

Thomas Starzl founder of transplantation passes away at 90 – see this issue

Next General Meeting: Wednesday April 12

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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Transplant Profile: Mary Graffeo

PKD has ravaged my family. My grandfather, aunts, uncle, father, and brothers all died - young - from it. Today, I have my sister and one brother left (transplanted in 2011). I decided that PKD would never get me. What follows is the story of my odyssey through transplant - and back.

After 17 years with a nephrologist who never mentioned the word "transplant," my new life began, very auspiciously, on August 26, 2008, the day that I arrived at the North Shore/LIJ Transplant Center for evaluation for a kidney transplant.

Meeting **Dr. Ernesto Molmenti**, **Dr. Madhu Bhaskaran**, and the whole transplant team was very exciting. For the previous two years, I had been searching for a living donor and having tests at a different hospital while watching my steadily-rising creatinine. Thanks to my new nephrologist **Dr. Lionel Mailloux**, I was still healthy enough to stay off dialysis, my biggest fear, as I had seen the process with my father, who was the first experimental dialysis patient on the first hemodialysis machine on Long Island, from 1964 until his death in 1968.

At the NS/LIJ Transplant Center, I was told that I had to have a number of tests, the appointments for which were all made immediately and soon

accomplished. Then we discussed my donor, my sister **Valerie Heslar** who, disqualified by the first hospital, was found to be a good match for me at North Shore, but for the fact that she was 35 pounds overweight. The team dietician and a transplant coordinator worked with Valerie so that she could lose that extra weight. She then finished all her tests, and was cleared for surgery.



Thus, on February 23, 2009, Valerie and I entered North Shore University Hospital together, and the transplant was done at 7:30 AM that morning. I remember joyously

hopping up onto the operating table in great anticipation of my surgery and with complete confidence in Dr. Molmenti. **Dr. Louis Kavusi**, the inventor of the laparoscopic nephrectomy, performed my sister's surgery, so that Valerie has only a small scar to mark the occasion of her donation to me. I left the hospital just 48 hours after my transplant, and have not had one problem since!

How thankful I am for this transplant, for giving me back my life - and my future! Each morning, I wake up just so excited to be able to

do whatever I want and to have all the energy I need to do it - something I couldn't say for the first 60 years of my life! I can now eat anything I want and go wherever I please.

Since my transplant, I have travelled to the Caribbean several times, Alaska (2009, 2001), twice to Phoenix, Arizona, Bermuda (2012), three trips to Canada, and to my VERY FAVORITE PLACES - the Mediterranean and Adriatic countries of Europe (2013, 2015). Most of my vacations are cruises on the Queen Mary 2, the Queen Victoria, and several Princess ships. Upcoming cruises are planned for this



Mary and Mason aboard the Queen Mary2

year and next, to the Mediterranean again, and one more trip to Canada. Mason has already made dinner reservations at our favorite restaurants in Florence, Rome, and Venice! Yes, I do love to travel!

My wonderful transplant has also allowed me to engage more in my favorite hobbies. Since 1973, I have done much crewelwork, and in 2009, I decided to join the Long Island chapter of the Embroiderer's Guild of America, so that I could learn the advanced needlework techniques of goldwork and stumpwork. While there, I met a master knitter, my friend Erika, who taught me to knit, which I have practiced and studied daily for over three years.

As a teacher, I am always looking for new things to learn, and have found many opportunities to do so. The Great Courses have given me much joyful knowledge, from the most superb professors, in every conceivable subject area - Art, History, Science, Needlework, Music, Photography, Archaeology, Literature, Health, Cooking, etc. I have also taken online courses and made projects from Craftsy, Needle 'nThread, and CreativeBug, and heard interesting lectures, via iTunes, from Oxford, Cambridge, Harvard, and Princeton Universities, the Metropolitan Museum, etc. Then, there are the Audiobooks which I "read" while doing needlework and knitting! I have also amassed a large "library" of Ebooks in my Kindle apps!

There's a whole world of knowledge out there that I can study and put into practice!

While studying and researching, I wrote my second Early Childhood textbook, "Humanities for Kindergarten," as a hardcopy and an Ebook. Research also takes me daily into new areas of information on transplantation, drug trials, usage, and side effects, and health in general. My brother and I attend LI TRIO meetings, to learn all we can in order to keep our grafts healthy, along with sticking closely to our medication schedules.



Mary and Margie Ng-Reilly spread the word about organ donation

Before my transplant, I searched everywhere for someone who had been through the

transplant process, to talk to and to answer my many questions.

There was no one available at that time. Today, I delight in talking to people - especially prospective transplant patients - about transplant and what to expect from it. I have also spoken at various transplant events, at dialysis centers, and to patients "in the pipeline" for transplant at the North Shore/LIJ Transplant Center, during the monthly Transplant Discussion Group meetings. In the eight years since my transplant, I have learned much, the sharing of which I hope will help others on their own transplant journey.

Life after transplant is just fabulous! There is nothing that I may want to do that I can't do! Mason and I enjoy dining at fine restaurants - several times a week! Being able to eat anything I want is truly fantastic! Food and wine just taste better since my transplant!

During my teaching career, I was always exhausted - all day, every day - and would come home without even enough energy to play with my parrots. I couldn't even stay awake past 9:00 PM on New Year's Eve! Now, I'm on the go all day, sometimes until 2:00 AM, doing everything I want or need to do. My parrots play all day with me and all the toys I make for them!

My transplant life is just one exhilarating day after another!!!

Upcoming Events

Saturday, April 8 – American Liver Foundation Re-Birthday Celebration of the gift of life and the miracle of liver transplantation – 10:00AM – Homewood Suites, Carle Place – Speaker: Lewis Teperman MD, FACS, Northwell Health –phone (646) 737-9408 for more information

Wednesday, April 12 – General Meeting –Speakers from NewYork-Presbyterian/Columbia Univ Medical Center–Jen Reilly, Chief Nurse Coordinator, Lung Transplantation, Carlo Baldasare, Clinician-7:00 PM – 145 Community Dr, Manhasset

Saturday, April 22 – Remember and Rejoice – St. Patrick’s Cathedral – 2:00-4:00PM - Donors and recipient speakers, spiritual leaders, music, singing and a dedication to our donors and their families during a candle lighting and white rose distribution ceremony.

Saturday, May 6 – National Kidney Foundation Kidney Walk – Eisenhower Park - raises awareness and funds lifesaving programs that educate and support patients, their families and those at risk – more info at (212) 889-2210 x 296

Wednesday, May 10 - General Meeting - Lewis Teperman MD, FACS, Northwell Health - 7:00 PM – 145 Community Drive, Manhasset

Saturday, May 13 – American Liver Foundation Liver Life Walk – Eisenhower Park -9:00AM - *One Step. One Walk. One Future... a future without liver disease.*

April Re-Birthdays

Fran Addazio	April 11, 2002	Kidney
Taylor Clarke	April 20, 2016	Heart
Gillian Cohen	April 17, 2005	Liver
Margaret Gonzalez	April 18, 2002	Kidney
Kristen Margolies	April 22, 2010	Bone Marrow
Kate Mayerhofer	April 1, 2010	Kidney
Iris Pappalardo	April 26, 2012	Kidney
Sandrajane Rios	April 16, 2008	Liver
Mark Sakitt	April 18, 2014	Kidney
Christian C. Siems	April 25, 2015	Heart
Robert Skaretka	April 28, 1991	Heart
Steven Taibbi	April 9, 2001	Heart

May Re-Birthdays

Ralph Greener	May 8, 2008	Kidney
Victor Haymer	May 1, 2014	Kidney
Melvin Kershner	May 29, 2009	Kidney
Leslie Kreisman	May 5, 2000	Kidney
Hopeton Lue	May 30, 2000	Kidney
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

As of March 25, 2017 there were 118,274 candidates for transplant, according to the United Network for Organ Sharing (UNOS). In New York State, there were 9,560 candidates awaiting a transplant.

Living Donor Support Act ...makes its way to becoming a law

The Living Donor Support Act is making its way through both houses of the New York State legislature on way to becoming a law. Long Island TRIO’s **Mike Sosna**, Legislative Policy and Public Initiatives Coordinator, has followed and enhanced the progress of this bill (Senate Bill S2498 and Assembly Bill A05475) which provides state reimbursement to living organ donors who are state residents, for medical and associated expenses incurred as a result of the organ donation, when the organ donation is made to another resident of the state; and requires the provision of information on transplantation to patients with severe kidney disease. This bill would increase living donation by removing financial barriers and educating the public about living donation. It would provide reimbursement for living donors who are residents of NY and who make a living donation in which the ultimate recipient is also a NY resident. Eligible reimbursement would include financial costs incurred by living donors as a result of living donation, including lost wages, sick and vacation

days, child care, or medical expenses. This bill has been endorsed by a broad coalition of stakeholders including the Greater NY Hospital Association, Northeast Kidney Foundation, Long Island Transplant Recipients International Organization, and Mt. Sinai Hospital. The bill was sponsored in the State Senate by Sen. Kemp Hannon and co-sponsored by fifteen other senators.

On February 7, The Senate Health Committee unanimously voted and moved the bill to the Finance Committee. On February 10, the Act was introduced in the New York State Assembly with 26 co-sponsors and assigned a Bill Number in the Assembly. On March 1, the Assembly Health Committee reported the bill favorably to the Ways & Means Committee.

For this bill to become law, our representatives still need to be prodded to take action. Not only is this bill important as a promoter of living donation, it will thereby enhance the chances of those on the waiting list for deceased donation. If you believe that this law would boost living donation rates, you should contact your state representatives and urge them to move the bill forward and give it their full support.

LI TRIO at Hofstra Northwell School of Medicine



Every year, members of Long Island TRIO are invited to speak at the **Hofstra Northwell School of Medicine**. Two liver recipients, **Gillian Cohen** and **Dave Rodgers**, as well as donor mom **Kelli Cutinella**, educated the first-year medical

students on the issues of organ donation and transplantation. They shared their life stories and told how organ donation had affected them. There was an open question-and-answer session and then the medical students were separated into groups to discuss means by which more individuals would be open to donate their organs. Incentives to organ donation were proposed and discussed including insurance coverage, payment for funeral services, etc. Dave Rodgers reported that it was a tremendous day of interaction with future doctors, which received tremendous support from Transplant Services senior members **Lewis Teperman MD**, director of organ transplantation, **David Bernstein MD**, Chief of Division, Hepatology of Medicine, and **David Marcus MD**, Assistant Professor of Emergency Medicine.

Dr. Thomas Starzl Passes Away at 90

Editor's Note: The following article appeared on the bbc.com website on May 5, 2017. We in the transplant community mourn the death of the person who performed the first liver transplant, created the regimens for immunosuppressive drugs, and mentored countless professionals who carry his standard of excellent care.



Thomas Starzl, the man who performed the world's first liver transplant, has died days short of his 91st birthday.

The American surgeon pioneered the procedure in 1963, but his first patient did not survive.

After creating a new blend of anti-rejection drugs, he carried out the first successful transplant in 1967. Since then, thousands of lives have been saved by the procedure.

He died at home among his family, a spokesperson said.

In a statement, the University of Pittsburgh, which he joined in the 1980s to work on his drugs research, said Dr Starzl was known as the "father of transplantation" for his work in advancing the surgery from "from a risky, rare procedure to an accessible" one.

'A great human'

In addition to performing the first successful liver transplants, he experimented with transplants from cadavers, and refined the process by using identical twins and blood relatives.

He also pioneered animal-to-human liver transplants, including baboon to human experiments, which he showed could briefly extend life when there was a shortage of human organs.

His family issued a statement saying he "brought life and hope to countless patients".

"He was a pioneer, a legend, a great human, and a great humanitarian," it said.

"He was a force of nature that swept all those around him into his orbit, challenging those that surrounded him to strive to match his superhuman feats of focus, will and compassion."

Dr Starzl was also known for his research work on developing anti-rejection drugs. He blended azathioprine, a

drug which suppresses the immune system, with steroids to aid in his pioneering transplants in the 1960s.

His research later in life would lead to the acceptance of improved drugs including cyclosporine and tacrolimus.

He retired from clinical work in 1991 and published his autobiography, *The Puzzle People*.

In it, he revealed that despite all his accolades, he felt a great anxiety about actually performing surgery.

"I had an intense fear of failing the patients who had placed their health or life in my hands," he wrote.

"Even for simple operations I would review books.... then, sick with apprehension, I would go to the operating room, almost unable to function until the case began."

"Instead of blotting out the failures, I remembered these forever," he said.

16-17 Year Olds Can Now Donate

The law allowing 16 and 17 year olds in New York State to make an anatomical gift went into effect on February 14. The NYS Senate and Assembly passed S5313A/A4990B which was signed by Governor Cuomo on August 16, 2016. The bill went into effect 180 days after it was signed. It allow New Yorkers age 16 or older who wish to consent to donate the ability to enroll in the New York State Donate Life Registry, while preserving the parent's ability to give final authorization should the under aged individual be considered for organ, eye or tissue donation. The bill was sponsored by **Senator Kemp Hannon** and its passage promoted by Long Island TRIO and other organ donation organizations throughout the state. As Assembly Assistant Speaker **Felix W. Ortiz** said at the time, "Right now, there are so many New Yorkers in need of this lifesaving gift and this law plays an important role in expanding New York State's Donate Life Registry so ill New Yorkers can be connected with the organs they so desperately need. Many young adults would like to be able to become an organ and tissue donor." The legislation will allow New Yorkers who apply for a learner's permit at age 16 or 17 to also register for the NYS Donate Life Registry, subject to their parents' approval until they turn 18.

February General Meeting



We were privileged to have as our guest speaker in February **Dr. Daniel Glicklich MD**, a specialist in nephrology at the Westchester Medical Center Transplant Center. Dr. Glicklich is well known for his work and academic interest in complications and management of chronic renal failure following transplantation. His topic on this night was kidney disease, nephrotoxicity, and other new information related to kidney disease.



Dr. Glicklich characterized nephritic syndrome as the excretion of protein in the urine; the more protein excreted, the worse the condition. The total protein to creatinine ratio should be 0.1. For those with nephritic syndrome, the ratio can be 3.0.

The presence of proteinuria (excess proteins in the urine) is most often caused by diabetes. Kidney diseases may be characterized as affecting either the glomerulus or the tubular, with most affecting the former. A primary disease will only affect the kidneys, an example of which is FSGS, causing serious scarring which leads to permanent kidney damage and even failure. FSGS will require five to ten years of dialysis and may reoccur.

ACE inhibitors and other drugs may reduce protein excretion. Such drugs can delay progression of the disease before a transplant is required. A kidney biopsy is used to diagnose kidney disease. Dr. Glicklich stressed the imperative to avoid overuse of NSAID pain relievers (aspirin, ibuprofen, naproxen) as multiple doses may cause problems for those with heart, kidney, or liver issues.



Meeting moderator Dave Rodgers (left) with Dr. Glicklich and two of his patients Mike Sosna and Kathie Gerlach

As usual, the LI TRIO audience members had a number of questions regarding their individual problems that were ably addressed by Dr. Glicklich. He commented favorably on the potential for stem cell procedures, either the growth of organs or for injections into organs, which is projected to take place in the next ten to twenty years. He spoke of survival after kidney transplants: FSGS can be treated with drugs, improving survivor rates. There is no treatment, however, for glomerulopathy following a transplant. 30% of kidney transplant recipients become diabetic. Malignancy will cause protein excretion.

Dr. Glicklich advised that the best way to reduce protein is to eat a vegetarian diet. Avoidance of meat will result in a lesser incidence of kidney and cardiovascular disease.

February Meeting at Stony Brook

(Editor's note: Long Island TRIO has continued its efforts to expand its outreach into Suffolk County. Meetings are held periodically at the Stony Brook Transplant Center in East Setauket. On February 18, two expert speakers – **Frank Darras MD**, Medical Director of Stony Brook Transplant and **Steve Knapik**, Living Donor Coordinator at Stony Brook – spoke on the subject *How to Champion Your Own Living Kidney Donor*. **Dave Rodgers**, the coordinator of the Suffolk meetings, submitted the following highlights)

- 🌳 Always direct anyone interested in learning about live kidney donation to the transplant professional;
- 🌳 All conversations between the living donor coordinator and the potential live kidney donor ALWAYS remains confidential;
- 🌳 Living donor coordinators will have direct communications with the potential Kidney Donor.

How to find a Living Kidney Donor:

- 🌳 Share your story with friends, family and community;
- 🌳 Talk to your family about who can be your spokesperson or champion;
- 🌳 Send a letter about your need for a living donor to family, friends, and places of worship;
- 🌳 Let your community know about your need for a transplant and that living donation would provide you with the best outcome.

The meeting was well attended and there was time for questions and answers, since most were new to this initiative.



Also at the meeting LI TRIO members **Dan** and **Pat O'Neill** shared their touching story of living donation. Pat gave Dan one of her kidneys; Dr. Darras was one of the physicians involved with the transplant.

March General Meeting

Long Island TRIO's March General Meeting was unique in the fact that it featured a team of surgeons from the Transplant Center of Northwell North Shore University Hospital. The audience got to hear a variety of perspectives from the individual doctors, who were also very enthusiastic about their collaborations toward improving transplant procedures.



Before the doctors spoke, we heard from **Amanda Vesey-Askey**, the Hospital and Community Liaison at The Eye-Bank for Sight Restoration. Amanda emphasized that almost anyone can be an eye donor, that there were only a few conditions that ruled out eye donation. The Eye-Bank has been in existence since 1944 and has vast experience in donation procedures.



Before the Northwell doctors spoke, we heard from **Nicholas Ginzburg**, the Senior Administrative Director of the new Sandra Atlas Bass Center for Liver Diseases at Northwell Health. Mr. Ginzburg provided a lucid overview of the Northwell system, which now includes 21 hospitals, a medical school, nursing school, and a pharmacy. He described his own reasons for being part of the transplant team, which included the opportunity to see patients on a continual basis long after their transplant, to see them prosper, and meet their families. He is helping to build Northwell's liver transplant program, which is slated to begin in 2018.

Mr. Ginzburg identified liver disease as a silent killer, as the patient does not know of it until symptoms appear late in the process. Five to seven million people have hepatitis C, two to three million are afflicted with hepatitis B, and fatty liver disease and liver cancer are increasing in incidence. In 2016, the Sandra Atlas Bass Center for Liver Disease was created and is currently focused on recognition of liver disease, education, and research.

President's Corner

As the season changes and we embrace springtime, Donate Life Month, Volunteer Appreciation Month, and Mitzvah Season, I can think of no better time to say thank you.

Thank you to our corporate sponsors.

Thank you to our Celebration of the Season sponsors.

Thank you to our event sponsors, contributors, supporters, volunteers, and attendees.

None of our events would be successful without you!

Thank you in advance to those who come forward with ideas, those interested in participating in events, our school speakers program, community events, awareness events, and invite others to join our special group.

Your participation and personal commitment enhances our mission. More lives are saved and touched by the caring actions of each and every one of you.

As a TRIO family we share our time with each other, our happy moments, our sad moments and our wisdom with each other. I would like to share the following lovely thoughts with you dear members.

As TRIO members we have learned how much we can accomplish together.

As TRIO members we have learned that friendships made, and support that is extended, are priceless.

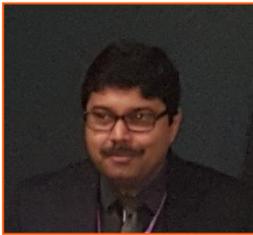
As TRIO members we have learned that lives can be saved by love.

As TRIO members we have learned that gifts of life and love come in many sizes and shapes.

It's National Donate Life Month

Donate Life Blessings Month to You!

Joy Oppedisano



Clockwise from upper left: Ernesto Molmenti MD, Vinay Nair DO Nephrology, Ahmed Fahmy MBBCH, Aaron Winnick MD and Madhu Bhaskaran MD

Each doctor spoke, spearheaded by **Dr. Ernesto Molmenti**, the Vice Chairman of Surgery, Director of Transplantation, Professor of Surgery and Medicine, Hofstra North Shore-LIJ - North Shore University Hospital. Dr. Molmenti portrayed Northwell as an already highly functional unit with great promise of transforming transplant procedures for Long Island. He cited the hiring of **Dr. Lewis Teperman**, formerly of NYU Langone Medical Center, as director of transplant surgery as a boost to the program's status (Dr. Teperman will be the guest speaker at LI TRIO's May General Meeting). **Drs. Madhu Bhaskaran, Ahmed Fahmy, Vinay Nair, and Aaron Winnick** took turns describing their roles at Northwell. The doctors spoke of future innovations, such as the single port donor nephrectomy and preservation machines which will facilitate and improve the transplant procedure. The single donor port nephrectomy will minimize incisions; the preservation machines use warm preservation to extend the shelf life of organs. Stem cells may help to repair and improve organ function.

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