

# 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.*



AUGUST 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*

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

### Transplant Profile: Jennifer Lentini

What would it be like to undergo a heart transplant at age 13? **Jennifer Lentini** did just that and can speak at length about the good parts and the bad about receiving a new heart at such a young and vulnerable age. She did so to me from a temporary home after her and her family's Hicksville house was damaged in a fire. While this was a terrible experience, it only seemed mildly upsetting compared to Jennifer's life experiences in undergoing heart disease and transplant at such an early age.



A very active girl suddenly found her grades slipping and her social contacts curtailed in seventh grade. Jennifer was active in several sports, dancing, and baton twirling. Doctors conjectured every type of physical ailment for her, mostly centered on her complaints of stomach ailments, none of which turned out to be accurate. The school's

nurse's office became the subject of daily visits and her parents regularly accompanied her to hospital emergency rooms as her illness worsened. Doctors hypothesized all manner of physical ailments – urinary infections, viruses, appendicitis, twisted ovaries – none of which were verified by tests. She was sent home from a twirling competition, admitted to a local hospital where exploratory surgery was performed on her where her appendix was removed, but nothing else was discovered that would explain her debilitating symptoms. When Jennifer left surgery, she had ballooned in size and then went into cardiac arrest.

One doctor at the local hospital was able to accurately diagnose Jennifer's symptoms as caused by heart disease. She was so sick that it was thought that bringing her by ambulance to Columbia Presbyterian Hospital was too risky. Jennifer was dying: A priest administered last rites, her younger brother (who had open heart surgery as a two-year old), and parents came to say their final farewells. The doctor, however, was able to stabilize her and she was transported, with police escort, to Columbia Presbyterian Hospital.

Age thirteen was a traumatic time for Jennifer. Imagine how difficult it is for most early teens and then multiply that by a thousand: She was so sick after a lifetime of good health, no one could correctly diagnose her illness for a long period, then she was relegated to a sterile hospital environment for months, not knowing if and when she was to receive a new heart, waiting with other children and not knowing where she stood on the transplant list, seeing some of them pass away while waiting, hooked up into multiple intravenous drugs, and ingesting a barrage of pills every day just to stay alive. She was virtually immobilized, shuttling between a wheelchair and her bed. Although she was supposed to be isolated due to her susceptibility to infection, Jennifer was frequently transferred between

double occupancy rooms due to space shortages at the hospital. Luckily, Jennifer's mom and dad took turns as her constant day-and-night companions.

Perhaps her worst moment came when Jennifer received a phone call directly telling her that a heart was available to her. It turned out that the call was a mistake and the heart was intended for someone else (There was a nurses' strike at the time which resulted in some procedural chaos). Jennifer acted out frequently, leading the other kids into removing their telemetry tubes and swinging them over their heads defiantly. Friends from school sent cards and flowers but rarely visited. When priests and Make-A-Wish representatives visited her, the young teen feared that death was imminent.

A 14-year-old boy named Matthew had died in upstate New York. After months of waiting, his heart became available to Jennifer on July 6. With more than three months in the hospital, the teen had become accustomed to being a resident and part of her did not want to leave the now safe hospital environment. Having been there for so long, Jennifer felt like she was the facility's queen, and she coveted its institutional security. Nevertheless, she was out of the hospital two weeks after her transplant.



Matthew, Jennifer's Deceased Donor

Her post-transplant teenage years were filled with insecurities exacerbated by the effects of her transplant. She would sometimes stop taking her assortment of medications, had to wear a mask to school, blew up physically, and grew unwanted hair. She was in and out of school for tests.

As she grew older, Jennifer became more comfortable in her own identity. She has realized that she must be her own advocate for proper health care. She is now a fierce advocate for organ donation and frequently speaks to teenagers who, she says, are really open to hearing about her experiences. She feels part of her is still 13 and trying to recover the years lost to bad health and medical treatment. She appreciates every day and has engaged in some fast-paced living including kickboxing, zumba, interval training, ziplining, parties, amusement park rides, and she "I-o-o-o-ves" movies. She spent a year living in Las Vegas even though heart specialists were non-existent there. She desperately wants to go the Transplant Games next year in Houston and wants to try her hand at skydiving. She feels she will always be behind and wants to make up for it. Although she had a major rejection episode at the age of 25, she does not let health issues govern her life. She

goes to the doctor when she needs to and does not let the precariousness of her health status get her down. She has been told that her heart will not last forever, yet she just celebrated her 17<sup>th</sup> re-birthday.

Jennifer's formula for success is 25% staying on a drug regimen, 25% positive attitude, 25% luck, and 25% "everybody's different." With such an outlook, even having your home go up in flames seems like another event to be dealt with instead of a permanent barrier.

*Howie Pohl*

## Upcoming Events

**July 31 – August 4** – Organ Donation Sign-Up Desk at Our Lady of Mercy Summer Fair - Hicksville

**August 24** – Organ Donation Awareness Picnic at Long Island Ducks Game – Bethpage Ballpark – Central Islip – See this issue for more information

**September 11** – LI TRIO general Meeting – Guest Speaker: Khalid Butt MD – Professor of Surgery, New York Medical College

**September 21** – Rose Garden Ceremony – Eisenhower Park – Rededication Ceremony to Honor Organ Donors – See this issue for more information

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



Congratulations to **Mike Sosna**. Mike received a Certificate of Appreciation from the National Transplant Recipients International Organization for his exemplary service on behalf of organ donation.

**August Re-Birthdays**

Richard DeRocher	August 24, 1999	Kidney
Eileen Dimino	August 10, 1996	Kidney
Iris Edelson	August 2, 1995	Liver
Mary Ferris	August 14, 2001	Kidney
Bob Graziani	August 20, 2010	Lung
June R Herman	August 30, 2005	Kidney
James Jewell	August 13, 1986	Liver
Michael Marchetti	August 19, 2011	Liver
Richard Marrone	August 31, 2010	Liver
Chris Russo	August 13, 1997	Kidney
Joan Sabal	August 31, 2005	Kidney
George Tietjen	August 23, 2001	Kidney
Luis Torres-Ayalaway	August 18, 2008	Liver

**September Re-Birthdays**

Hugh Collins	September 13, 1990	Liver
Alice Dillon	September 5, 2007	Kidney
Neila Farber	September 29, 2007	Kidney
Elise Folk	September 25, 2007	Kidney
Robert Gabe	September 15, 1997	Heart
Kathleen Gerlach	September 8, 2005	Kidney
Judith Gluck	September 3, 2002	Kidney
Helena McDermott	September 18, 2008	Kidney
Arthur Menendez	September 19, 2002	Kidney
Margie Nq-Reilly	September 27, 2010	Kidney
Jack S Panes	September 17, 2008	Kidney
Karen Paulick	September 8, 1996	Liver
Richard Randall	September 3, 2005	Liver
Barry Rose	September 12, 1995	Kidney
Eric Young	September 7, 1979	Kidney

Reader **Josephine Recine** wants to remind us that we should be eternally and continually grateful to our donors, for providing us with the **Gift of Life**. Thank you, Josephine.

**Duck Tickets May Still Be Available****Contact Walter ASAP!**

Although tickets to the Long Island Ducks game of August 24 have sold out, we may be able to obtain additional tickets. LI TRIO will once again be promoting the importance of organ donation and transplantation as we perform the National Anthem at our annual outreach event. To see if tickets are available, contact Walter Ruzek at [wruzek@hotmail.com](mailto:wruzek@hotmail.com). This year's outing will include an in-game "All you can eat" picnic area that includes hamburgers, hot dogs, chicken, ribs, roasted corn, tossed salad, Pepsi beverages, Entenmann's cookies, potato chips, snacks, watermelon, potato, and macaroni salad. The picnic food and beverages as listed above runs from the end of the 1st inning through the end of the 7th inning or 1 1/2 hours, whichever comes first. We all have the flexibility and privilege to dine in the picnic area set aside exclusively for our Long Island TRIO group and can feel free to take the food back to our seats.

A special ticket deal is available to members whose LI TRIO 2013 dues have been paid as of June 15, 2013. Our chapter is paying \$30.00 for each ticket. Here's the special deal: Your first 2 \$30 tickets purchased will be 1/2 price – 2 tickets for \$30. Additional tickets are \$30 per ticket. For your children we have a special deal as well: After a member in good standing's first two tickets are purchased at fifteen dollars each, pay only \$24 each for children 9 and under and children 3 and under are admitted FREE as long as they sit on someone's lap. Children under 3 can enjoy the picnic at no charge.

Checks should be made out to Long Island TRIO and sent to: TRIO - Long Island Chapter PO Box 81 Garden City, NY 11530.

## THE REDEDICATION OF THE ROSE GARDEN AT EISENHOWER PARK

The Rededication of the Eisenhower Park Rose Garden is part of the Long Island Transplant Recipients International Organization's (LITRIO) annual ceremony to recognize and honor organ donors and donor families. The ceremony will be held on Saturday, September 21<sup>st</sup>, 2013 from 12:00 p.m. to 2:00 p.m. at the Eisenhower Park Rose Garden located near parking fields 6 and 6A.

This year's Rose Garden Ceremony will be very special as we honor our Heroes; the Donors and Donor families who gave so generously and who provided the Gift of Life and a second chance at life for transplant recipients. They are lifesaving heroes who have shared life. Many recipients are thrilled and very lucky to thank Long Island and New York Donor Families for creating a brighter tomorrow. Among the speakers at the ceremony will be elected officials and healthcare professionals, donor families and organ and tissue recipients.

The LITRIO maintains the Rose Garden as part of their participation in Nassau County's Adopt a Park Program in recognition and celebration of life giving organ donations. LITRIO is the local chapter of Transplant Recipients International Organization, which is a all Volunteer non-profit international organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness.



## MEET CO-PRESIDENT DAVE RODGERS



### Meet Co-President Dave Rodgers

My journey with transplantation started back in 2002. I became jaundiced and fatigued working as a Corporate Executive. My work week had to be reduced to forty hours a week from sixty. Upon being admitted into the hospital. It was determined that my liver was dying, which was later confirmed through testing. I was put on the transplant list and quickly moved to the top of the list. Over the next four weeks, my kidney shut down, I went on dialysis, stayed alive via a regiment of 35 pills twice a day, was confined to bed, and had three proposed cadaver livers rejected. Finally, the fourth liver was a match and I received my liver transplant. My kidneys started working within a couple of days and my new life as a liver transplant patient began.

This was all possible, due to my 27-year-old donor Scott, who died of a brain aneurism. Scott is my hero. It took 9 1/2 years to make contact with my donor's mom and we have met the last two years to discuss My Celebration of Life & what Scott did as a donor and as a person. Here is what Scott's gift has done for me: Walked my oldest daughter down the aisle, saw my two Grandchildren be born, my younger daughter open her own business and my youngest son become a teacher and pursue a second career in administration. My likes are my dog, camping & fishing, classic cars, football (just attended my 42nd reunion) and traveling. Oh, I almost forgot babysitting my grandkids, the best job in the world; I always find energy and make time for that.

Upon my successful recovery, I realized that I needed to give something back, pay it forward for the next person and pay honor to Scott for the Gift of Life. In 2003 I joined the American Liver Foundation and began raising money for the ALF Walks. I just completed my 11th year of walking & fundraising. I also serve on the Executive Board of the ALF-NY Chapter and am a Delegate to the ALF National Board. Later in 2003 I joined LI TRIO, to learn more about transplantation, organ donation and post-transplant life. I have participated in the school talk programs, Rose Garden Ceremony and many other activities, and have served on the LI TRIO Board of Directors since 2006. Every day I try to do something that makes the Gift of Life a rewarding day and to pay respect to my donor and his family. It all comes down to volunteering, paying it forward for the next person and honoring my donor Scott.

## A Letter From Mike Sosna

### To LI TRIO members and friends,

A few months ago, I made the decision to step down as president of our chapter. I explained to the board that I would continue many of my volunteer tasks and would continue to serve on the board of directors.

I'm writing this letter not as a way of saying goodbye but as a way of saying "Thank you."

Our chapter's accomplishments were made possible by the involvement and participation of our chapter's general membership. It is the result of the everyday efforts and dedication of our members that Long Island TRIO has become the largest TRIO chapter with the most paid membership of any TRIO chapter in the nation.

As I reflect on our chapter's accomplishments and future goals, I want to be clear that I have always felt and said that this is your chapter and your organization; that is you- the members of Long Island TRIO have made our vibrant chapter successful as we support and advocate for transplant recipients and their families, candidates and their caregivers as well as donors and donor families. To the membership, thank you for so much for your continued support over the years. It is your support that allowed LI TRIO to function and excel. Your ideas, feedback and communication are our fuel and our energy. As I exit the presidency, please know that I'm not going far. I'm readily available for help and consultation and that promise not only extends to the new officers but to you, the membership. I'm available via email and phone and I also administer our chapter's website and telephone hotline. I find it particularly rewarding helping new members and experienced members with peer to peer support and now I will have more time for those endeavors.

We have met many challenges as a chapter in recent years. Among other obstacles we met the challenge of continuously funding our organization by successfully obtaining grant funding. The state of our chapter's financial situation is excellent. In recent years I managed to arrange for our chapter to be issued insurance and I saw to it that our organization is in complete compliance with respect to the federal government's IRS requirements and required filings for nonprofit organizations.

I have the utmost confidence in the abilities of the incoming board of directors and the new officers.

We have two co-presidents who have each made a commitment to our chapter and they each have an enormous amount of expertise. Dave Rodgers has been in charge of our Donor Rose Garden and has worked very hard with the maintenance and coordination of the Donor Rose Garden. Dave has accomplished many and varied administrative tasks related to this most significant annual event.

Ed Burki has an enormous amount of experience getting things done and Ed has been an extraordinary advocate for our chapter. Both Ed and Dave have been wonderful volunteers serving our chapter and I'm completely comfortable and optimistic about our organization's future under their leadership.

Thank you for allowing me to serve as president. I know firsthand how hard so many of you work in order for us to fulfill our chapter's vital mission and I hope you'll keep volunteering. I look forward to continuing to work together and will count you all as family and as an inspiration long into the future.

I have truly enjoyed and appreciated my experience serving as president of our chapter. The wealth of experience, feedback and knowledge that I'm taking away is absolutely priceless. I will continue to support Long Island TRIO as director and I will continue my passion and my work with Legislative Initiatives with respect to transplantation as well as other volunteer tasks to which I have committed.

I wish you all good health and happiness and I'll see you at the meetings and events.

Very truly yours,

Mike Sosna 516.902.9111  
[mike@sosproductions.com](mailto:mike@sosproductions.com)

**Tom Bush** has provided a link to a site that monitors online pharmacies, many of which are not legitimate. The registry shown in this link, at a site maintained by LegitScript.com, lists online pharmacies determined to be legitimate:  
<http://www.legitscript.com/pharmacies>.

## LI TRIO June Meeting



Dr. Carole Hazan presents dermatology for transplant patients at June meeting of LI TRIO.



Co-Presidents Ed Burki and Dave Rodgers present Dr. Hazan with a token of appreciation.

The June monthly meeting of LI TRIO featured a presentation by **Dr. Carole Hazan MD**. Dr. Hazan is a specialist in dermatology and MOHS surgery at New York University (NYU) Hospital – Langone University Hospital. She is also a Clinical Assistant Professor at the hospital and maintains an office in New Hyde Park as well.

Dr. Hazan's presentation focused on skin disorders, particularly those to which transplant patients are susceptible. She described the evolution of squamous-cell carcinoma, which is the most common form of carcinoma for transplant patients, and described the risk factors for contracting the cancer. Dr. Hazan's discourse was wide-ranging, describing the causes, prevention, symptoms, and treatments, including MOHS microscopic surgery, whereby the surgeon examines tissue as it is removed in order to determine where next to remove tissue.

After Dr. Hazan's presentation, she received numerous questions from transplant recipients and their supporters.

All appreciated the depth of her expertise and her lucid presentation style.

*Howie Pohl*

## Letters to the Editor

*Hello Howard,*

*IT'S SOOOO EXCITING!!!*

*I received the recent Trio newsletter the other day and was excited to see the article you wrote for me.*

*That must make it official - we are finally in print!!*

*My husband wanted a copy and every time he reads it he says you did a good job.*

*I look forward to reading about other peoples' transplant stories you write for TRIO in the future.*

*Thanks again*

*Best Regards,*

*Carol Heins*

*Hi Howie,*

*We just received your first newsletter and want to thank you for it. It's well written with interesting content and the photos of Carol makes it very pleasingly picturesque. It's colorful as well with the TRIO icon on the red background and the orange and red stripes. Congratulations to you Helena and Richard!*

*Walter Ruzek*

***118,895 people are on the waiting list  
for transplants as of July 26, 2013.***

## LI TRIO Appreciation Dinner

The Inn at New Hyde Park hosted the LI TRIO Appreciation Dinner on June 26. The event was created to honor those who had given service to the principles of organ donation and transplantation support. Debra Conte, the widow of the late Assemblyman Jim Conte, was a guest of LI TRIO. Rep. Conte was a tireless worker on behalf of organ donation legislation.



Standing: Dave Rodgers, Jeff Fenn, Barbara Fenn, Joy Oppedisano, George Tietjen Seated: Sarah Conte, Debra Conte, Jo Michaels.



Standing: Tom Bush, Bobby Seebach, Pauline Feltkamp Seated: Iris Edelson, Walter Ruzek, Peggy Ruzek, Anne Bush.



Standing: Jerry Sosna, Florence Sosna, Nadia & Richard Prete, Tommy Bolger, Ruth Pohl, Howie Pohl Seated: Liz Fidel, Ed Burki, Mike Sosna, Jennifer Lentini



Richard Prete, Kathy Vliet, Dick Harrington, Nadia Prete, Ann Harrington

## Chapter Officers

Co-Presidents: Ed Burki and Dave Rodgers  
 Vice-President: George Tietjen  
 Treasurer: Walter Ruzek  
 Secretary: Jo Michaels  
 Immediate Past President: 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 Jerry Sosna 516-620-5900  
 Welcome Committee Tom Bush Call Hotline  
 E-Mail Tree -Outgoing email Joe LaBarbera [.litrio@optonline.net](mailto:litrio@optonline.net)  
 Corresponding Secretary Ruth Pohl 631-884-0482  
 Website Design, Legislative Initiatives and  
 Public Policy Mike.Sosna 516-902-8111  
 Special Projects Ed Burki 516-620-3700  
 Rose Garden Logistics Dave Rodgers 516-449-1421  
 Rose Garden Program Jo Michaels 516-798-8411



Database Manager Howie Pohl 631-884-0482  
 Donor Families and Social Secretary Barbara Musto 516-314-5793  
 School Speakers Jeff Fenn 516-799-9447  
 The Ways and Means Committee and  
 Holiday Party Chairpersons Florence and Jerry Sosna 516-482-2908  
 Publicity Iris Edelson 516-627-2918

## Newsletter Staff

Howie Pohl - Editor  
 Helena McDermott  
 Richard Prete

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