

# 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 2014

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: Tony Scro

As I line up the photograph of Tony Scro on his balcony overlooking the Throgs Neck Bridge and Little Bay, I am having difficulty believing this man is ten years older than me. He looks about ten years *younger* and his demeanor does not look to be that of a senior citizen. It is initially remarkable that he underwent a liver transplant in 1999 and is thriving now, until he tells you his story and his philosophy that caused his medical odyssey to end in triumph. He enjoys his time on the planet and feels fortunate because "I could have been six feet under."



Tony Scro

This is in stark contrast to the worst of times in May of 1999, when a suspicious mass led Tony's doctor to refer him to Memorial Sloan-Kettering Cancer Center. A doctor there told him, essentially, that he could not be saved, that his hepatitis B, C, and cancer made him inoperable and unsalvageable. After a good cry at the bus stop outside Sloan-Kettering, Tony and wife Edie came to the realization that he had to take charge of his own medical outcomes. The tone of his prognosis began to change when the Scros visited Mount Sinai Hospital and Dr. Myron Schwartz. Tony's wife Edie took it as a good sign when they found a rare parking space on 98th Street and Fifth Avenue on the day of the initial visit. During dinner that evening, a fortune cookie at Tony and Edie's favorite Chinese restaurant predicted that his luck was about to change completely.

Tony was presented with two procedural choices to combat his condition, progressive hepatitis C disease that had developed into cirrhosis and liver cancer: He could undergo surgery to remove the tumor, where his recovery was uncertain, or undergo a liver transplant from a living person. Tony had little chance to receive a cadaveric liver because he was not sick enough even though his platelets were dropping precipitously. His liver cancer would have metastasized before he became eligible to receive a liver. The problem with a living transplant was that Tony's two daughters were in different stages of childbirth: One was about to give birth and the other had just undergone her six-week checkup following the birth of her baby. Older daughter Elyse was firm, however. She told dad Tony "You gave me life – I want to give it back to you." At the time of the transplant, the baby was only eleven weeks old. Despite the new arrival, Elyse's husband was supportive as was his family.

*(continued on next page)*



**Edie and Tony Scro**

The June 24, 1999 operation to transplant part of his daughter's liver into Tony was difficult. She gave her right lobe which constituted more than 60% of her liver, a highly unusual procedure in 1999. Tony has flashbacks of waking up during the procedure and hearing frantic activity, as the doctors had to stop periodically to check on his progress. Because of the extent of her donation, Tony's daughter had complications, running high fevers in the days immediately following the surgery. After Tony was wheeled across the hall from her, Tony's wife Edie stayed with their daughter all night, and shuttled back and forth between the two rooms. Tony's other daughter, Vanessa, gave a birth on June 28th at Winthrop Hospital thus revealing, as Tony puts it, "the whole cycle of life."

Complications ensued for Tony after the transplant also. He was hospitalized frequently in the first six months until he was diagnosed with blockage of his bile ducts. He was consumed by itching and frequent high fevers. His bile ducts were repaired in December ("plumbing") and, since then, there have been few complications. High blood pressure was regulated because high BP can cause kidney damage in liver transplant recipients. After a three-month recovery period, his daughter was able to return to work and resume all her normal activities.

Tony is a strong advocate of the care he received at Mount Sinai. When a liver donor died there in 2002, the hospital enlisted Tony to tell the story of his own successful experience. Tony and family appeared on Sixty Minutes II, helping to educate the public about the life-saving benefits of live organ donation. Tony proudly showed me a picture of him and his family with Dan Rather.

Tony and Edie have learned valuable lessons from his experiences. Recovery, he says, is 50% science and 50% attitude, family support, and prayers. "You have to work at smelling the roses," he says. He joined a HEP C support group and returned to work in April 2000 on a part-time basis, benefitting from the massive amounts of leave donated to him from other New York State employees, a testament to his popularity at the workplace. He finally retired in 2004 and is now a consultant to drug treatment facilities. Tony had worked for the NYS Office of Alcohol

and Substance Abuse Services as well as a volunteer advocate for the National Alliance for Medication Assistance (NAMA) Recovery, and is a proponent of drug treatments that prevent the spread of hepatitis C and HIV. Now he advises drug treatment facilities on how to meet Medicaid requirements by providing sufficient documentation and adherence to rules and thereby avoid rejected claims and resultant financial difficulties.

He and Edie regularly attend American Liver Foundation (ALF) events and plan to attend the upcoming ALF Re-Birthday ceremony and Liver Walk in Eisenhower Park. Since retiring, the couple has travelled frequently, to Europe, various tropical islands, and across the United States. His children and three grandchildren also keep him busy. He modestly told me he had taken up golf and was a regular at nearby Christopher Morley Park. Wife Edie, who was a social worker for New York State, now attends adult education classes and makes beautiful handmade jewelry.



I asked Tony to summarize the lessons he had learned from his arduous medical history and he provided the following:

A positive attitude is going to help you through ordeals.

Be very active and involved in managing your own condition. Seek a second or third opinion if necessary.

Find a doctor who communicates well and is accessible.

If you want to change, you have to work at it. Even "life-changing" events won't change you by themselves.

**Howie Pohl**

## Upcoming Events

April 9, 2014 – General Meeting – Speaker TBA

April 12, 2014 – Transplantation Re-Birthday Party: Celebrating The Gift of Life and the Miracle of Liver transplantation – American Liver Foundation – 10:00 AM – 12:00 PM – Speaker: James S Park MD, CNSC, at NYU Hospital – Homewood Suites, Carle Place

April 26 – Remember and Rejoice Ceremony for Donor Families – St. Patrick’s Cathedral – 2:00 – 3:30 PM

May 14, 2014 – General Meeting – Speaker TBA

May 18 – Liver Life Walk – Eisenhower Park – 10:00 AM

May 18 – Kidney Life Walk–Eisenhower Park–10:30 AM

For more information about these and other activities, see the LI TRIO website at [www.litrio.org](http://www.litrio.org)

## Have An Interesting Story?

Every transplant recipient, donor, and support person has a story to tell. Let’s find out about one another. Contact Howie Pohl, the LI TRIO Newsletter Editor, to be interviewed. He can be reached via email at [litriolnews@gmail.com](mailto:litriolnews@gmail.com) or telephone (631) 884-0482.

## April Re-Birthdays

Fran Addazio	April 11, 2002	Kidney
Gillian Cohen	April 17, 2005	Liver
George Donohue	April 12, 1996	Kidney
Margaret Gonzalez	April 18, 2002	Kidney
Anne Melican	April 20, 2009	Kidney
Iris Pappalardo	April 26, 2012	Kidney
Sandrajane Rios	April 16, 2008	Liver

**Have you paid your dues for 2014?**

\$25 per year allows Long Island TRIO to continue its activities on behalf of organ transplantation and donation. Fill out the green card you received in the mail.

## May Re-Birthdays

Ann Grasso	May 5, 1995	Liver
Ralph Greener	May 8, 2008	Kidney
Melvin Kershner	May 21, 2009	Kidney
Leslie Kreisman	May 5, 2000	Kidney
David Krugman	May 13, 2006	Kidney/Liver
Hopeton Lue	May 30, 2000	Kidney
Brian Maguire	May 10, 1992	Kidney
Richard Prete	May 8, 2008	Liver
Vito Riservato	May 6, 2002	Liver
Vinny Santalucia	May 27, 2000	Kidney
James P Schneidmuller	May 23, 1987	Liver
Joe Senatore	May 19, 1999	Heart

## CMS Backs Off and Transplant Recipient Support Organizations Win The Battle - For Now

In January 2014 CMS proposed changes to the Medicare Part D prescription drug program that currently covers medication for more than 39 million people in the United States. The proposed changes included eliminating the protective status for immunosuppressant medications (prescribed to transplant recipients to protect the transplanted organ from rejection), antidepressant medications and antipsychotic medications.

Medicare has six protected drug categories at this time. The proposal would have removed two of those (immunosuppressant and antidepressant medications) as of January 1, 2015 and considered the removal of protected drug status of antipsychotic medications in 2016.

### So, what is "protective status", anyway?

When a class of medications has a protective status, there is a requirement that Medicare Part D plans include “all or substantially all” drugs within the protective class on their formularies. This allows the physician and patient to have the ability to decide what is best for an individual person. Each person is

different and there can be different side effects and effectiveness of various medications regimens.

The rule proposal we are discussing herein would have removed immunosuppressant medications for example, from the list of protected classes. In some cases physicians would not be allowed to choose which medication (even if it's available as a less expensive generic medication) could be prescribed to a transplant recipient. As you know, transplant recipients must take immunosuppressant medications to prevent the transplanted organ from being rejected. Some of these recipients receive their immunosuppressant medications via Medicare Part D. As transplant recipients, we sometimes require adjustments to our immunosuppressant medication regimen and this can involve changing from one immunosuppressant to another. Transplant recipients and physicians prescribing on behalf of transplant recipients need to have access to all immunosuppressants.

Now that CMS has backed off and withdrawn this proposed rule for now, Medicare Part D insurance must continue to cover all FDA approved immunosuppressive medications.

The policy, known as the “six protected classes” policy, has been in effect since the commencement of Part D and has always had the support of members of Congress.

***Who is CMS and why did CMS think that they could easily just remove immunosuppressant medications from their protective status?***

CMS is a federal agency that is part of President Obama's Department of Health and Human Services. CMS is responsible for administering Medicare and Medicaid. CMS actually stated that they proposed this rule because having a physician forced to prescribe a transplant recipient a different medication (other than the one the physician prefers to prescribe to the patient) would not necessarily cause a hospitalization seven days after not receiving a prescription (to the physician's first choice of medication to prescribe) so therefore CMS concluded that all immunosuppressant medications are interchangeable.

Long Island TRIO reacted quickly and effectively and was on top of this issue the moment the proposal was released to the public. We joined ten other organizations and those organizations networked to many other patient groups and other healthcare organizations to organize a rapid response. We effectively communicated individual and organizational comments that were delivered to CMS and to members of Congress. This issue was posted on our chapter's website and on our Facebook group and on twelve other Transplant Facebook groups in which we participate. As the March 7th deadline approached, 370 organizations were on board in this battle. This incredible effort helped abrogate the

proposed rule for now.

Members of Congress on both sides of the aisle (Democrats and Republicans) in both houses of Congress overwhelmingly supported our position and stated that they were against the CMS proposals and that for all intents and purposes, their constituents were wholly and unconditionally against the CMS proposed rule. Subsequent to a Congressional hearing, the CMS administrator inventoried a prodigious amount of written comments and had to conclude that there was overwhelming opposition to and disapproval of the proposed rule. *(continued on next page)*

The proposal was open to comments until March 7, 2014. I'd like to especially thank many of our members and volunteers who submitted formal comments about the proposal and also wrote to me letting me know that they took the time to help in this regard. For transplant recipients that receive their immunosuppressant medications via Medicare Part D (some receive immunosuppressant medications via Medicare Part B) this issue is one that is a matter of life and death.

After the rule proposal's huge number of negative comments by individuals, members of Congress and patient and healthcare organizations, CMS administrator Marilyn Tavenner drafted a letter to Congress promising not to move forward at this with the proposed rule time but keeping open the option of moving forward with the proposed rule in the future.

“Given the complexities of these issues and stakeholder input, we do not plan to finalize these proposals at this time,” Marilyn Tavenner wrote, adding that the CMS will “engage in further stakeholder input before advancing some or all of these changes in these areas in future years.”

Our chapter will stay on top of all future proposals from CMS and other agencies and we know that this issue will likely come up again in the future.

**- Mike Sosna**

As of March 25, 2014, there were 121,835 candidates waiting for an organ transplant in the United States.

On April 12 at 10:00 AM, the American Liver Foundation (ALF) of Greater New York will hold a **Transplantation Re-Birthday Party** to celebrate the gift of life and the miracle of liver transplantation. The party will take place at the Homewood Suites, 40 Westbury Avenue, Carle Place NY. The speaker is **James S. Park MD, CNSC** - Gastroenterology, Hepatology and Transplant Hepatology, Assistant Professor of Medicine, Division of Gastroenterology, Department of Medicine, Co-Clinical Director, NYU Hepatology Associates, Clinical Director, NYU Langone at Great Neck, NYU Mary Lea Johnson Richards Organ Transplantation Center. **For further information, contact Jenna Adolph at (212)943-1059.**



## LI TRIO at Hofstra School of Medicine

On February 28, three members of Long Island TRIO appeared at the Hofstra University North Shore – LIJ School of Medicine. Liver transplant recipients Dennis Fearn, Dave Rodgers, and Ruth Pohl spoke of their successful journeys through liver disease and transplant operations, as well as the aftermaths with staying healthy through immunosuppressants. All three participants emphasized the power of positive commitment to good health and communication with doctors and other medical personnel.

After the TRIO members handled the first-year medical students' questions, the students presented cases for transplant of three hypothetical individuals in need of a liver transplant. Each of the three patients had factors which alternately encouraged or discouraged the case for transplant. The factors and whether the patients could overcome their issues – age, language aptitude, alcoholism, tobacco addiction, obesity – were presented to the Transplant Committee which makes these same type of decisions in real-life situations.



(Clockwise from top left) Dennis Fearn, Ruth Pohl, Dave Rodgers with Dr. David E. Bernstein MD, Gastroenterology, North Shore-LIJ Hospital, First-year medical students listen to liver transplant recipients tell their story, the Transplant Committee makes their decision, a student group presents the case for their candidate's transplant.

As Dave Rodgers, LI TRIO President, pointed out in his presentation, the Transplant Committee's discussions would be unnecessary if there were enough organs for all those in need but, since donation is so below average in New York State, the students' presentations are needed to apportion organs to those who stand the best chance of avoiding rejection.

The presentation to first-year medical students at Hofstra is in its third year and is arranged through the office of Dr. Samuel Packer MD who is the Chairperson of Medical Ethics at North Shore-LIJ Hospital. After the seminar, many students thanked the LI TRIO members for their presentations and sought additional information on how they could become more involved in the cause of organ donation.

## February General Meeting

**Dr. Vivian Tellis MD**, Director Emeritus of the Montefiore Hospital Transplant Program and Professor of Surgery at the Albert Einstein College of Medicine, was the guest speaker at the Long Island TRIO February General Meeting. Dr. Tellis presented a thorough overview of the status of transplant surgery. His discussion focused on the factors which contribute to graft survival.

(continued)



Dr. Vivian Tellis MD at the February LI TRIO General Meeting

Dr. Tellis raised and then debunked the various myths surrounding organ donation, which include religious reasons, age of the potential donor, preference of donation to famous people, premature removal of organs from the deceased. He discussed the need for a new system of distributing organs because the current system results in higher than necessary discard rates of kidneys that could benefit candidates on the waiting list, variability in access to transplantation by candidate blood type, sensitization level, and geographic location, and many kidneys with long potential longevity being allocated to candidates with significantly shorter potential longevity and vice versa. This results in unrealized graft years and unnecessarily high re-transplant rates.



The Kidney Profile Donor Index (KDPI) is designed to promote better longevity matching between donor and recipient in order to utilize the maximum amount of graft years. The plan for reaching this goal involves allocation by age-matching and by allocating some kidneys by matching KDPI with estimated post-transplant survival.



Dr. Vivian Tellis describes the prospects for survival of transplant patients.

## President's Corner

### Long Island Transplant Recipient International Organization

#### What is LI TRIO?

**LI TRIO is a non-profit all volunteer organization committed to improving the quality of lives touched by the miracle of transplantation through education, support, advocacy, and organ donation and transplantation awareness.**

**We are a chapter of TRIO National, an independent, not-for-profit, international organization.**

#### Who is LI TRIO?

**LI TRIO is an all Volunteer Board of Director and Staff, to support the cause of Education, Support, Advocacy and Organ Donation & Transplantation.**

#### How do I get information from LI TRIO?

**Newsletter: Published & mailed to each member, every other month**

**Website: LITRIO.org**

**Facebook: TRIO.org**

**Hotline: 516 620-5900**

#### How do I get involved with LI TRIO?

**Meeting: Our meetings are held on the second Wednesday of each month, from September to June. Our holiday party substitutes for the December meeting. Our meetings begin at 7:30 PM and are held at 145 Community Drive, Great Neck NY.**

#### 2013 Topics:

- **How Renal transplant can work for you**
- **New developments in the world of Transplantation**
- **Kidney Transplant – State of the Art 2013**
- **Healthy Transition – a comprehensive health education program**
- **Dermatology for the Transplant patient**
- **Organ in a Box – new technology for Organ survival & transporting**
- **Nutrition & Diabetes**
- **Living donor – Liver & Kidney Transplantation**

**2014 The fall of 2014 we are planning a weekend daytime meeting, as requested by our membership. Details will follow.**

#### 2014 Topics:

- **Specialty Pharmacy, mail order, Medicare compliance Immunosuppressant**

- **LIFE-SAVING DISCUSSION ON KIDNEY TRANSPLANTS, with an emphasis on Living donation of Organs.**

- **Care of your Kidney - Post Organ Transplant**

**Volunteer speaking:** Our greatest outreach is through our School speaking program, where we have reached out to more than 25,000 students in High School & College, since 2010. If you have a story to tell, please contact Jeff Fenn at [LITRIOTALKS@OPTONLINE.NET](mailto:LITRIOTALKS@OPTONLINE.NET) and see how rewarding it is to tell your story.

**Volunteer Rose Garden:** Our largest & most rewarding event is the Rose Garden Ceremony, where we Re-dedicated our "Long Island TRIO Donor Rose Garden" to Donors and Donor Families in a ceremony held in our part of Eisenhower Park, East Meadow, NY in Nassau County. Spring clean-up & weekly maintenance are needed. Whether you are a Rose Garden expert or want to learn more about Roses, please contact Dave Rodgers at [DRLITRIOGM@GMAIL.COM](mailto:DRLITRIOGM@GMAIL.COM). Have some fun & get some fresh air!!

**Volunteer for Organ Donor signup drives at Fairs, DMV & Voting registration,** please contact Dave Rodgers at [DRLITRIOGM@GMAIL.COM](mailto:DRLITRIOGM@GMAIL.COM)

**LI TRIO is Your organization and its strength is in you as a MEMBER, so why not make 2014 a year to get involved. Spring is officially here, what a time to get out & smell the Roses!!!**

Dave Rodgers  
President LI TRIO

### March General Meeting

**Dr. Madhu C. Bhaskaran**, a nephrologist in the Kidney Transplant Program of the North Shore-LIJ Health System, spoke at the March General Meeting of Long Island TRIO. Dr. Bhaskaran is also an Associate Professor at the North Shore-LIJ School of Medicine. His topic was *Care of Your Kidney – Post Transplant*. Dr. Bhaskaran emphasized the role of immunology in post-transplant treatment and discussed recent trends of immunological treatment. These are: lowered doses of medication, tailored specifically to individuals' needs, avoidance of corticosteroids, tolerance induction, and lower doses of calcineurin inhibitors.



Dr. Bhaskaran discussed the side effects of immunological drugs and the role of opportunistic infections in post-transplant kidney patients. A common aftereffect of kidney transplant is CMV where white blood cells attack the new organ. Valcyte is employed to prevent CMV disease in kidney recipients. Other topics included bk virus, donor derived infections and drug interactions.



Dr. Bhaskaran shows inclusion bodies indicating CMV

As a result of more sophisticated understanding of factors which cause rejection, there is now a lower incidence of acute rejection. CMV continues to be a major factor in renal transplant mortality.



Dr. Bhaskaran with three of his successful transplant patients (left to right): Margie Ng-Reilly, Monica Blum, Mary Graffeo, and with Dave Rodgers, LI TRIO President

Our thanks to Nadia Prete, who contributes coffee for our General Meetings. She does so to honor the Sosna family, Mike, Jerry and Florence.

(left): Madhu C. Bhaskaran MD

## Chapter Officers

Co-Presidents: Ed Burki and Dave Rodgers

Treasurer: Walter Ruzek

Secretary: Jo Michaels

Immediate Past President: Mike Sosna

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Howie Pohl - Editor

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- Become a friend of TRIO on Facebook:  
<https://www.facebook.com/groups/TRIOgroup/>
- Call our hotline: (516) 620-5900

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