

# 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 2013

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: Carol Heins

Carol Heins takes me on a tour of her backyard gardens with obvious pride. There are paths leading everywhere; trees, shrubs, flowers are arranged artfully, yet all of them have been allowed to grow fully and are only maintained to the point where they do not grow excessively.



It feels like a natural English garden, with stones providing a sense of boundaries but never a feeling of containment. There is a running stream, and even a foot bridge. Clearly, Carol has devoted a lot of energy to maintain this fabulous display. She has also devoted a lot of energy toward maintaining the quality of her life, and continues to thrive with determination and a

sense of humor, even while enduring our tough economic times.

Carol, a resident of North Babylon, is a dual transplant recipient of a kidney in 2008 and a pancreas in 2010. Both surgeries took place at Columbia Presbyterian Hospital. The surgeries occurred two years apart because the hospital was not certified to do pancreatic transplants at the time of the kidney transplant. Carol knew from the start that she would be required to have the pancreas transplant because she was an insulin-dependent diabetic and the doctors had informed her that her defective pancreas would damage her new kidney as it had her original. In fact, her kidney was transplanted into the left side of her body and her second surgery involved major rearranging of internal body parts. Her pancreas was moved parallel to her colon on the right side of her body, her bile duct was moved also, and her appendix was removed at the same time.

In what seems strange at first, Carol has created names for her two new organs. She has named her kidney *Patrick*, because she received it on St. Patrick's Day and the organ came from a male donor. Her pancreas is named *Dax*, because Carol and husband Walter Edwards are *Star Trek* fans and she figured that the donor, a twenty-one year old male, was likely a science fiction

aficionado so her new organ was named after a Star Trek character (a Trill symbiont, for those of you keeping score at home). While her doctors thought her a little crazy at first for naming her organs, they now refer to them as Patrick and Dax as well. Carol believes, and it makes sense, that giving names to one's transplanted organs imparts a sense of responsibility toward them and, indeed, she is very conscientious about taking her immunosuppressive drugs on schedule.

Her schedule of rapamune and tacrolimus has served her well by preserving her immune system and avoiding major complications. Although she keeps a supply of blood glucose testing equipment, she feels no need to test her blood glucose any longer as her pancreas is doing its job well. She swears by the doctors who performed her transplants: Dr. Michael Goldstein (now at Mount Sinai Hospital), who was so passionate about transplanting her new kidney, and Dr. Lloyd Ratner, who performed her pancreas transplant.

Although Carol is a highly qualified architectural planner and designer, with advanced computer skills, she has not been so lucky in the current job market. She has had three jobs in five years. Her unemployment benefits are soon to expire and she has widened her search for a suitable job, as did her husband, who is also an architect but is working outside of his area of experience. She states that employers are "looking for thirty-somethings with thirty years of experience." Like many other transplant recipients, she must deal with the high cost of immunosuppressives and the vagaries of insurance coverage.

In the meantime, this "energizer bunny," according to her friends, fills her days up with rewarding activities. In addition to her outstanding gardening efforts, Carol does things to improve her house. Last year, it got a new paint job, this year a warped fireplace flue was replaced. These and other improvements help to avoid anxiety or depression as do the numerous classes she has taken at the North Babylon Public Library, particularly yoga, crochet, and adult education classes. In the past, she and her husband spent time in their tandem kayak on the Connetquot River and the Great South Bay. She

loves English comedies and murder mysteries.



Carol pays it forward by volunteering with Donate Life when there are fairs and local events to raise consciousness

about organ donation. In fact, following her surgeries, Carol, her friends and family, including her 83-year-old mother, have all become organ donors. She stays structured by making a schedule and sticking to it and challenges herself to keep going with only minimal health setbacks and in the face of harsh economic times. Certainly, that backyard garden has proved a great source of activity and a haven of respite.

*Howie Pohl*

## Upcoming Events

June 12 – **LI TRIO General Meeting** – Dr. Carol Hazan MD – NYU Langone Medical Center – Specialist in Dermatology & MOHS Surgery – 7:30 PM

August 24 – Organ Donation Awareness Picnic at **Long Island Ducks Game** – Bethpage Ballpark

September 11 – LI TRIO General Meeting – Guest Speaker TBA

September 21 – **Rose Garden Ceremony** – Eisenhower Park – Rededication Ceremony to Honor Organ Donors

November 22 – **Holiday Party** – Leonard's of Great Neck

*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 [litrionews@gmail.com](mailto:litrionews@gmail.com) or telephone (631) 884-0482.

## Readers' Forum

*LI TRIO member Iris Pappalardo has submitted the following pieces of medical advice for the benefit of others. If you have any reactions to her letter, or wish to provide information on any transplant-related subject, please send your thoughts to: [litriionews@gmail.com](mailto:litriionews@gmail.com).*

I want to share some information that I think other patients with renal failure who are on dialysis and also post kidney transplant. I share these things as this is what I am dealing with. Firstly, people with ESRD become anemic and they are usually given meds like Aranesp IV after dialysis as well as Iron IV. I found out, post transplant that I have developed hemochromatosis and even though my iron levels became high while on dialysis and was stopped [for a while], no one checked into the fact that I have a "faulty gene" that caused the iron deposits causing IRON OVERLOAD that found my liver and spleen. And, because of anemia I cannot be phlebotomized. This could have been avoided before I received my transplanted kidney and that kidney could be in jeopardy because of the medication recommended.

Secondly, please advise others that sometimes after transplant their doctors need to monitor the patients remaining kidneys as it is possible to develop a malignant tumor within the diseased kidney. My transplant physician, Dr. F. Darras, from SBUH just removed my left kidney for same reason and he advised me that this is an issue that he and his associates are going to monitor carefully, as I apparently am not the first nephrectomy he has done on one of his patients.

To be aware is to be forearmed.

### July Re-Birthdays

Beth Chapman	July 11, 2008	Pancreas/Kidney
Dr Waled Chowdhury	July 21, 2008	Kidney
Fred Cohn	July 28, 2011	Liver
Anthony Devivo	July 8, 2007	Liver
Anthony DiMaria	July 19, 2007	Heart
Jeffrey Fenn	July 9, 2004	Kidney
Albert Ferro	July 28, 1998	Liver
Joanne Flores	July 13, 2011	Kidney
Purushottam Goyal	July 21, 2011	Kidney
Lauria Laria	July 6, 2006	Kidney
Alan Leavy	July 22, 2010	Kidney
Jennifer Lentini	July 6, 1996	Heart
Daniel Letvak	July 18, 2002	Kidney
Jean B Nassani	July 18, 2011	Kidney
Henry Prins	July 2, 1992	Liver
Michael Sosna	July 18, 1995	Kidney
Margaret Young	July 28, 1991	Kidney

### 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
Sandrajane Rios	April 16, 2008	Liver
Robert Skaretka	April 28, 1991	Heart

### 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
Gale Teney	May 23, 2011	Kidney
Ida Tesoriero	May 12, 2005	Kidney

### June Re-Birthdays

Monica Blum	June 7, 2010	Kidney
Stephen Fisher	June 29, 2011	Kidney
Rich Friedman	June 29, 2012	Kidney/Liver
Bob Geisler	June 28, 2009	Kidney
Tom Hackett	June 13, 2006	Heart
Jean A Kelly	June 16, 2005	Liver
Charles Lawlor	June 12, 2003	Lung
Mel Lerner	June 10, 2008	Kidney
Mary Lou Murphy	June 1, 2009	Kidney
Daniel O'Neill	June 28, 2007	Kidney
Ruth Pohl	June 1, 2003	Liver
Sharon Ross	June 10, 1995	Kidney/Pancreas
Anthony Scro	June 24, 1999	Liver
Steven Wolf	June 10, 1998	Kidney

## Chapter Officers

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

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## Newsletter Staff

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- 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



*118,594 people are on the waiting list for transplants as of June 14, 2013.*

## MEET CO-PRESIDENT ED BURKI

### Meet Co-President Ed Burki

I'm a kidney and pancreas transplant recipient for over 13 years and have worked for LI TRIO about as long. After three months of dialysis, I received a transplant and awoke to a fully functioning kidney and pancreas. My internal need to 'give back' led me to LI TRIO, where I used my prior business skill sets and personal journey to work with the Board of Directors to help others. I strive to do more each day while dealing with complications that many transplant recipients experience. I temper this by appreciating each day and enjoying all that life has to offer. I'm a car fan and just sold one of my two convertibles. I'm in the process of "retiring" to Florida but will support my friends and associates to the best of my ability. I look forward to my daughter's graduation from Berklee College of Music and singing the National Anthem with her as she leads the LI TRIO Singers at the Ducks game this summer, so we can once again spread the word about organ donation.

Wishing you all good health and a positive outlook as we share our journey into the future.

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