

**Next General Meeting: Wednesday June 14**

**Priya Grewel MD – Mt. Sinai Medical Center  
plus Celebrating 25 Years of Transplant  
with our Quarter of a Century members and friends**

**7:00 PM**

**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*

P.O. Box 81 Garden City, NY 11530 516-620-5900 Website: [www.litrio.org](http://www.litrio.org) Email: [litrioreads@gmail.com](mailto:litrioreads@gmail.com)

# 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.*



JUNE 2017

Transplant Profile: Alice Dillon

*(Editor's note: Like many of us in the transplant community, kidney recipient Alice Dillon has a resolute support staff of family and friends who helped her along the way and carries it forward by participating in organ donation and transplant-related activities. Alice's mother Susan is active on Long Island TRIO's Board of Directors and has been particularly successful as a liaison to transplant centers throughout LI TRIO's servicing area. The Dillon family has now relocated to Westchester County but continues to support all of our local activities. The article below recreates the events surrounding Alice's transplant of September 5, 2007. Those who are now candidates for a kidney transplant and those who have successfully made the journey from candidate to recipient can identify with many aspects of Alice's story.)*

The Dillon family received an email on February 16, 2007, that would change Alice and her family's life forever. It was sent by Lisa Millard, a stranger to the Dillons, who were living in Merrick at that time. It read in



part: "I . . . saw your flyer looking for a kidney donor. While this is nothing that I had ever (seriously) considered, I am an organ donor and figured why wait 'til I'm dead." A year before, Alice's story had appeared in Newsday. Alice was on dialysis three times a week as her kidneys were failing. The family plastered Merrick with leaflets hoping to find a donor with a matching blood type of O positive or negative. No one in Alice's family had the requisite blood type. Finally, a Merrick man, who requested anonymity, volunteered. Unfortunately for Alice, the man had a medical problem that prevented him from donating his organ. After finding out about the problem, the Dillon family began posting flyers again in Merrick. That is when Lisa Millard stepped up to the plate....

Lisa had spotted the flyer at a tax preparer's office. She offered a kidney and saved Alice's life. As Marty, Alice's father, said at the time: "There's really nothing you can say to a person like that. She knew what she was doing for us and

we knew what she was doing . . . It just brings me to tears."

After Alice's kidney functions began to decline, the family quickly mobilized into Internet and social media masters. They created a website, posted the flyers, and telling anyone who would listen about their daughter's situation. "For the whole year, it consumed us," Sue Dillon said. Strangers from all over the world responded. The family methodically listed all of the potential donors in a red spiral notebook. On February 16, Lisa came calling via her email. She passed all the tests required of living donors by June 13. The family got the procedure off to a celebratory start by having a backyard barbeque and birthday party for Alice, who had just turned 40. The party, in effect, continued at the Westchester Medical Center when they arrived on the day of the surgery. As Marty Dillon said, "When we went there and I saw her sitting there, I knew we were home."



Alice Dillon

Alice reported feeling excited, happy, and ecstatic after the surgery, although she wondered "whether it was real or not"

following surgery. Alice has done well since and

now the family is closer together and closer to Alice's hospital in Westchester. The Dillons consistently advocate for organ donation at every opportunity.

On October 16, 2007, Lisa Millard was presented H&R Block's Block Hero Award by her company for donating her kidney to Alice. The presentation took place at H&R Block's U.S. Tax Services National Conference in Las Vegas. As Bill Birkins,

Block's vice-president and managing director at the time, stated "When H&R Block says 'We got people,' we mean it, and our communities are stronger for it. We'd like to honor H&R Block heroes -- leaders in the field who have performed selfless acts."

In January 2008, the Nassau County Legislature presented Lisa with its Humanitarian Award:

*In recognition, of the fact that all too often, exemplary acts often go unacknowledged and it is this deed that enriches a community, I, David W. Denenberg, Nassau County Legislator for the 19th Legislative District, on behalf of the Nassau County Legislature and the people of the 19th Legislative District, do hereby recognize, acknowledge, commend and applaud **Lisa Millard** and award her with the **Humanitarian Award** for her courageous and selfless act of kindness on the 28th day of January, 2008.*



Lisa Millard

As author Tim Sanders reported in his book *Saving the World at Work: What Companies and Individuals Can Do To Go Beyond*

*Making A Profit to Making a Difference (2008):* *Dozens of*

*H&R Block's district managers and staff were moved to action. One went home and signed up for a local community-service organization that connects at-risk kids with their favorite sport; another responded to a request from one of his coworkers to participate in a Big Brother program. Still another told me (Sanders) afterward, "This raises the bar for what we can do for each other at work. Lisa showed us that we could and should treat our tax professionals like family. I don't think this place will ever be the same."*

## Upcoming Events

**Wednesday, June 14** – General Meeting – Priya Grewal, MD, Recanati Miller Transplant Inst, Mt Sinai Medical Ctr. - 7:00 PM – 145 Community Dr, Manhasset

**Sunday, June 25** – Hearts for Russ Housman Texas Hold ‘Em Tournament to benefit transplant-related causes – 2:00 PM – Howard Beach – see article below

**Friday, September 8** – LI TRIO at Citi Field – Mets vs. Reds – stay tuned for more information

**Wednesday, September 13** – LI TRIO Night at the Movies – *Perfect Strangers* – a story of altruistic organ donation, followed by film discussion – 7:00 PM – 145 Community Drive, Manhasset

**Saturday 23** – Rose Garden Rededication Ceremony – Eisenhower Park Field no. 6/6A – Honoring organ donors and their families – 12:00 to 2:00 PM

**Friday, October 6** – Russ Housman Golf & Charity Dinner – Wind Watch Country Club, Hauppauge – Registration to begin in late spring

**Thursday, November 30** – Celebrations of the Season Holiday Party – The Carlton – East Meadow – more information to follow

**WE WISH TO THANK AND SALUTE OUR  
CORPORATE MEMBERS FOR 2017**

**LiveOnNY**

**The Mount Sinai Hospital  
NYU Langone Medical Center**

## June Re-Birthdays

Monica Blum	June 7, 2010	Kidney
Rich Friedman	June 29, 2012	Kidney/Liver
Janice Gosule	June 6, 2007	Kidney
Jean A. Kelly	June 16, 2005	Liver
Mel Lerner	June 10, 2008	Kidney
Daniel O'Neill	June 28, 2007	Kidney
Ruth Pohl	June 1, 2003	Liver
Anthony Scro	June 24, 1999	Liver
Steven Wolf	June 10, 1998	Kidney

## July Re-Birthdays

Alexandra Agathos	July 28, 2015	Kidney
Beth Chapman	July 11, 2008	Kidney/Pancreas
Waled Chowdhury MD	July 21, 2008	Kidney
Fred Cohn	July 28, 2011	Liver
Anthony Devivo	July 8, 2007	Liver
Anthony DiMaria	July 19, 2007	Heart
Jay Director	July 2, 2000	Kidney
Jeffrey Fenn	July 31, 2016	Kidney
Karen Laferrera	July 2, 2014	Liver
Laura Laria	July 6, 2006	Kidney
Alan Leavy	July 22, 2010	Kidney
Jennifer Lentini	July 6, 1996	Heart
Jean B. Nassani	July 18, 2011	Kidney
Michael Sosna	July 18, 1995	Kidney #1
Kathy Vliet	July 24, 2002	Kidney
Margaret Young	July 28, 1991	Kidney

As of May 25, 2017 there were 117,941 candidates for transplant, according to the United Network for Organ Sharing (UNOS). In New York State, there were 9,884 candidates awaiting a transplant.

## LI TRIO at the Williston Park Rotary Club

Members of Long Island TRIO are regularly called upon to present information about organ donation and transplantation. **Walter Ruzek** received a kidney from his wife **Peggy** in 1989 and has been a staunch advocate for organ donation since. He is a past president of LI TRIO, member of the Board of Directors, treasurer, and soon-to-be publicity coordinator. Walter spoke at a meeting of the Williston Park Rotary Club on April 5, 2017.



Walter Ruzek holds a paperweight presented to him as a token of appreciation by the Williston Park Rotary Club

The Rotarians had many queries and had many of the same questions that LI TRIO presenters typically receive. Like most audiences, some were surprised to hear that organ donation rates New York State are well below the national average. They were much appreciative of Walter's presentation.



Robert A. Montgomery MD, NYU Langone



Attendees hold candles to honor donors



Matilda Smith, in the arms of mom Kelly, received a liver in 2012 at 6 months

## Remember and Rejoice at St. Patrick's Cathedral

In April of each year, the Manhattan chapter of TRIO gives thanks and honors organ donors and their families. The ecumenical service at St. Patrick's Cathedral in New York is always the most moving of ceremonies, as donor families and transplant recipients relive the difficult moments when the Gift of Life was received.

**Margaret O'Reilly**, a former speaker at the Remember and Rejoice service and a donor mom herself, attended the service and reported back by providing the lovely photographs below (see the August 2014 LI TRIO Newsletter for Margaret's story at [www.litrio.org](http://www.litrio.org)). In addition to the donor families and recipients, **Robert A. Montgomery MD**, D. Phil and FACS, and new Director of the NYU Langone Transplant Institute spoke to the packed audience. Thanks to Margaret for supplying the wonderful photographs.



Donor family members William and Kyle Hankee speak of Krysta Hankee's Gift of Life



## April General Meeting

We were privileged to hear three speakers from New York Presbyterian Hospital's lung transplant team at the April general meeting. **Carlo Baltazar**, a clinician, **Rachael Begler RN**, and **Genevieve Reilly**, RN Chief Nurse Coordinator, provided a lucid portrait of lung transplant procedures and issues. NY Presbyterian (NYP) is the only hospital in New York that performs such transplants.

Before they spoke, organ donation activist **James Mateiko** made a presentation. James is a donor son; his mother saved five lives. He recently completed the New York City Triathlon as a member of the Donate Life Team. He informed the audience of the North Fork Bike Tour on May 21, which raises money for organ donation activities.



Genevieve Reilly

Genevieve Reilly is the post-transplant coordinator. Lungs come to NYP from all parts of the country. Doctors make the referral for transplant, receiving

from NYP a package of what is required of them to complete the transfer to NYP. The hospital is consistently recognized as one of the ten best in the country and as a Center for Excellence. 25 lung transplants had already been completed in January of 2017; 800 had occurred for the program as a whole.

Whether a recipient requires a single or double lung transplant depends on the nature of their disease: Cystic fibrosis requires a double transplant, COPD and pulmonary fibrosis a single. There are 52 candidates currently awaiting transplant. Genevieve described the unit as “a big team with the same goal,” the survival of the transplanted patient.

Lung recipients spend 24 hours on a ventilator, then engage in exercises to revitalize, then are moved to a regular floor. NYP emphasizes patient education; attendance at seminars is required. Patients typically spend 6-10 days in the hospital and some are required to enter rehabilitation. At the start, patients return once a week, then less frequently over time.

Lungs are harder than some other organs to regulate, so travel is prohibited until one year. Patients may wear masks, and fresh fruits are prohibited for the first three months due to the threat of mold and fungus.



Rachael Begler serves as a pre-transplant

Rachael Begler

coordinator. As such, she assures that no alternatives exist to the transplant for the patient's survival. The pre-transplant interview attempts to determine if any condition will preclude transplant. A baseline evaluation and a battery of tests are completed and the results presented at a committee meeting.



Carlo Baltazar

Carlo Baltazar detailed some of the technical aspects of lung transplants. He emphasized the need to find ways to get more lungs. The unit goes outside of

New York State frequently to expand its pool of available lungs. He discussed exvivo, a technology to profuse lungs and LAS, the score which determines how the organs are allocated.



(left to right) Genevieve Reilly, LI TRIO President Joy Oppedisano, donor son James Mateiko, Rachael Begler, Carlo Baltazar

## LI TRIO at Harborfields High For Donate Life Month

The Suffolk County team of The Long Island TRIO's School Speaker Program had two great days at **Harborfields High School** in Greenlawn, New York. The team spoke to 874 students during the sessions with the unqualified support of the school staff. **Kathie Gerlach, Kelli Cutinella, Dan O'Neill, and Dave Rodgers** told their stories of transplant and organ donation and, in the process, encouraged students to help save lives. The photograph below displays those who contributed to the success of the program (left to right): **Stefan Serie**, football coach and physical education teacher, **Michael Potter**, dean/physical education teacher, **Kathie**

**Gerlach**, LI TRIO kidney recipient, **Joan Verardo**, nurse, **Suzanne Scheer-Legge**, physical education teacher, **Robert Franco**, physical education teacher, **Dan O'Neill**, LI TRIO kidney recipient, and **Dave Rodgers**, LI TRIO liver recipient (not pictured: **Kelli Cutinella**.)



### ALF Long Island Re-Birthday Celebration

The American Liver Foundation (ALF) is the nation's leading non-profit organization promoting liver health and disease prevention. Each year at this time, its Greater New York Division hosts the Long Island Re-Birthday Celebration, which celebrates the gift of life and the miracle of liver transplantation. Liver transplant recipients and their supporters hear guest speakers, singers, and share in candle lighting and re-birthday cake.



The guest speaker at this year's event was a perennial favorite **Lewis Teperman MD, FACS**, Vice Chair, Surgery, and newly-appointed Director of Organ Transplantation at the Transplant Center of Northwell Health. Dr.

Teperman has spoken numerous times at Long Island TRIO meetings and made another appearance there on June 10. His presentation on innovations in liver transplant was enlightening.



Donor Jesse Rosen with recipient mom Laurie

Also speaking was **Jesse Rosen**, who movingly delivered the story of his donation of a partial liver to his mother. LI TRIO was fortunate to have Jesse as

one of their speakers at last year's Rose Garden Rededication Ceremony at Eisenhower Park.



**Maria Petsanas** did an outstanding job singing songs of inspiration to the audience, who had a lot for which to be grateful.

At the conclusion of the ceremony, the liver recipients gathered around the re-birthday cake, proud to be able to reflect on the gift that had been given to them. The staff and board of the ALF, including LI TRIO's own **Dave Rodgers**, did their usual outstanding job of organizing the event.



### Hearts for Russ Housman Texas Hold 'Em Charity Event

When: **Saturday, June 25, 2:00 PM**

Where: **159-13 102nd Street, Howard Beach NY**

Hearts for Russ Housman honors the memory of Russ by raising funds to battle heart- and transplant-related illnesses and supporting the people affected by them. HFRH strongly supports LI TRIO. At this poker tournament, a \$150 buy-in includes a donation, food, and a prize pool.

For more information and to register, go to [HeartsforRussHousman.com](http://HeartsforRussHousman.com).

## May General Meeting



Long Island TRIO's May General Meeting featured one of the organization's favorite and most regular speakers. **Lewis Teperman MD, FACS**, Vice Chair of Surgery and Director of Organ Transplantation at Northwell, spoke on a variety of topics affecting transplants. He is in the process of developing the liver transplant regimen at Northwell. He

spoke of equalizing the distribution of livers throughout the United States which, as a UNOS board member, is a proposal he is advocating when it comes up for consideration in December 2017. He urged the audience to contact its political representatives to help the process. He described new machines which use warm infusion, a process first imagined in the early twentieth century, which will allow organs to be safely transported to farther locations which will, in turn, aid in the process of taking organs where they are more abundant and moving them to places like New York State where the demand is greater. His point was that geographic disparity should not be a factor in deciding who receives the gift of life. Dr. Teperman also discussed the possibility of transplanting livers afflicted with hepatitis C and using the new drugs that cure Hep C in the recipient.

The question-and-answer period addressed a wide spectrum of issues on the minds of recipients, including the ethics of giving organs to alcoholics, new drugs that can substitute, in part, for traditional immunosuppressives and thereby lessen the harmful effects of the latter on kidneys.



LI TRIO President Joy Oppedisano presented Dr. Teperman with a TRIO umbrella following his presentation

## President's Corner

***"Step right up — for this famed final act."***

Yes, many of you, dear readers, know the above inference is to the circus as we know it.

Others, yet, may have also thought of the gifts of life through donation of organ and tissue.

Each day there are reminders of how precious life is.

Often, our thoughts are private. Other times, as a group we galvanize to make a difference and help save lives.

We had one of our yearly group events in May.

It was an honor recently to join so many dedicated transplant colleagues as we journeyed to Albany to present our latest request for lifesaving legislation. We were organized and grouped so that we could share a "full picture" with the legislators, aides and just about anyone that would listen! The groups included donor families, volunteers, transplant professionals, and other leaders. The legislators and their staff were humbled. The story of lives cut short, lives extended and the science of lifesaving transplantation created many moving moments.

Petitions for changes presented and reviewed were:

### Portal Expansion:

This will encourage enrolling in the statewide registry.

Information will be linked to:

-  All licensing in the healthcare practitioner profile (Hannon)
-  -Student applications for city and state colleges (Peralta)
-  -Applications for library cards (Jacobs)

### Transplantation Bill:

- All vehicles carrying organs to be designated emergency vehicles since every moment counts when it comes to transplanting lifesaving organs (Serrino)

A great big thank you to the organizers and each and every participant.

This was a day well spent.

*Some other fun summer events this year will include:*

- *Saturday, July 29<sup>th</sup> – 3:00 pm - Kayak, Canoe, or Paddleboard -and see the sights in Riverhead, NY. A group rate will be determined and shared – dine afterwards at a local restaurant.*

*Friday, September 8<sup>th</sup> – Citifield- NY Mets – with free Met's T-shirts and LI TRIO Bags. Seats: field level, centerfield, left of Big Apple, great view of home plate! Possible surprise visit by Ed Kranepool, NY Met. \$40.00 first come first serve, cash. Contact: Joy Oppedisano, James Mateiko, Laura Laria, or the LITRIO Board)* **Joy Oppedisano**

**Chapter Officers**

President: Joy Oppedisano  
 Treasurer: Walter Ruzek  
 Secretary: Jo Michaels  
 Immediate Past President: Dave Rodgers

Board of Directors: Ed Burki, Sue Dillon, Jeff Fenn, Mel Lerner, Jo Michaels, Margie Ng-Reilly, Howie Pohl, Walter Ruzek, Florence Sosna, Jerry Sosna, Mike Sosna

*The content of this publication including text, graphics, images, and other material contained herein is for informational purposes only. The content is not intended to be a substitute for professional legal advice, tax advice, professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any medical questions you may have.*

LI TRIO Main Number/Hotline Mike Sosna 516-620-5900  
 Welcome Committee Call Hotline  
 Corresponding Secretary Ruth Pohl 631-884-0482  
 Website Design, Legislative Initiatives and  
 Public Policy Mike.Sosna 516-767-7300  
 Special Projects Ed Burki 516-620-3700  
 Rose Garden Logistics Dave Rodgers 516-449-1421  
 Rose Garden Program Jo Michaels 516-798-8411  
 Donor Families & Social Secretary Barbara Musto 516-314-3285  
 Database Manager Howie Pohl 631-884-0482  
 School Speakers Jeff Fenn 516-382-4678  
 Ways and Means Committee Florence and Jerry Sosna 516-482-2908  
 Publicity Mel Lerner 516-484-2417

Volunteer Coordinator Joy Oppedisano 516-232-3151  
 Transplant Center Outreach Sue Dillon 914-342-3003  
 Meeting Logistics & Member Outreach Margie Ng-Reilly 516-938-5101

**Newsletter**

Howie Pohl - Editor



Address all correspondence to:

LI TRIO  
 PO Box 81  
 Garden City NY 11530

- Visit [www.litrio.org](http://www.litrio.org) for more information and articles about transplantation.
- Become a friend of TRIO on Facebook: <https://www.facebook.com/groups/TRIOgroup/>
- Call our hotline: (516) 620-5900

Long Island TRIO

PO Box 81  
 Garden City NY 11530