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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 2019

Transplant Profile: Kristin Quatrale

It's All About the Community



When **Kristin Quatrale** and her older brother **Keith** both needed a kidney in 2000, their East Patchogue community stepped up in a big way. Community members rallied behind the Quatrale family to help defray the costs associated with the two transplants to ease the enormous

financial burden. The Congregational Church of Patchogue, to which the Quatrale family had belonged for many years, sponsored a benefit brunch at the local Knights of Columbus Hall, to which six hundred people were invited. As **Nan Cozine**, one of the co-chairs of the brunch said at the time, "We know the great-grandparents, the grandparents, the parents are active members and the children have been acolytes of the church and attend when they could, Sunday School." In a remarkable gesture of community support, I was shown a large brown envelope that arrived during that time which contained \$4,000 in small bills; the return address included the name *A. Friend* and the return Patchogue

address was fictitious. A note read "Let's go forward each day."

KeySpan, where parents **Paul** and **Janice Quatrale** worked at the time, also did a benefit. Long Island TRIO Board of Directors member **Margie Ng-Reilly**, a two-time kidney recipient who also worked at KeySpan then, reached out to the family and greatly helped them through the transplant experience. Kristin's dad Paul says they will always have a connection with Margie and husband **Tom**.

In 2001, Paul, Kristin's and Keith's father, gave a kidney to his daughter, while Janice, their mother, did the same for Keith. The children were 9 and 12 years old respectively. Both children suffered from familial juvenile nephronothosis, a genetic disease that results in life-threatening kidney failure. Before their transplants, both were connected to dialysis machines for ten hours every night, and sometimes had to sleep or finish their homework while hooked up to the machines. Paul and Janice had to frequently shuttle the children back and forth to Stony Brook University Hospital during bouts of infection. The case of two parents donating kidneys to their two children received much attention at the time, in major newspapers and well as local ones, as evidenced by the pile of yellowing papers that Paul has kept

all these years and brought out when I visited their home.

Unfortunately, Kristin's kidney did not fare very well and she soon needed another one. The community, in the form of a next-door neighbor, stepped up again. **Mary Kate Goff** donated her kidney to Kristin in 2004. As Mary explained at the time, she had no fear or doubts. "Physically, I am very strong, and I heal fast. I'm tough, and I knew I could take it." When Janice told her she was a match, Mary Kate described herself as "the happiest woman in the world."



Kristin with donor dad Paul Quatralo

Now again, Kristin is in need of a kidney. Her kidney function is greatly reduced, which leads to feelings of fatigue. At the age of 27, however, after years of medical difficulties, Kristin is

finding herself and setting a course for her life. She attends St. Joseph's College all day on Mondays and Wednesdays, majoring in Human Services, with the goal of becoming a social worker. She has a deep love of animals, especially cats, and volunteers at Petco and at Shabby Tabby, a cat cafe in West Sayville. She baby sits on some days, and enjoys the beach and the family boat in summer. Of course, frequent doctors' appointments take up a great deal of time. She visits **Dr. Heesuck Suh** of Stony Brook, a nephrologist. She is looking for a part time job but it is difficult as the work must correspond to her medical and scheduling needs. Kristin has ambitions to travel to London upon her 30th birthday.

Facing kidney failure, Kristin and her family are thinking about how to publicize her need for a new kidney. We discussed practices that others had used, including social media, local television news shows, billboards, etc., but Kristin is unsure how to proceed.

In her online blog, Kristin revealed the optimism that maintains her spirit and keeps her going:

Having kidney disease does not slow me down from living my life...I live my life one day at a time. I drive, go out to eat, go to the mall, hang

out with family, basically anything I want to do, this disease does not slow me down...I don't want anyone feeling sorry for me because this is who I am. I want to teach people about this disease because a lot of people do have it, we just don't know. I also want to let those who do have it that they are not alone and I know what they are going through.

No matter what the future holds for Kristin Quatralo, we can sure that her loving family and her community will be there to support her.

Howie Pohl

Upcoming Events

April 10 – General Meeting – Nicholas Ginsberg, Administrator Northwell Transplant, Elliott Grodstein MD Surgeon Northwell Health, Lionel Mailloux, MD Northwell, Nephrologist, Spelman Awardee for Excellence in Research, Pete Prudente, Altruistic Kidney Donor, Min Zhou, DNP and Annual Business & Election Meeting – 145 Community Drive, Manhasset – 7:00 PM

April 13 – Remembrance and Rejoice Memorial Service for Organ Donors – St. Patrick's Cathedral – 2:00 – 4:00 PM – more info: triom@aol.com or visit www.trio-manhattan.org

April 27 – American Liver Foundation Re-Birthday Celebration – Homewood Suites – Carle Place – 10:00 AM – 12:00 PM – Guest Speaker: Tomoaki Kato MD, MPA, FACS, MBA, Chief, Division of Abdominal Organ Transplantation, NewYork-Presbyterian/Columbia, Surgical Director, Liver and Gastrointestinal Transplantation

May 7 – Join Donate Life New York State for their Legislative Education Day in Albany – info: (518) 326-3237

May 8 – General Meeting – Speaker To Be Announced – 145 Community Drive, Manhasset– 7:00 PM

May 18 – American Liver Foundation Liver Life Walk Long Island – Eisenhower Park – contact Nicolette Illiano (646) 737-9401

May 19 – National Kidney Foundation Long Island Kidney Walk – Belmont Lake State Park – contact Sean Rugenstein (212) 889-2210 x296

As of March 25, 2019, there were 113591 candidates for transplant, according to the United Network for Organ Sharing (UNOS). In New York State, there were 9,881 candidates awaiting a transplant.

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
Melvin Kershner	May 21, 2009	Kidney
Leslie Kreisman	May 5, 2000	Kidney
Hopeton Lue	May 30, 2000	Kidney
Joe Senatore	May 19, 1999	Heart
Rosalind Siegel	May 5, 2014	Kidney
Ida Tesoriero	May 12, 2005	Kidney
Florence Zoeller	May 24, 2013	Lung

February General Meeting



We were introduced to **Robert A. Montgomery, MD, D. Phil, FACS**, Professor of Surgery and Director of the NYU Langone Transplant Institute at the General Meeting of February 13. Dr. Montgomery gave an effective overview of NYU's transplant facilities,

which have made important innovations in the way transplants are conducted and NYU's position in the transplant community.

The NYU program has consistently expanded and increased the number and types of transplants performed. The first heart transplant there was performed on January 5, 2018. The world's most extensive face transplant took place there and a lung transplant program has been approved. See p.6 for news about pancreas transplants.



Dr. Montgomery has changed the way the center is run, establishing it as a separate department in a single institution with a unified vision and culture accompanied by the sharing of resources allowing for economies of scale.

Dr. Montgomery cited the litany of organ shortage statistics facing any prospective candidate from New York: Only one in four are registered as donors; 40% of residents in need do not get a transplant, and 40% are compelled to travel out of state to receive a transplant.

So NYU "adopted a growth strategy not dependent on availability." An overall increase in transplants has resulted. Onsite representatives approach families and are able to convince more to donate. An increased living donor program and more paired donations have helped to increase the total number of transplants to 287 in 2018. Desensitization via the removal of antibodies has increased the availability of donated kidneys as has a greater willingness to transplant HIV and hepatitis C donors. As a result, NYU Langone now has the highest percentage of those on the waiting list transplanted in the NYC OPO. Those on the waiting list are three times more likely to get a kidney within a year and mortality rates are lower.



Dr. Montgomery with John Redican, LI TRIO President Joy Oppedisano and Doug Housman. John and Doug represented Hearts for Russ a group which sponsored the meeting in honor of Russ Housman.

Dr. Montgomery's story is punctuated by his own tale. Four months ago, he received a heart transplant at his own center. He never expected that the surgeons he hired after he arrived from Johns Hopkins would save his own life. His very effective presentation was testament to the success he has achieved at NYU Langone.

Altruism in Action

*(Editor's Note: Firefighter **Pete Prudente** attended LI TRIO's General Meeting in January and let it be known that his altruistic spirit extends beyond his already awesome civic responsibilities. He wants to donate a kidney to a firefighter and gave us the notice below. If you are a firefighter or first responder, or know of anyone who might benefit from Pete's generosity, please get in touch.*

Pete Prudente
P.O. Box 942
Glen Cove, NY 11542
516-606-0014

To My Fellow Firefighters & First Responders:

My name is Pete Prudente. I am a proud member of the Glen Cove Volunteer Fire Department, Engine & Hose Company 4, Badge #446. I am also a member of the North Shore Fireman's Holy Name Society and many local civic organizations.

I want to donate a kidney to a Firefighter who desperately needs a kidney transplant and is also B blood type.

I have been thoroughly evaluated, tested and cleared as an altruistic living kidney donor at the Manhasset North Shore University Hospital Renal Transplant Center. Potential recipients can contact Min Zhou, the Transplant Program Manager at 516-562-0567.

I feel that my wife and I have been blessed by my being able to help change someone's life by making this living donation to someone who desperately needs it.

Thank you,

Pete Prudente



'PW Pete'

Postscript: Pete Prudente is scheduled to donate a kidney to an unknown recipient on March 25 at Northwell Health in Manhasset. Although his kidney will not go to a firefighter or first responder, Pete is grateful to be able to save the life of a deserving recipient in need. Pete celebrates his birthday on March 23 and we all surely wish him the happiest of birthdays!

March General Meeting



Milan Kinkhabwala MD was the guest speaker at Long Island TRIO's March General Meeting. He is a Professor of Surgery, Director of the Hepatobiliary Section of the Center for Cancer Care and the Director of Abdominal Transplantation at the

Montefiore Einstein Center for Cancer Care. His topics for the day included Montefiore's collaborative approach, advances in transplantation, and the role and future of stem cell treatment.

The liver transplant program at Montefiore is well established, having celebrated its ten-year anniversary recently. It is multi-faceted and includes transplant and hepatology in adults and children, hepatobiliary/pancreatic surgery, angioaccess surgery, a Liver Research Center, Liver Cancer Program, and a Transplant Immunology Lab. The center transplants kidneys, livers, hearts, lungs, pancreases, and bone marrow. Montefiore is regional in its outreach with centers throughout the Bronx and Westchester. Their faculty includes more than fifty transplant doctors and their team comprises seven social workers, two psychiatrists, a psychologist, and the Helping Hands Program, a resource network that helps patients navigate and better manage their health and their lives as they go through the transplantation process.

As a means to alleviate the lack of available organs for transplant, Montefiore emphasizes live donor transplantation, which has featured a 100% survival rate, and encourages altruistic liver donation. The hospital has also participated in improving swaps and chains to increase live donor matches. Dr. Kinkhabwala himself has been an advocate for greater equality in waiting time between regions.

The doctor's presentation focused on stem cell therapy. A stem cell defined as a cell of a multicellular organism which is capable of giving rise to indefinitely more cells of the same type, and from which certain other kinds of cell arise. Stem cells are classified as blood cells and

organ-specific cells. Liver cells are injected into the portal vein. Thus, stem cell therapy is less invasive than open surgery and works best when derangement is cellular in nature rather than for whole organ failure. Liver cell transplantation can provide metabolic support for liver failure, correct inherited metabolic disorders, augment cancer therapies, and even make animal livers function more like those of humans.



After the meeting, with
LI TRIO President Joy
Oppedisano

Dr. Kinkhabwala was less sanguine about the future of islet cell transplantation for pancreases. He noted that the treatment fails usually after two or three years yet the patient must remain on immunosuppressive drugs. Pancreas transplants remain the only effective alternative.

Cell transplant, according to the doctor, offers a potential pathway for patients to treat organ failure without the need for traditional whole organ transplant. While there are still issues with long term success and sources of cells, cell-based therapy is being evaluated at Montefiore and other medical centers for a number of diseases, and are already in use for bone marrow conditions.

LI TRIO at the Hofstra School of Medicine

Members of Long Island TRIO and other transplant recipients spoke once again to first-year medical students at the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell on February 15. This year's speakers included heart recipient **Shelby Caban**, donor mom **Kelli Cutinella**, kidney recipient **Sam Muszel** and his donor wife **Sally**, and liver recipients **Ruth Pohl** and **Dave Rodgers**. Faculty and administrators believe that it is beneficial for those entering their field to hear the stories of those who have benefitted from the gift of life and to understand the stresses of shortages of suitable organs for transplantation. **David A. Marcus**, Assistant Professor in Emergency Medicine, made the arrangements and served as host for the panel.



(left to right): Dave Rodgers, Shelby Caban, Ruth Pohl, Kelli Cutinella, Sally and Sam Muszel

The students benefit from the real-world experiences of transplant recipients and donor families and better understand the accomplishments of donors, recipients, and physicians alike.



(left to right): Howie and Ruth Pohl, Kelli Cutinella, Lewis Teperman MD, Shelby Caban, Sally Muszel, Dave Rodgers, David Bernstein MD, Sam Muszel

Record-Breaking Year for New York State Donate Life Registry

The following was reported by Donate Life New York State located in Troy NY:

More New Yorkers joined the New York State Donate Life Registry in 2018 than in any other year since the consent Registry was established in 2008.

"A record-breaking total of 604,163 New Yorkers documented their consent to donate organs and tissues in the New York State Donate Life Registry. This represents a growth of 12.3 percent," said **Aisha Tator**, Executive Director of Donate Life New York State, a nonprofit organization dedicated to increasing organ, eye and tissue donation throughout New York State.



Policy initiatives aimed at increasing donor registration have had a significant impact in the state. Lauren's Law, which changed the donor enrollment question on the driver license, learner's permit, and non-driver ID

application and renewal form from an optional section to one requiring an answer, resulted in a more than 50 percent increase in the number of New Yorkers saying "yes" to joining the New York State Donate Life Registry while at the DMV.

Policies to expand enrollment portals for New Yorkers have also been successful. "There has been an overwhelmingly positive public response to diversified Registry enrollment opportunities, and these portals, which are unique to New York, have been significant contributors to the Registry's growth," said Tator. These enrollment portals include the New York State of Health application, New York City Municipal Identification card application, and the voter registration form. "In 2018, one out of every five registrants, more than 116,000 people, enrolled through one of these three innovative enrollment portals," said Tator.

A new law implemented in 2017 also positively impacted enrollments by lowering the age of eligibility to join the Registry from 18 to 16. Currently, more than 55,000 16 and 17-year-olds have enrolled in the New York State Donate Life Registry.

"Collaboration may be the single most important thing we do," said Tator. "Bringing together partners and allies from across the state to develop creative solutions and new strategies to increase donations is the foundation by which progress is made."

These partners include organ procurement organizations, eye and tissue banks, the Department of Health, Department of Motor Vehicles (DMV), New York State Legislature, and other companies, organizations and institutions throughout the state. Important efforts to increase enrollment in the Registry include the expansion of registration opportunities with the support of **Governor Andrew M. Cuomo** and New York State lawmakers.

New Pancreas Transplant Program Launches at NYU Langone

*Editor's Note: The following appeared in the PR Newswire of February 14. Thanks to **Mike Sosna** for providing the article.*

NYU Langone's Transplant Institute has launched a new pancreas transplant program, completing the health system's comprehensive offering of solid organ and blood and bone marrow transplant. The new program will expand regional access to specialized care for patients with serious health complications from diabetes and other illnesses.



Zoe A. Stewart Lewis MD

The program is led by two renowned experts in the field: **Zoe A. Stewart Lewis, MD, PhD**, a transplant surgeon who joined NYU Langone from the University

of Iowa in May 2018, serves as surgical director of the kidney and pancreas transplant programs; and **Nicole M. Ali, MD**, clinical assistant professor in the Department of Medicine, Division of Nephrology, serves as medical director of the pancreas transplant program and of transplant outreach at the Transplant Institute.



Nicole M. Ali MD

This is the third new transplant program to launch at NYU Langone's Transplant Institute within a year, following close on the heels of new heart and lung

transplant programs. "With the addition of the pancreas transplant program led by **Dr. Stewart Lewis** and Dr. Ali, we further enhance our reputation as a leading comprehensive transplant center in the region, with the advanced expertise to take on the most complex cases," says **Robert Montgomery, MD**, professor in the Department of Surgery and director of NYU Langone's Transplant Institute.

"I'm thrilled to join NYU Langone to help develop the pancreas transplant program, which will provide services that can dramatically improve the quality of life of the sickest diabetes patients," says Dr. Stewart Lewis. "Together, our team of transplant nephrologists and surgeons, endocrinologists, dieticians, social workers, and

other specialists is committed to ensuring the best possible outcomes for our patients."

"A successful pancreas transplant can be life-changing for the right patient," says Dr. Ali. "Not only does the kidney and pancreas transplant treat a patient's advanced kidney disease—it's also a cure for diabetes, which is a phenomenal improvement in the quality of life of patients who have struggled with disease management for many years."

Have You Paid Your Dues?

Long Island TRIO is an all-volunteer organization dedicated to the promotion of organ donation as a means of improving the lives of transplant recipients. We do this through support, advocacy, education, and awareness. Some of our major activities include speaking to high school students throughout Long Island, the Rose Garden Ceremony honoring organ donors at Eisenhower Park, the Celebration of the Season Holiday Party, monthly meetings featuring the top transplant experts of the New York region, the yearly Mets game at Citi Field, this publication, and the LI TRIO website.



All of these activities cost money and we rely, in part, on the collection of dues from our membership. Dues are only \$25 per year and have remained at that level for many years.

We ask kindly that you pay your dues as soon as possible, so that we are not obligated to send

out expensive follow-up requests. We understand if you cannot afford to pay dues; just indicate on the blue card that you are unable to pay at this time but wish to stay on our mailing list.

If we don't hear from you, we will have to cease our mailings and you will no longer be able to receive the latest news about transplants, organ donation, and LI TRIO. If you have already paid for 2019, please accept our heartfelt thanks.

President's Corner

Can we say that we have had a good life?

A ponder-able probably contemplated by many at one point or another. An interesting question that perhaps has you wondering why I am even bringing this up.

As I write my column my thoughts are with a Long Island TRIO member who, in this lifetime, is on her final journey.

Earlier this week I received a call from Stephen Edelson. His mom, Iris, had decided to go into hospice care and stop her dialysis treatments.

Iris, a liver transplant recipient, had been told by her physicians that she desperately needed a kidney nearly two years ago. Her heart and health in general had deteriorated making it impossible for her physicians to place her on the waiting list for a transplant. Iris a trained nurse, a healer, needed healing.

With each trial and tribulation Iris experienced, she remained grateful for each moment in life.

Iris loved to talk about her son, daughter-in-law, two grandchildren and late husband, Sandy. She said that her husband's love had given her a good life. She talked about how she met her husband, the early days, living in a tiny apartment with roommates, enjoying music in New York City parks, and, better yet, music while on vacation in New Orleans. Her family and friends were treasured. Recently, even while struggling on dialysis she planned on going to see family in California and Florida. Unfortunately, she was only able to make one of the planned trips.

Iris also dedicated herself to LI TRIO. She found support and enjoyed coming to meetings when she could. Iris was on the Board of Directors for several years. She worked to further LI TRIO's efforts in a variety of ways including as a school speaker, publicity coordinator, holiday party committee, raffle prize collector and expert coordinator. Those who attend our functions will recall her gentle yet persistent spirit.

It was this beautiful, spirited personality that continued as she fought her fight, with elegance and gratitude.

She always said that she was grateful. She had a good and colorful life.

Her name, Iris, is a striking, colorful flower.

Iris is also the Greek goddess of the rainbow.

As our Iris travels over her goddess rainbow to join her husband, I hope she knows how much she will be missed.

Chapter Officers**President:** Joy Oppedisano**Treasurer:** Walter Ruzek**Secretary:** Mel Lerner**Immediate Past President:** Dave Rodgers**Board of Directors:** Sue Dillon, Barbara Fenn, Jeff Fenn, Mel Lerner, James Mateiko, Margie Ng-Reilly, Howie Pohl, Dave Rodgers, Walter Ruzek, Florence Sosna, Jerry Sosna, Mike Sosna

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