Many recipients honor their donors each day in some way by their thoughts and even more so by their actions. Some give back by volunteering, helping others, and sharing the life saving message. Each recipient is unique and their appreciation is extended in different ways.

This year, 2016, is also a little different. We are given an extra day in February! It is a leap year! Thanks to Julius Caesar and his astronomers an extra day was added to the second month of the year every four years. This was done so that the solar year and calendar year could be synchronized. It is amazing that the foresight to do this was done in the year 46 B.C.

So, happy leap year 2016!

Enjoy this extra day.

Make the most of the extra 24 hours.

Make it count.

What will you do?

Joy Oppedisano

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