

**Special  
ROSE GARDEN  
REDEDICATION CEREMONY  
Edition**

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.*



SEPTEMBER - OCTOBER 2014

### See Inside for Information about the Rose Garden Rededication Ceremony of 2014

#### Transplant Profile: Jim Jewell

The beginning of my transplant journey starts in 1971, shortly after my discharge from the Army. I contracted hepatitis and was admitted to the Houston VA hospital. After a week's stay, an Army Doctor diagnosed me as non-A non-B and sent me on my way.



Jim Jewell

A year after accepting a job offer with Pall Corporation in Glen Cove, I bought a house in Centerport where we lived for 23 years. During this time I was cared for by Dr. Fenton Schaffner of Mt. Sinai Hospital who headed the Liver program. Through all of this timeframe, unknown to me, my liver was slowly being attacked by the hepatitis C virus which had been identified by serology. Throughout this time I slowly started to show signs of liver disease, manifest in the classical signs, darkening urine, fatigue, and yellowing of the skin etc. I maintained my job with Pall as best I could. I contracted ascites, and for the last

year pre-transplant I was on Lasix, and was put on a restricted no salt diet, and the Canadian exercise regimen for exercise every morning. At this time, my wife, pregnant with our first daughter Jaeme, was told to stay in bed in order to hold our child. I still held my job sans travel, I came home and cooked dinner, and a lunch meal for my wife, cleaned the house and fell in to bed exhausted. I pretty much did this until Jaeme was born and to my duties I added child care. My wife was no longer bedridden but her muscles needed time to repair.

I had made my peace, and knowing my family was protected with adequate life insurance, I prepared to die. I slowly deteriorated and when the time came Dr. Schaffner sent me to Presbyterian University Hospital in Pittsburgh for evaluation for a liver transplant. Until that time I had no idea that such an operation was possible! I went to Pittsburgh for evaluation which at that time was composed of both a Physical and Mental component in a grueling one-week hospitalization. I was discharged from the hospital and told to go to clinic. I was told by Sandy Staschak Sr. Transplant Coordinator, the uber nurse for Dr. Starzl, to get with the program and let the doctors get to know you. So on Tuesday I went to clinic, to meet all of the Transplant Surgeons, and at the end one doctor said "you are sicker than you look. Don't leave town." They gave me a beeper, told me to eat everything I could to fatten myself up and I left. We went back to Long Island, closed the house in Centerport, and rented an apartment in Pittsburgh for the duration.

At this time Dr. Starzl was under attack by the Pittsburgh Gazette for favoring wealthy Arabs and Iranians. Dr. Starzl clearly stated that the payment from this kind of candidate allowed him to give life to 3 candidates who had no insurance or money to pay for surgery. Eventually the story died down as it lost its news value. Dr. Starzl covers this in his autobiography "The Puzzle People."

Two weeks later, at about 4:00 PM, my beeper went off. We raced to the hospital and we were met by Dr. Teperman who was, at that time an apprentice at transplantation. Up until I was wheeled into the OR, there was about a four week interval from the time I found about the possibility that transplantation was an option until I underwent the transplant operation. I hadn't met anyone who was transplanted; I had no visit to the transplant ward to meet anyone who could describe the recovery experience, or to

meet the nurses and so forth. I had no idea about what the whole experience was about.

When I woke up in the critical care recovery ward, with the JP tubes, the T tube, the various and sundry intubations (main line) etc., you can imagine what I speculated on until I fell back asleep. I was experiencing a phenomenon called ICU Psychosis, whereby reality was changing and I serially experienced hallucinations – some not pleasant. Finally I recovered and I was moved to the step down unit and ultimately the transplant ward. My recovery went well after a one time massive rejection event which was cut off by an experimental drug called OKT3. Within a day the rejection episode was shut down and I was good to go. Then at the one month mark a massive leak from the T-tube was discovered. I had a high fever and painful bowel and the surgeons opened me up immediately, rinsed me out and spliced my bile duct directly into my small intestine. They didn't use staples and left the large incision open to drain and packed with gauze. I watched that open 1" x 2" x 20" incision heal, repacked every day for a month until it healed inside out. Such was the state of transplantation in 1986 but I was good to go from there on.

My transplant was performed by Dr. Todo who was second only in surgery to Dr. Starzl. It was policy at that time that Dr. Starzl would go on recovery teams because he was the fastest and would then accompany the retrieved organs back to Presby whereby a senior transplant surgeon would perform the transplant with Dr. Starzl holding the number two position on the team. I was on the table for 13 hours.

My recovery was relatively benign except my bilirubin cycled between 2.0 and 4.0 up and down in a week. Two senior doctors (I know who they are but I will withhold their names) were having a disagreement why and so I was kept in the hospital 81 days. Dr. Starzl examined me in clinic and said "Do you want to go home?" – "Let's stop screwing around" and I was released to go back to Centerport.

During this thirty day hospitalization I was visiting a little girl who was lonely and who appeared to have no friends. She

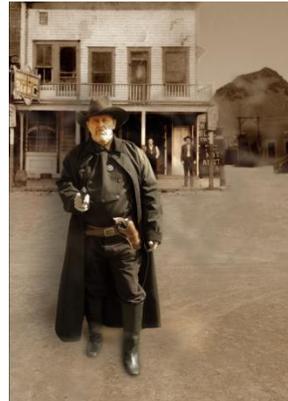


**Jim Jewell with award for work on unmanned aircraft systems design and performance**

was also experiencing complications. In the next bed, sitting in a chair was a lady named Ann Treffiesson. This began a long relationship with Ann who was my friend, with Don, until their deaths. One night, at their tennis club, after Don and I had hit some volleys, they presented the idea of forming a Chapter of TRIO. Ann, Don and I were the three signatures on our application. Until that time the first chapter was formed by the Junior League of Pittsburgh. These ladies were mostly consumed of arguing about the format of their stationary. They proposed many rigid rules which all new chapters must abide by. Ann and Don were all about helping people and specifically creating a local chapter of TRIO which would help

candidates and recipients which could help each other by

sharing their experience and knowledge. The first several years we tried this and then that until the organization was functioning. At the four year mark Jarron and I travelled to Paraguay to adopt our second daughter, Jesse. I served on the Board for 4 years and then job and family started to make my participation no longer possible. It is now about 29 years later and LITRIO, shepherded through the years by so many, is functioning as we had originally envisioned. I thank you all for this.



**Jim Jewell as Old West Reenactor**

I should mention that the argument about my cycling bilirubin was finally resolved when I was switched from Cyclosporine to Prograf. It seems I had a sensitivity to cyclosporine. Switching is not to be done lightly. It took me two weeks where I was started on a normal dose of cyclosporine by IV while administered simultaneously a high dose of Prograf, again administered by

IV. I was emetic every hour for two weeks until the dose of Prograf was reduced to a level

with which the surgeons were satisfied. They were very protective with survival number at that time however I am now on a dose of 1mg/day which is minimal. I had a splitting headache which dissipated but not only did my bilirubin stay below 2.0 the migraine headaches which plagued the first five years of my post-transplant life also stopped.

Finally, I would like to mention until 1986, liver transplantation had a six-month survival rate of about 20%. The introduction of Cyclosporine replacing a variety of experimental mixtures of steroids and other meds led to a reversal of the numbers. Six month success rate jumped from 20% to 80%. Dr. Starzl was responsible for this as well as the introduction of Prograf. I went from a man who was unaware of transplantation as a heroic intervention to a man who, 29 years later, is going strong. I have several annoying complications, lichen planus, and, recently, Type 2 diabetes (Neuropathy, Stenosis, etc.) but my liver is strong and I am pushing ahead at age 69.

## Upcoming Events

**Saturday, September 20 – Rose Garden Ceremony honoring organ donors and their families – Eisenhower Park – Parking Fields 6 & 6A – 12:00 noon.**

**Saturday, October 11 – Special Weekend Edition of LI TRIO's General Meeting – 12:00 noon – Long Island Jewish Medical Center – Teaching Center – Joseph Scott Weiner MD – Psychiatry – Associate Professor, North Shore-LIJ School of Medicine.**

**Wednesday, November 5 – General Meeting – 7:30 PM – Lewis Teperman MD – NYU Langone Medical Center – Advances in New Drugs and Transplants**

**Friday, November 21 – Holiday Party – Leonard's Palazzo – Great Neck**

## October Re-Birthdays

Angela Barbosa	October 29, 2002	Liver
Roberta Baumstein	October 7, 2003	Kidney
Jeffrey Callaghan	October 5, 2006	Heart
Joseph DiMartino	October 17, 1999	Liver
Anthony Fama	October 28, 2001	Liver
Rachel Feldman	October 25, 1994	Liver
Susan Joffe	October 28, 2010	Heart
Michael Kahne	October 11, 2009	Kidney
Joel Pope	October 22, 2002	Liver
Josephine Recine	October 1, 2001	Kidney
Dave Rodgers	October 22, 2002	Liver
Jan Schichtel	October 21, 1982	Kidney
Ellen Schulman	October 23, 1999	Liver
Deborah Taylor	October 28, 1999	Kidney
Irene Torino	October 25, 2011	Kidney
Eileen Vento	October 27, 1999	Kidney
Bob Violino	October 25, 1995	Kidney
Mike Zangari	October 22, 2009	Kidney

## November Re-Birthdays

Barry Brennan	November 21, 2006	Liver
Dennis H Fearn	November 16, 2011	Liver
Tonia Finkelstein	November 26, 1997	Kidney
Debbie Greenberg	November 21, 2004	Heart
Skip Knell	November 23, 2010	Liver
Alan Krieger	November 19, 2010	Liver
Stefani Letvak	November 23, 2009	Kidney
Denise McCullough	November 17, 1997	Kidney
Susan Mei	November 10, 2010	Liver
Fran Oreckinto	November 25, 2010	Kidney
Russell G. Tisman	November 7, 2009	Heart
Ralph Zegel	November 26, 1997	Heart
Jennifer Zuccato	November 30, 2006	Liver



New York's Team Liberty posed for a group portrait before heading off to the Transplant Games in Houston, Texas, in July 2014. The team is comprised of organ transplant recipients and their families, donor families, living donors, and transplant professionals from New York City, Long Island, the Hudson Valley, Northern and Central New Jersey, and Fairfield County, Connecticut. Included in the team portrait were Kathleen Gerlach, a kidney transplant recipient, and Jennifer Lentini, a heart recipient. Kathie and Jennifer's accounts of their experiences in the Transplant Games appeared in the August 2014 edition of the Long Island TRIO Newsletter.

### EXCITING NEWS !!

Based on preferences expressed by members, Long Island TRIO's October General Meeting will take place on **SATURDAY, October 11 at 12:00 PM**. The meeting will take place at the **Teaching Center of the Long Island Jewish Medical Center**. The guest speaker will be **Dr. Joseph Scott Weiner**. He is a doctor of psychiatry and an Associate Professor at the North Shore – LIJ School of Medicine.

Directions to the meeting will be forthcoming.

Long Island Transplant Recipients International Organization (LI TRIO) is proud to announce the *Rededication of our Donor Rose Garden*.

Long Island TRIO's most cherished event will be held on *Saturday, September 20, 2014*

*From 12 noon until 2 pm. Lunch will be served.*

Please join Long Island TRIO and the New York Organ Donor Network (NYODN) as we honor those that donated their organs, The Gift of Life. The Rededication of the Rose Garden is our annual event, where we recognize, pay tribute to, and honor our Living Donors and Donor Families. This annual Rededication of our Rose Garden is just a small way that we pay honor to our heroes and their families who gave so generously in order to give us a second chance at life.

The Rose Garden is maintained by LI TRIO volunteers.

The Donor Rose Garden is located at  
Eisenhower Park  
1899 Hempstead Turnpike East  
Meadow, New York 11554  
Adjacent to Parking Fields 6 & 6A  
**This is a Rain or Shine Event**  
**Directions can be found at**  
**[www.LITRIO.org](http://www.LITRIO.org)**

At this time, while living donors are considered heroes and have saved and extended lives, insurance companies have all too often flatly denied insurance coverage to living donors (in some cases immediately denying applications after the surgery question is answered), limited coverage to living donors, raised premiums (which has drastically affected living donors) and declined life insurance, disability insurance, or long-term care insurance applications submitted by living donors.

This bill will protect living donors from insurance discrimination. The bill also has provisions for the promotion of education with respect to living donation.

H.R. 5263 makes it unlawful for insurance companies to discriminate against living donors by declining insurance, terminating insurance, limiting coverage and charging higher premiums for life insurance, disability insurance, or long-term care insurance policies just because someone identified as a living donor and stated that they gave the Gift Of Life as a living organ donor.

Additionally, the bill clarifies that living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from the transplant surgery.

On July 30, 2014 the bill was referred to committees within the House Of Representatives including the Committee on Energy and Commerce, Committees on Oversight and Government Reform, House Administration, Education and the Workforce, and Financial Services.

While the bill is in committee discussions, LI TRIO will once again call on our friends and members to participate in our advocacy efforts by joining us in writing to our Members of Congress.

We will need to email and send letters to Members of Congress as we try to garner support and additional co-sponsors for this bill. We'll publish more information here in the newsletter and also on our chapter's website at [www.litrio.org](http://www.litrio.org) inclusive of sample letters so if you so desire, you will be able to express your support for this bill.

## **Support the Living Donor Protection Act (HR 5263)**

**The Living Donor Protection Act (HR 5263)**, sponsored by Representative Jerrold Nadler (D-NY) and Representative Michael Burgess (R-TX) was introduced on July 30, 2014 during the 113th Congress- 2013-2014.

**Mike Sosna**

*Editor's note: The following article appeared on the website Health News from HealthCanal.com on June 29, 2014. It is based on an article that appeared in the online version of The Lancet on June 27 authored by the 3C Collaborative Group.*

## **Kidney transplant drug halves the early risk of organ rejection**

Oxford University scientists have shown that a drug given at the time of a kidney transplant operation halves the risk of early rejection of the organ. The drug, called alemtuzumab, also allows a less toxic regimen of anti-rejection drugs to be used after the operation.

The researchers have reported their results in the medical journal *The Lancet* and have presented their findings at the World Transplant Congress in San Francisco.

Kidney transplantation is still the best treatment for patients with kidney failure, but much more subtle approaches are needed if success rates are to be improved.

Around 2,000 people have a kidney transplant in the UK every year, and 15,000 people receive a transplant annually in the USA. Patients need to take drugs to suppress their immune systems in order to reduce the chances that their body will 'reject' the new kidney. It is a risky procedure since disabling the immune system in this way can lead to an increased number of infections and cancer.

Doctors are often faced with a difficult conundrum: using powerful combinations of treatments to prevent early kidney rejection can cause kidney damage later, and may subsequently be a cause of transplant failure.

One of the main culprits is a class of drugs known as calcineurin inhibitors. These drugs are very effective at preventing rejection in the first weeks and months after a transplant, but their effects can have serious consequences for the kidney later on.

The 3C study, led by Oxford University scientists, tested whether the anti-rejection drug alemtuzumab with low-dose tacrolimus (a calcineurin inhibitor) could reduce transplant rejection when compared with existing treatment.

The study recruited 852 patients who had a kidney transplant in the UK between 2010 and 2013.

'Our primary aim was to find out whether alemtuzumab-based induction therapy would produce worthwhile reductions in acute rejection,' explains chief investigator Professor Peter Friend, from Oxford University's Nuffield Department of Surgical Sciences, 'but we also wanted to see whether we could use it with a lower dose of tacrolimus, because there is some evidence that tacrolimus contributes to long-term transplant failure.'

7.3% of those receiving the alemtuzumab-based therapy experienced early rejection of the organ, compared with

16.0% of those on basiliximab-based therapy – a halving in the risk of early rejection.

'These are important findings which we hope will guide treatments in the future,' said Professor Friend.

Although alemtuzumab has been available for many years, its use has been limited by concerns about possible side effects, in particular infections. But the scientists report that there was no increased risk of serious side effects – such as infections and cancer – among patients on the treatment.

Dr Richard Haynes of the Clinical Trial Service Unit at Oxford University said: 'The safety data from the 3C Study are reassuring. There was no overall excess risk of infections or other known complications of immunosuppression.'

Professor Colin Baigent, one of the other lead investigators, said: 'These results from the first six months of the 3C Study demonstrate the importance of large randomized trials in transplantation. The planned long-term follow-up of the 3C Study will provide a unique opportunity to investigate whether these differences in short-term outcomes translate into improvements in the long-term which will be of great interest to patients and their doctors.'

Professor James Neuberger, associate medical director at NHS Blood and Transplant, said: 'NHS Blood and Transplant is delighted to be supporting this multi-centre UK study into the immunosuppression treatment of patients who have received a kidney transplant. We would like to congratulate the investigators on the good outcomes they are reporting and we hope these results will be sustained in the long term. Improving outcomes for patients and their families will help us to achieve our aim to make every donation count and enable even more patients receive the transplants they need.'

## **We Value Your Input**

At the Long Island TRIO Newsletter, we welcome your contributions. Each of you has had an array of experiences in the transplant field, and we look forward to hearing your stories, questions, opinions, and advice. Please help us to make this Newsletter more relevant by sending your entries to the editor at [litrinews@gmail.com](mailto:litrinews@gmail.com).

The following article appeared in the September 2014 issue of *Scientific American Magazine*. The article, authored by Dina Fine Maron, describes a technique whereby livers, and eventually other organs, can be supercooled for a longer period and thus improve access for patients awaiting transplant.

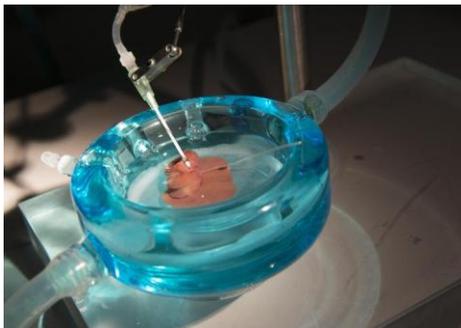
## Supercooled Organ Donations Could Last for Days

About 6,400 liver transplants took place in 2013 in the U.S., but demand far outpaces supply: more than 15,000 patients are on the current waiting list. Compounding the lack of availability, livers have only a small window of time to reach their destinations. The organs stay fresh for just 12 hours, during which they are kept on ice with a cold preservation solution. That is because freezing them is not an option—the process creates ice crystals that slice through the cells on thawing.

At Harvard Medical School, researchers are ditching the conventional storage technique in favor of a method that could extend the shelf life of livers and other organs. In results published in July in *Nature Medicine*, they report preserving viable rat livers for three whole days.

To preserve the organs for that long, the team used a specialized machine to erect a chemical buffer zone around the organ's cells. That buffer protected the cells' membranes against the threat of ice. The team then slowly cooled the livers to  $-6$  degrees Celsius without actually freezing them—"supercooling" them.

In the experiment, six rats received livers supercooled for three days, and each one survived for three months (at which point the experiment ended, and they were euthanized). As expected, rats that received three-day-old livers preserved on ice all died. The supercooling method, however, cannot work indefinitely: only about 60 percent of rats receiving livers stored for four days managed to survive for the study's duration. Next, the team plans on testing the method with pigs and humans.



A supercooled rat liver sits in the preservation solution in the machine perfusion system.

The success with this approach, the authors say, could extend the reach of organ transplants and so provide greater access to patients. In

the U.S., the national map for liver distribution is currently far from equal. For instance, patients living near trouble spots, such as big highways prone to traffic accidents, have a higher chance of receiving a viable liver.

In the future, supercooling may also support research with organs on a chip, according to Korkut Uygun, who was part of the liver experiment and is an assistant professor of surgery at Harvard Medical School. Organs on a chip are collections of laboratory-grown human cells designed to mimic the organs in the body. They are a highly anticipated way to study how our organs work and how they respond to various drugs. Supercooling would make shipping them from manufacturing labs to researchers more practical. For now the promise of getting transplant organs to patients remains the primary focus. The waiting list for all organs has climbed above 122,000.

## President's Corner

During June and July 2014, members of Long Island TRIO went back to school at Hofstra University to attend the National Youth Leadership Forum for Medicine. Our role was to explain, communicate, and engage the students while providing statistics on organ donation and transplantation. Additionally, we needed to present our personal stories on how organ donation and transplantation changed our lives forever. Our goal was to make an investment in their personal growth, knowledge, and career opportunities.

The students came from around the world (Turkey, Puerto Rico, Canada, Mexico, US and many more countries), representing the highest achieving high school students, looking to gain real world information and experience in the field of medicine. These students were looking for important insight as they navigate their careers, exploring and preparing to match their interest and passion for a future in medicine.

In all we were able to touch the lives of over three hundred students with information on the Gift of Life. I personally had encounters three students that had express specific interest in the field of organ donation and transplantation and the other presenter had experiences with other students.

*continued on next page*

As the new school year kicks off on Long Island, we are gearing up for another eventful year of high school and college presentation on organ donation and transplantation. Led by **Jeff Fenn**, our director of the school speakers program, we were able to communicate and touch the lives of over seven thousand students in 31 schools last year. The 2014 – 2015 school year represents a tremendous opportunity and challenge for LI TRIO. In the past, most of our schools have been concentrated in Nassau County, due to the location of our school speakers. This school year, we are opening the door to Suffolk County schools, as we have some volunteers that have stepped up and stated, "I want to give back and help educate others." We will be starting a program in western Suffolk (Huntington – Smithtown) and a smaller pilot program in Hampton Bays. As these two areas develop, we will be looking for more volunteers to help support the initiatives of "Organ Donation Saves Lives," "Don't Take Your Organs To Heaven, Lord knows we need them here on Earth" or "The Gift of Life."

So if you can tell a story of how organ donation and transplantation have changed your life, please contact us at [LITRIOTalks@optonline.net](mailto:LITRIOTalks@optonline.net), [DRLITRIO@gmail.com](mailto:DRLITRIO@gmail.com) or call our Hotline @ 516 620-5900.

**No one can tell your story better than YOU!**

**Dave Rodgers**  
President LI TRIO

As of **August 29, 2014**, there were **123,342** candidates for transplantation waiting to receive an organ.

### LI TRIO Tribute Cards

**Florence Sosna has LI TRIO Donation Tribute Cards "In Memory Of" or "In Honor Of" a loved one.**

**You can contact Florence at 516-482-2908. At your request, Florence will customize, address and mail the card to your party in honor of a loved one and/or special occasion or in memory of a loved one.**

## The LI TRIO School Speaking Team is Looking for Volunteers

Have you ever considered making a valuable and unforgettable impact on today's students? Then consider joining the LI TRIO High School Speakers. By sharing your "transplant" story, you will help enlighten and encourage students to consider signing up to be organ donors when they are eighteen years old.

If you are interested or want additional information, contact Jeff Fenn at [litriotalks@optonline.net](mailto:litriotalks@optonline.net) or at 516-382-4678.

ALBANY >> Far fewer New Yorkers have signed up as organ donors than Americans as a whole, prompting the state to seek help boosting enrollment and shortening its list of patients who die waiting.

A study from Excellus Blue Cross Blue Shield showed 22 percent of New York adults in the donor registry, compared with 48 percent nationally.

The study also said 539 New Yorkers died awaiting a transplant last year while others became too sick and ineligible.

*-from a July 29, 2014 article by Michael Virtanen of the Associated Press, "New Yorkers Lag As Potential Donors."*

## Chapter Officers

Co-Presidents: Ed Burki and Dave Rodgers  
 Treasurer: Walter Ruzek  
 Secretary: Jo Michaels  
 Immediate Past President: Mike Sosna

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