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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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OCTOBER 2015

# 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.*



## Transplant Profile: Karen Paulick

*Editor's Note: Kaitlyn Doorhy was a junior at Sacred Heart University and a 2012 graduate of Mattituck High School when she was killed crossing the street near her Bridgeport CT sorority house. At age 16, she decided she wanted to become an organ donor. Karen Paulick received a liver donation in 1996. On the first anniversary of Kaitlyn's passing, Karen was asked to speak at a memorial service at Our Lady of Good Counsel Church in Mattituck. Karen had previously spread the word about the benefits of organ donation to Mattituck High School students with Dave Rodgers, former LI TRIO President. Karen's speech proved to be a stirring memorial to Kaitlyn and an important reminder about how each person can give the Gift of Life by signing up to be an organ donor:*



Transplant recipient  
Karen Paulick at  
Kaitlyn Doorhy's  
Memorial Service

I am privileged to speak to you today about the importance of organ donation. There are many people here today to honor the memory of Kaitlyn Doorhy. Although we never met I felt a deep emotional connection to her when I heard about her passing. It touched my heart in more ways that you can imagine.

I am a recipient of a liver from a young man in Atlanta 18 years ago. I learned that I would need a transplant when I was 32 years old. I had an

autoimmune disease that would eventually cause my liver to shut down. I knew nothing about organ donation. I had never heard anything about it and none of my friends or family knew anyone who had a transplant. Dr. Fenton Schaffner, a liver specialist in New York told me on our first

meeting that everyone dies but I would die with someone else's liver in me. That was the beginning of my journey into organ donation.

There were 1,826 lives saved in New York State in 2014 because of organ donation. Currently more than 122,446 people are waiting for a transplant in the United States. More than 10,152 people are on the waiting list in New York State alone. One person who donates can save up to 8 people. Twenty two people die every day waiting for a transplant. New York State ranks at the bottom of the list~ #50 out of 50 states for organ donations. Only 24% of the population that's eligible in New York State has signed up. That's unbelievable to me! People are dying everyday waiting for an organ.

Kaitlyn's mother told me that she and her daughter had a conversation about organ donation when she was only 16. Darla told her she would have to wait until she turned 18 and signed her license. That brief conversation is what has led us to this mass to remember Kaitlyn's life

She must have been a very special girl to all of you who are here today. Her life has changed the lives of people who will always be grateful for her gift of life.

I reached out to her family because I wanted them to know what a difference organ donation has made in my life. Although there is deep sorrow and pain with the donor's family, much hope and joy is given to numerous other families on the transplant list through the gift of donation. I had my liver transplant in Pittsburgh, Pa on Sept. 8, 1996. It was life changing for me. Without a new liver I never would have been able to watch my 6 year old son grow up, graduate from high school and then college. My husband and son were there for me every step of the way.

Through all of this I believe that my strong faith in God got me through this trial in my life. It has truly been a blessing these past 18 years. I celebrate my transplant anniversary every Sept. 8<sup>th</sup> and remember my donor.



(left to right): Dave Rodgers, Karen Paulick, Lucas Pia (Doorhy family friend), Darla & Joseph Doorhy, Kaitlyn's parents)

Please remember that Kaitlyn Doorhy has left us too soon. I believe that her decision to be an organ donor has impacted others who might never have survived without her organs.. Have a conversation

with your loved ones about organ donation. You just never know what life has in store for you. You can sign up online at [longlivenewyork.org](http://longlivenewyork.org) or on your license. But most importantly you must tell a family member your decision to be an organ donor.

Dave Rodgers, also a liver recipient and past President of LI Transplant Recipients International Organization will be handing out pamphlets at the back of the church about organ donation. Please feel free to ask any questions you might have.



Karen's car promotes organ donation and her license plate shows the date of her liver transplant

Finally, I will always remember Kaitlyn Doorhy even though we never met. Her gift of life to others was monumental. May God Bless her, the recipients of her organs and her family. Thank you for letting me share my story of organ donation with you today. I hope you will sign up to be an organ donor.

*(Editor's Note: Dave Rodgers, former President and current Board of Directors member, reports that Karen and he presented to over 1300 people at the service and subsequent masses and distributed over 700 brochures).*

## Upcoming Events

**Tuesday, October 6 – Organ Donor Enrollment Day – An effort to enroll massive amounts of donors by LiveOnNY – Find out more at <http://www.liveonny.org/take-action/enrollment-day/>**

**Saturday, October 10 - *Eight Parts of Life* Organ Donation Awareness Stage Play – Kaye Playhouse at Hunter College, 68<sup>th</sup> Street between Park & Lexington Avenues – 8:00 PM – discount available, see article.**

**Wednesday, October 14– LI TRIO General Meeting – Guest Speaker: Frank Winter, Partnership Manager, Centers for Medicare and Medicaid Services– 7:30 PM**

**Thursday, November 12 – LI TRIO Holiday Party – Westbury Manor, 1100 Jericho Turnpike – 6:00 PM: Cocktail Hour – 7:00 PM: Dinner & Dancing.**

## October Re-Birthdays

Angela Barbosa	October 29, 2002
Roberta Baulstein	October 7, 2003
Jeffrey Callaghan	October 5, 2006
Joseph DiMartino	October 17, 1999
Anthony Fama	October 28, 2001
Rachel Feldman	October 25, 1994
Pete Fogel	October 30, 2014
Elizabeth Hinst	October 2009
Susan Joffe	October 28, 2010
Michael Kahne	October 11, 2009
Kate Mayerhofer	October 4, 2010
Joel Pope	October 22, 2002
Josephine Recine	October 10, 2001
Dave Rodgers	October 22, 2002
Jan Schichtel	October 21, 1982
Ellen Schulman	October 23, 1999
Deborah Taylor	October 28, 1999
Irene Torino	October 5, 2011
Eileen Vento	October 27, 1999
Bob Violino	October 25, 1995

## November Re-Birthdays

Debbie Greenberg	November 21, 2004
Stefani Letvak	November 23, 2009
Denise McCullough	November 17, 1997
Susan Mei	November 10, 2010
Fran Oreckinto	November 25, 2000
Jennifer Ruzek	November 30, 2006
Russell G. Tisman	November 7, 2009
Ralph Zegel	November 26, 1997

## Remembering George Tietjen

**George Tietjen**, a powerful voice for Long Island TRIO, passed away on July 17, 2015. George served on LI TRIO's Board of Directors for many years and worked hard on behalf of organ donation and transplantation. George himself was a 2001 kidney recipient and volunteered as a way of giving back. His wife **Sue**, who predeceased George, also volunteered for LI TRIO, leading the organization's singers in their appearances at stadiums and other venues. Several members of LI TRIO have fond memories of George and wrote about him for the newsletter:

***George's sons and his beautiful family welcomed us at the memorial service at Our Savior Lutheran Church in Port Washington and asked that we post this message on our blog.***



Sue and George Tietjen 2005

***Mike, my father greatly enjoyed being part of your great organization over the years. Thank you for your thoughts. Best, George (on behalf of our family).***

He also sent the following announcement:

***Friends, it is with sadness that I inform you that my father George Tietjen joined my mother Susan Tietjen in Heaven on the morning of July 17, 2015.***

***He went peacefully with family at his side at North Shore University Hospital.***

***A memorial service honoring his life was held on Tuesday morning July 21 at 11 AM at Our Savior***

***Lutheran Church, 12 Franklin Avenue, Port Washington, NY.***

***He took pleasure in serving your organization for many years, and our family thanks you for including him in your work - George Tietjen***

***I'm reminded of how intelligent, candid, logical and assertive George was and at this time I've been recalling his enthusiastic laugh as well. George is sorely missed. I remember how George and Sue interacted with LI TRIO volunteers and friends and they truly made a difference while providing important anecdotes that helped people new to transplantation. Many of these appreciative people were first told they needed an organ transplant and gift of life. They met with their physicians and it was a great help when those who had experienced donating a kidney and receiving a kidney transplant offered tips and discussed important issues to be considered. Sue and George provided helpful support.***

***Sue nursed and provided care to our LI TRIO Donor Rose Garden for years and she and George were fierce advocates of organ donation and transplantation. George led the LI TRIO Schools Speakers Bureau, served with me as an officer of our organization and was a dedicated volunteer of our chapter.***

***Sue and George are sorely missed and always remembered. -Mike Sosna***

***Dear Tietjen Family,***

***I am saddened to hear of the passing of George but find peace knowing that he and Sue will be together in heaven.***

***I will always remember George for how truly grateful he was about the gift of life he received, his dedication to LI TRIO, easy smile, his sense of humor, his love of cookies and his positivity. I remember his power point presentations and his kind invitation to join all of you for the luncheon after Sue's memorial.***

***I regret that I wasn't able to attend his memorial in person as I didn't find out in time.***

***I wish your Family peace and healing and mourn the truly remarkable man that was George.***

***Sincerely,  
Beth A Chapman (Cookie Lady)***

As of September 25, 2015 there were 122,543 candidates for transplant, according to the United Network for Organ Sharing (UNOS). In New York State, there were 10,107 candidates awaiting a transplant.

## State Senator Peralta introduces bill to expand ways to register as a donor in New York State

**State Senator Jose Peralta** today unveiled legislation that would require certain state forms and applications to include a space allowing New Yorkers to sign up for the Donate Life Registry. The bill (S.6022) would increase opportunities for New Yorkers to register as organ donors in the state that ranks last nationwide per capita.



State Senator Jose Peralta

Senator Peralta made the announcement as part of the National Minority Donor Awareness Week (August 1-7) and in collaboration with donors' family members, living organ donors and recipients, representatives from LiveOnNY, and special guest **Mariana Villarreal**, a

Hooters Girl from Georgia who donated a kidney to a patron she knew for only for a few weeks.

National Minority Donor Awareness Week is especially important to recognize in New York, with its diverse population and where only approximately 25% of residents are registered as part of the Donate Life Registry. The national average of residents registered as organ donors exceeds 55%. Notably, the percentage of registered residents in Queens is even lower than the state average at 11.25%

For instance, the legislation would require all applications for admission to state-operated institutions of higher education (SUNY) and community colleges to include a space on forms for enrollment in the Donate Life Registry. The bill also would require additional state-issued forms to offer New Yorkers the possibility to register as an organ donor, including:

- 🌳 Applications for teaching certifications/licenses issued by the New York State Department of Education;
- 🌳 Applications for admission to State University of New York (SUNY) and City University of New York (CUNY);
- 🌳 Applications for professional licenses issued by the New York State Department of Education;
- 🌳 New York income tax forms;

- 🌳 Applications for participation in the State's healthcare exchange;
- 🌳 Biennial registration renewal forms, filed by attorneys;
- 🌳 Applications for admission to practice law;
- 🌳 Applications for the registration and renewal of motor vehicles; and
- 🌳 Applications to conduct a profession or occupation as licensed by the New York Department of State.

We encourage everyone to contact their local state senator to support S.6022. In addition, we encourage everyone to contact **John J. Flanagan, the State Majority Leader**, in support of this bill. Senator Flanagan's email address is [flanagan@nysenate.gov](mailto:flanagan@nysenate.gov). His address is the following:

Senate Majority Leader John J. Flanagan  
Room 330  
State Capitol Building  
Albany, NY 12247

### Save the Date

SAVE THE DATE LI TRIO HOLIDAY KICK-OFF PARTY

Thursday, November 12, 2014

Westbury Manor

1100 Jericho Turnpike, Westbury, NY 11590

6:00 PM - 7:00 PM Cocktail Hour

7:00 PM - Dinner, Dancing & Cheer

### Eight Parts of Life

***Eight Parts of Life*** is a new stage play that will be presented in New York City on **Saturday, October 10, 2015 at 8:00 PM**. The play encourages organ, eye, and tissue donation. This heartfelt narrative delivers a riveting performance with a dual story-line highlighting a young child's battle with severe kidney disease and need for a lifesaving organ transplant, coupled with the challenges and struggles of a blended family. After the play, prominent speakers, including Sandip Kapur MD, Chief of Transplant Surgery, NY Presbyterian Hospital and Weill Cornell Medical Center, and Costa

Constantinides, NYC Council Member, will discuss issues regarding organ donation.



The Kaye Playhouse at Hunter College

The play will take place at the Kaye Playhouse at Hunter College, West 68<sup>th</sup> Street between Park and Lexington Avenues. Tickets may be purchased online at [www.hunter.cuny.edu/kayeplayhouse/calendar](http://www.hunter.cuny.edu/kayeplayhouse/calendar) or

by calling the box office at (212) 772-4448.

Long Island TRIO's membership has been provided a special discount code that offers a 10% discount on all tickets in every seating selection. The discount code is **nebula55//**.

### **\*\*Bill Heider Receives His Transplant\*\***



Bill Heider speaks to students at Massapequa High School in 2014

We received word that former Long Island TRIO member **Bill Heider** received a kidney transplant in Myrtle Beach, South Carolina. Bill and wife **Cathy** had moved there a year ago after waiting for a kidney for three years in New York.

Bill received his kidney from a six year-old girl. **Jeff Fenn**, the School Speakers coordinator for LI

TRIO reports: *Bill joined my school speaking team and did talks with me for 6 months before he moved to South Carolina.*

*He was a great speaker and delivered an important message regarding diabetes and the problems associated with the disease. He was a great addition to my team, even for the short time that he was here. He previously received a liver transplant from his sister, then found out that he needed a kidney transplant as a result of diabetes and transplant drugs.*

## Rose Garden Rededication Ceremony

One of Long Island TRIO's highlight activities, the Rose Garden Rededication Ceremony took place on Saturday, September 26, beyond the publication deadline of the Newsletter. We will have complete coverage of the ceremony in the December 2015 edition of the LI TRIO Newsletter.



Correction: The August 2015 edition of the LI TRIO Newsletter contained an incorrect headline for the September Re-Birthdays. The headline read *July Re-Birthdays* and should have read *September Re-Birthdays*. The birthdays shown are, however, for the correct month of September.

## Working With COPE

The Long Island TRIO Board of Directors has elected to work and co-promote events and information with **COPE – Connect Our Paths Eternally**. COPE is a non-profit grief and healing organization dedicated to helping parents and families living with the loss of a child.



Since 1999, **COPE** has connected individuals who have experienced similar losses by providing ongoing emotional, therapeutic and spiritual programs. These include monthly parent and sibling bereavement support group meetings, weekly art and movement therapy workshops, and a variety of special programs for members mourning a child's passing, as well as the community.

In addition to assisting local families on Long Island, the **COPE** grief hotline and website have enabled the organization to also provide grieving individuals outside of Long Island with immediate

support and resources and referrals. Dedicated to the spirits of our children who have passed, **COPE** helps sustain and build upon the bonds of love and energy that connect us with our children. For more information, see [www.copefoundation.org](http://www.copefoundation.org).

### The Medicare Prescription Drug Savings and Choice Act of 2015

*Mike Sosna published the following information to the Long Island TRIO website regarding two important bills that address the rising cost of prescription drugs and difficulty encountered by Medicare recipients with changing coverage of medication.*

S. 1884 is in the United States Senate and H.R. 3261 is in the House of Representatives. These bills create Medicare administered plans with a standard premium and confirmed formulary. The proposed legislation could reduce confusion on the part of those with Medicare coverage who have to navigate so many plans that have formularies that can change annually. The legislation could also reduce confusion on the part of those with Medicare coverage who at times receive notices that their plan is no longer available. Prescription prices could be lower and the federal government could save money as well. These bills will amend title XVIII of the Social Security Act so it will deliver lower prescription drug prices under the Medicare program. The Medicare Prescription Drug Savings and Choice Act of 2015 and 2016 would permit the Secretary of Health and Human Services to negotiate Medicare prescription drug prices. This is currently not allowed though other governmental bodies such as the Veterans Administration can in fact negotiate Medicare prescription drug prices.

When asked [respondents to KFF's Health Tracking Poll] whether they think the federal government should be allowed to negotiate with prescription drug manufacturers to secure lower prices on medications for people with Medicare, 84 percent said they were in favor of this policy.

### September General Meeting

Memories of yesteryear were shared by long time Board member **Walter Ruzek** as we began the September general meeting. Walter told the group about the history of LITRIO saying that it was started in 1987. Walter showed pictures of many long time TRIO members along with the founder of LITRIO, liver recipient **Anne Trefieson**, and her

husband **Don**. In addition to being the founder of LI TRIO, Anne who was so grateful after receiving her transplant, also searched for a public place for a memorial honoring those who give the gift of life. By doing this she reasoned that she would also express her eternal gratitude to her donor and the family who said, "yes" when given the opportunity of organ donation. She was determined to find the perfect spot for this living sanctuary and the LITRIO Rose Garden was born in Eisenhower Park.



LI TRIO Holiday Party 1998

Each year the Rose Garden becomes more and more beautiful as it is cared for by LITRIO volunteers coordinated by past president **Dave Rodgers** with the help of his team of volunteers. Our green thumb crew coached by Dave (who claims you do not need a

green thumb to help) included **Joe Baumgartner, Tom Reilly, Rochelle Bove, Christopher Fenn and Ryan Fenn**. The Rose Garden team of volunteers worked diligently throughout the spring and summer. They revved up the pace throughout the past few weeks in preparation for the yearly Rose Garden Re-Dedication Ceremony which took place on September 26.



**Dr. Devon John** joined the LI TRIO members at the September General Meeting sharing interesting information about transplantation. Members enjoyed a comfortable conversation where a "fireside chat" atmosphere prevailed.

Dr. John confessed that he initially considered pediatric medicine. He acknowledged a mentor who asked him if he considered the field of transplant medicine. His mentor explained that kidney, liver, and pancreas transplant was all-encompassing where patients could experience disease processes which include lung, heart, and other organ failures. Reducing and preventing the incidence of disease is important. Intrigued and knowing how lifesaving transplantation could be, Dr John did a residency in surgery at Downstate Medical Center. He went on to complete the NYU-SUNY Downstate ASTS-accredited fellowship in Kidney and Liver Transplant Surgery in 1997. Dr. John joined the full-time faculty at NYU Medical Center in 1997 and continued to receive positions of increasing responsibility, culminating in his appointment as Director of Kidney and Pancreas Surgery in 1997. Five years ago he was recruited back to Downstate Medical Center as

Director of Surgery,



Dr. John with Joy Oppedisano, LI TRIO President

Dr. John discussed the fairness of transplantation, reminding members of the 123,000 people waiting for transplants. He stated that 22 people die each day

waiting. The ever present question is why. Is the reason that people are cynical, have diverse backgrounds, varied beliefs or is it due to misconceptions that exist?

Difficulty with end of life discussions and understanding the process also reigns as a factor, for some, when it comes to deciding whether or not to donate.

Putting everything into perspective is the cost of healthcare where \$50 billion a year is spent while \$2 to \$3 billion is spent on transplantation. The cost of dialysis is more than the cost of transplantation which saves money in the long run. This information is important as the population grows older and the cost of healthcare increases.

This is all key learning information for legislative bodies and the public. Large hospital centers and corporations are educating staff about transplantation with the support of organ procurement organizations, such as LiveOnNY, and their partners like LITRIO volunteers. This will help increase the number of lives saved through transplantation.

All is not bleak. There is good news - 25,000+ lives are saved each year by transplantation.

*Joy Oppedisano with contributions from Sue Dillon*

### President's Corner

*My column this month is dedicated to all who give the gifts of life and the special families who chose to make a difference during a most difficult time.*

*It is many of these special people, who along with the healthcare professionals, and those dedicated to making a difference who have become dear to me.*

*I cannot imagine a world where each day, we are not reminded of the goodness of humankind.*

*The world of transplantation reminds us each day of this.*

*Ginny Ingenito, RN has become a friend. I met Ginny after her husband died tragically. Recently she shared her daughters writing, which completely amazed her. She never realized that the annual Rose Garden Dedication, which she took her family to, had impacted her daughter so much.*

*As you read Laura Ingenito's story imagine her as a little girl who goes bowling with her dad every Saturday. Afterwards, daddy and daughter go to the park for a bike ride. The park is Eisenhower Park.*

**Joy**

**Oppedisano**

### Organ Donation—Life is Good

I pedal faster and faster, surging down the hills of the concrete bike path, my pink-sparkled streamers flying through the cool breeze. On Saturday mornings at Eisenhower Park, the freedom of youth is all that matters. With my dad right beside me, I absorb the thrill of being eight years-old. Life is good. Life is simple.

The following fall I sit along the same bike path, the one that I was very acquainted and comfortable with. This was

my first of many ceremonies in the rose garden. My perspective of life changed that day. I was no longer privileged to the feelings of an eight-year old. Instead of the simplicity of a day in the park, my viewpoint on the appreciation of life grew up. Most children my age would quiver at the thought of organ donation. When it became part of my life, I had little knowledge of what organ donation actually was.

On that day, I would learn a lot. My attention was drawn instantly to a speaker, a girl my age. Gillian told her touching story as a liver recipient, and as a person who had a second chance at life. She knew the gift she was given. I was amazed at how someone my age had experienced such a serious medical condition so young. How she handled her situation was admirable. She was so young and so proud of the opportunity to relive her young life.

In that moment, I felt proud that my family had decided to make my dad an organ and tissue donor. When my dad died suddenly, my family and I were introduced to The New York Organ Donor Network. My mom decided this was the right thing to do. It is difficult for many families to make this decision in their time of grief. I believe it would be easier if more people understood the tremendous benefits. Donations benefit not only recipients but their families too. Our loss lessened because of my dad's recipient's gain. We were able to donate my dad's corneas, which were given to two men who are now able to see. My hope is they see the world as my father did. My dad's skin was given to the New York Firefighters Skin Bank. This tissue can be multiplied and shared with people who have had their own skin burned or damaged. My hope for these recipients is that they feel the way my father did. My dad's bones were also donated. Many people, whether they are cancer patients or trauma victims may receive part of my dad to heal their lives. My hope for these people is that they have my dad's inner strength. My dad taught me lessons on giving to others always, both in his life and after. His life goes on through these people and that makes my family happy and proud.

At this time, I will be making many important life decisions, such as choosing a college and a career. One of the most important decisions I have made is becoming an organ donor. My experiences with this organization have influenced my plans to go into the healthcare field. I plan to help others have better lives. I hope to have a life-long impact on the people I meet along my journey.

As I drive past my high school, I pass the bike path and the rose garden. I remember fondly my simple, carefree days at the park. I also recall the day I learned to appreciate my life. I am reminded of my goal to help others in the best way I am capable of and to never take life for granted.

## 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, Howie Pohl, Walter Ruzek, Florence Sosna, Jerry Sosna, Mike Sosna

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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

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