

LITRIO UPDATE

THE LONG ISLAND CHAPTER OF TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION ▲ MARCH 2009

THE LONG ISLAND TRIO GENERAL MEETINGS ARE HELD ON THE SECOND WEDNESDAY OF EACH MONTH FROM SEPTEMBER TO JUNE.
OUR DECEMBER HOLIDAY PARTY SUBSTITUTES FOR THE DECEMBER MEETING. THE MONTHLY MEETINGS BEGIN AT 7:30 PM AND ARE HELD AT:
145 COMMUNITY DRIVE, MANHASSET, NY

LI TRIO February 2009 General Meeting with Dr. Ortiz

LI TRIO had an interesting February monthly meeting with Dr. Ortiz as our guest speaker. Dr. Ortiz is Director of Liver Transplantation and Hepatobiliary Surger at Albert Einstein Medical Center Philadelphia, PA.

We would like to thank Dr. Ortiz for his guest speaker appearance at our meeting and as you can see below, he was very much appreciated and very well received by our members.

LI TRIO Members in their own words:

Hi Mike,

Thanks again for a terrific meeting. Dr. Ortiz is so well informed and so down to earth. Thanks Mike. The meeting really was one of the best of any organization I've attended.

-Joy Perla

Hey Mike,

I wanted to let you know how I felt about the TRIO meeting of February 11, 2009 with Dr. Ortiz. In a nutshell I have to say that the doctor's talk was one of the most worthwhile and fascinating I've had the privilege to attend. His grasp of anything that individuals in our group expressed was unparalleled. Any issue, whether about drug interactions, toxicities or the newest things in development were explained to us and this was so valuable to all of us, often personally.

It was quite astounding that as questions were posed he was able to address each individual. It was as if he knew a great deal of their medical history just from the introduction we all gave at the beginning of the meeting when you asked us to introduce ourselves.

I had the chance to address Dr. Ortiz about problems that have recently been affecting me. I felt as if he could

have been on my team at my transplant center at Mt. Sinai.



Photo by: Laura M Laria

Dr. Ortiz impresses me as someone with expertise who has the ability to look forward with enthusiasm to a degree that I had previously not known. I know that our usual meeting time was radically overextended. Listening to him was enlightening and I would be happy to hear him again some time in the future.

Thanks, Jules Feuer

UPCOMING EVENTS AT LI TRIO

◆ **March 11, 2009:** LI TRIO General membership meeting March 11, 2009 at 7:30 PM with special guest Tina Mein-Senior Clinical Intern in the Marriage & Family Therapy Clinic at Hofstra University

◆ **IMPORTANT MONTHLY MEETING DATE CHANGES:** Our April meeting will be held on April 15, 2009 instead of on April 8. Our May meeting will be held on May 20, 2009 instead of on May 13.

◆ **April 4, 2009:** TRIO Manhattan Chapter's wonderful annual "Remember

and Rejoice" Ecumenical Service event at St. Patrick's Cathedral, 5th Avenue and 50th Street on April 4, 2009 at 2 PM-3:30 PM.

◆ **April 20- 24, 2009:** LI TRIO volunteers at Mount Sinai for Donor Awareness Month in April (see article in newsletter).

◆ **April 21, 2009:** Legislative Initiatives Day: April 21, 2009- trip to Albany (see article in newsletter).

◆ **May 17, 2009:** The Kidney & Urology Foundation's Long Island Walk the Walk will be held on May 17, 2009. at

Eisenhower Park-Parking Lot 5. For more information please contact them at: <http://www.kidneyurology.org> or 212.629.9770.

◆ **May 31, 2009:** National Kidney Foundation's Long Island Walk is being held at May 31, 2009 at Hofstra University, Hempstead, New York. Please let them know you are walking with the LI TRIO team.

◆ **August 19, 2009** Organ Donation Awareness Night at Citi Field. Braves vs Mets.

LONG ISLAND TRIO UPDATE

The Newsletter of **The Long Island Chapter of Transplant Recipients International Organization** is published monthly and mailed free to all members. Please send any letters and any other correspondence to:

LI TRIO P.O. Box 81, Garden City, NY 11530

Please send all articles, member profiles, stories, anecdotes and other newsletter submissions to:

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LI TRIO GENERAL MEETINGS

The Long Island TRIO General Meetings are held on the second Wednesday of each month beginning at 7:30PM from September to June. Our December Holiday Party substitutes for the December Meeting. The monthly meetings are held at:

145 Community Dr., Manhasset, NY

LI TRIO MISSION STATEMENT

Long Island TRIO is a non-profit ALL VOL-UNTEER organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness.

LI TRIO BOARD OF DIRECTORS

Ed Burki Dave Rodgers

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Photo by: Laura M Laria



LI TRIO Monthly Meeting:

Our special guest speaker for the March 11 meeting is Tina Mein who will be discussing caregiver needs and those of their families. We will learn to gain better coping skills, learn tips to minimize stress as well as gain support from others with respect to caregiving. Tina Mein is currently a Senior Clinical Intern in the Marriage & Family Therapy Clinic located in the Saltzman Center at Hofstra University. In May of 2009, she will be receiving her Masters Degree in Marriage and Family Therapy. She is a member of the American Association for Marriage and Family Therapy. In addition, she possesses a background in Crisis Intervention Counseling and has volunteered her services to the Long Island community for over three years. Tina's extensive background consists of counseling individuals, families, and couples. She has developed and implemented workshops focusing on the empowerment of women and children of divorce. In addition, she has implemented an effective workshop aimed exclusively toward caregiver needs and those of their families.

LI TRIO member Larry Kata received his pancreas transplant and is feeling well.

In his own words:

To TRIO- Thank you so much for all of your help. I have received my pancreas at NY Pres. This has completed both my kidney from my wife and a

donor pancreas. Please pass this good news on to all.

-Larry

April 4, 2009: The Remember and Rejoice Event

Our friends at our sister chapter-TRIO Manhattan have scheduled the wonderful annual "Remember and Rejoice" event at St. Patrick's Cathedral on April 4, 2009 at 2 PM-3:30 PM.

The "Remember and Rejoice" Ecumenical Service for transplant recipients, candidates, donor families, living donors, family, friends and transplant professionals will be held at St. Patrick's Cathedral, 5th Avenue and 50th Street, Manhattan. The service includes prayer, speeches by recipients, donor families and living donors, and candle-lighting. No registration or reservations are necessary.

Please plan on attending this very special Ecumenical Service honoring and remembering donors and their families.

April 21, 2009: Legislative Initiatives Day

On Tuesday, April 21, we will be joining transplant recipients, donor family members, hospital staff, and organization professionals on a trip to Albany to meet with State legislators to discuss ways to help increase organ, eye and tissue donation. Each year close to 100

volunteers from the Greater New York Area have traveled to Albany to give our cause visibility. This has helped accomplish many goals including the New York State Gift of Life Medal law, a Donate Life license plate design, and a new Registry of Consent. No experience is necessary. More information will be coming soon and you can check our organization's website at www.litrio.org.

Remember, many of the people you'll meet represent you.

Organ Donor Awareness Month

Long Island TRIO will be represented at Mount Sinai. We will be promoting the importance of Organ Donation Awareness month in April at Mount Sinai Hospital in Manhattan.

The events are being held April 20th- 24th. This will be a week long event. We are seeking volunteers to help provide educational information and promote organ donation awareness. Time slots are flexible.

Please contact LI TRIO board member volunteer Dave Rodgers 516 449-1421 or dokholiday44@hotmail.com.

Changes in Kidney Allocation: What You Need to Know

For Dialysis Nurses, Patients, and Nephrologists

*Michael Shapiro, M.D.
Chief, Organ Transplantation
Chair, OPTN/UNOS Ethics Committee*

The National Organ Procurement and Transplantation Network (UNOS) is studying potential changes to the current system for deciding which kidney goes to which recipient.

Hear about the allocation policies under consideration that may impact you or your patients from an expert involved in the process.

This will take place on Tuesday, March 24, 2009 from 6 – 9 p.m. To be held at the Hekemian Conference Center, Hackensack University Medical Center, 30 Prospect Avenue, Hackensack, New Jersey 07601

For information and to RSVP call 201-996-2613 or jabrums@humed.com. Call 201-996-2867 on March 24, 2009 after 3 pm for a message regarding any changes in the schedule.

Medication Vouchers Assisted Our Members' Co-pays

Our chapter has helped recipients with discount Prograf medication valued at \$20,000.00.

As announced at our February's general meeting, Ed Burki coordinated the distribution of discount coupon vouchers for Prograf medication. This project also consisted of our chapter's volunteers mass emailing an offer of vouchers to our membership and these vouchers provided savings for Prograf. We would like to thank Astellas and LI TRIO board member Ed Burki for coordinating this worthwhile project for our members.

These vouchers are used by individuals with private insurance to reduce out of pocket payments for these medications up to \$100 per month for 12 months for a total of \$1200 per recipient.

Members contacted Ed via email address and he made them available to recipients on a first come first serve basis until they were all distributed. Instructions for use were provided in the kit. Although all of the vouchers have been distributed, you can request one through your transplant center and if you have any problems or issues, call our hotline and we'll try to see if we can get a voucher for you. Again, the vouchers have all been distributed but we'll see what we can do and try to find one more for you.

University of Iowa Study: Liver Transplant Recipients Wanted

Investigators at the University of Iowa are conducting studies to assess patients who have previously received a liver transplant and have clinically documented age-related macular degeneration (AMD). If you had a

liver transplant and have AMD and you are interested in learning more about how you might be able to participate in this research study, please contact Dr. Greg Hageman or his assistant Sheri McCormick by telephone (319-384-9722), email (shermccormick@uiowa.edu) or mail

Dr. Gregory Hageman
University of Iowa Research Park
2660 Crosspark Road
Coralville, IA 52241

If you have had a liver transplant and have undiagnosed eye disease or vision loss but are not sure if you have AMD you may also contact the above physician if you are interested in participating in the study.

About Dr. Hageman:

Dr. Hageman has worked on the relationship between complement factor H (CFH) and age-related macular degeneration (AMD) for several years. He discovered that certain genotypes for CFH protected against AMD and others increased risk for AMD. He also helped develop the production of the protein made by the protective CFH gene with the thought that this may help treat or prevent AMD in those with the risk CFH gene. Dr. Hageman approached Dr. Collins in the transplant department to help design a study to test his theory in liver transplant

patients. Because CFH is normally made in the liver, liver transplant patients potentially change CFH genotype. Together they are looking at liver transplant patients who have AMD to look for potential CFH genotype change after liver transplant and see how changing the CFH gene has affected the course of AMD.

SAVE THE DATE!

Organ Donor Awareness Night at Citi Field will be held on August 19, 2009 at the Atlanta Braves Vs New York Mets game.

LI TRIO is pleased to present this event again this year in the brand new stadium. Please save the date and more information will be forthcoming. The LI TRIO singers will perform the National Anthem.

HOT OFF THE PRESS!

by John Odermann
The Dickinson Press
March 6, 2009

As reported on our organization's website www.litrio.org. Pharmacy bill allows foreign imports of FDA approved medications.

Sen. Byron Dorgan, D-N.D. introduced the Pharmaceutical Market Access and Drug Safety Act Wednesday, which seeks to allow prescription drugs from other countries to be imported into the United States.

The bipartisan legislation, introduced by Dorgan and Sens. Olympia Snowe, R-Maine, John McCain, R-Ariz., and Debbie Stabenow, D-Mich., hopes to help lower prescription drug costs throughout the country.

"This is a common sense measure that will save both everyday Americans and the federal government billions of dollars, and improve the overall health of millions of people," Dorgan said. "The U.S. consumers are paying the highest prices in the world for prescription drugs, and that's unfair."

Bob Treitline, owner and pharmacist at ND Pharmacy in Dickinson said the new federal legislation has its heart in the right place, but it's important patient safety remains the No. 1 concern.

"Do we have concerns? Absolutely. Do we want cheaper drugs? Absolutely," Treitline said. "Sometimes you can't always have your cake and eat it too."

Treitline said there is a definite concern regarding the quality of drugs that would come in, but if there was FDA oversight it could be a good move.

"We have the protection of the FDA and if there's one bunch of folks I trust, it's those guys," Treitline said.

Dorgan said the move would force pharmaceutical companies in the United States to lower their prices to compete with the identical, less-expensive FDA-approved drugs coming into the U.S. from other countries.

The bill would allow U.S.-licensed pharmacies and drug wholesalers to import FDA-approved medications

from not only Canada, but also Europe, Australia, New Zealand and Japan.

Prices in those countries are 35 to 55 percent lower than in the U.S. and the bill's goal is to pass those savings onto the American consumer. According to the Congressional Budget Office the bill would save consumers \$50 billion in the next decade and the federal government would save \$10 billion.

"For far too long Americans have seen health care costs — especially prescription drug costs — increase year after year," McCain said. "Re-importation legislation would allow access to safe and effective prescription drugs at much lower prices than are available in the United States. If enacted, the legislation will provide the much needed relief to American families, especially seniors and others on fixed incomes, who are facing tough economic times."

Treitline said if you look at certain economic factors, the influx of out-of-country drugs could have the opposite effect.

If the supply isn't enough to meet the demand coming from the U.S., Treitline said, the theory of supply and demand could come into play, raising the price of the cheaper drugs.

Treitline said in the end, he doesn't think re-importation is the answer, but it's good the government is considering its options.

"We'd all like to have cheaper drugs. ... but I think we have to get a balance and I don't think re-importation is the answer," Treitline said. "I have to applaud them for looking at all the avenues we can to lower the healthcare costs in the U.S."

Source: *The Dickinson Press*

Simultaneous Transplants Boost Odds

By: John Schieszer
March 06 2009

Performing liver and kidney transplants simultaneously instead of separately reduces rejection risk

MARCO ISLAND, Fla.—Combined liver and kidney transplantation

(CLKT) may provide an immunologic benefit compared with first transplanting a liver and then a kidney, according to researchers. Graft rejection risk is reduced by 5%-10%, data show.

"It is a small but significant benefit," said David A. Gerber, MD, associate professor of surgery and chief of abdominal transplant surgery at the University of North Carolina in Chapel Hill.

CLKT is often a treatment for patients with hepatorenal syndrome (HRS), a liver-failure complication that has a poor prognosis without transplantation. Type 1 HRS, or liver failure accompanied by rapidly progressive renal failure, is associated with a median patient survival of only two to four weeks. Patients with type 2 HRS, or liver failure accompanied by a slower deterioration of renal function, tend to fare better, with a median survival of approximately six months. He spoke here at the American Society of Transplant Surgeons 9th Annual State of the Art Winter Symposium.

The overall course of HRS is unpredictable and likely influenced by the presence of other perioperative conditions or events. Recovery of renal function following CLKT may be delayed by hypovolemia, use of vaso-pressors, infection, subsequent reoperations, and nephrotoxic agents. Current data suggest older patients (aged 65 years and older) and those on dialysis prior to either liver transplant alone or CLKT tend to have poorer survival than patients under the age of 65 who were not requiring dialysis prior to their transplant.

When treating patients with recent-onset renal insufficiency, the decision to perform CLKT vs. orthotopic liver transplant (OLT) is often difficult. It has been demonstrated that the duration of pretransplantation renal dysfunction predicts six-to-12-month creatinine levels post-OLT. In this study, the researchers found that after adjusting for baseline characteristics, CLKT patients had lower creatinine levels than OLT patients at both six and 12 months post-transplantation. The

researchers also found that the duration of renal dysfunction and not the cause of renal dysfunction predicted renal outcome in OLT-alone patients.

A consensus conference sponsored by several societies recently convened to examine CLKT and determine appropriate indications for it. A prospective data registry and standard listing criteria for CLKT candidates were established. It is still being determined how patients will be listed for CLKT. It is likely that approval will be granted for patients with end-stage renal disease, cirrhosis and symptomatic portal hypertension or hepatic vein wedge pressure gradient of 10 mm Hg or greater; liver failure and CKD with glomerular filtration rate of 30 mL/min/1.73 m² or less; acute kidney injury or hepatorenal syndrome with creatinine levels of 2.0 mg/dL or greater and dialysis for eight weeks or longer; or liver failure and CKD with biopsy showing greater than 30% glomerulosclerosis or 30% fibrosis. Dr. Gerber said that depending on the automatic listing criteria the RRBs will need to evaluate all other requests to determine appropriateness.

"Nephrologists should care about this because they need to be engaged in the process," Dr. Gerber told *Renal & Urology News*. "They need to help identify which patients truly need a combined liver-kidney transplant. With the complexity of these patients we don't want the transplant surgeons and/or the hepatologists making this decision in isolation, without input from the nephrologists."

The number of CLKT procedures has increased substantially in the past decade, Dr. Gerber noted, jumping from 134 in 2001 to 440 in 2007.

Source: <http://www.renalandurologynews.com/Simultaneous-Transplants-Boost-Odds/PrintArticle/128378/>

Enroll in the Donate Life Registry

You can enroll in the *Donate Life Registry* by pointing your browser to our organization's website: www.litrio.org.

About the New York State Donate Life Registry

The registry is a secure and confidential database maintained by New York State's Department of Health. It is only accessed at or near the time of death by federally regulated organ procurement organizations such as the New York Organ Donor Network, and tissue and eye banks licensed by New York State. It records an individual's legal consent to the donation of his or her organs, tissues and eyes at the time of death. No one, including next of kin, can reverse this decision to save lives.

New Law May Allow Americans to Purchase Imported Drugs

President Obama is a supporter of the idea, and sees this as a way to reduce health care costs, both for the government and for the American people. He views the plan as one measure that can be used to lower costs so that medical coverage for the uninsured can be increased, a major part of his health care reform platform.

This type of legislation has been introduced before, but was shot down by the pharmaceutical lobby. Now that Obama has approved the idea, it is expected that the proposal will pass, providing immediate relief for the American people, many of whom can't afford the cost of their prescriptions. It is hoped that if the bill becomes law, pharmaceutical companies will be forced to lower their drug costs in the United States in order to remain competitive.

The Pharmaceutical Research and Manufacturers of America (PhRMA) strongly opposes the bill, arguing that allowing the importation of drugs from other countries will expose Americans to unsafe and counterfeit medications. In contrast the AARP, which is the largest advocacy group for the elderly, have always supported the idea of con-

sumers being able to buy their drugs from other countries at cheaper rates.

If the bill passes, many drugs will be available to consumers at lower cost. It is not surprising that companies, such as Pfizer, oppose the bill: one of their "star" drugs is Lipitor (atorvastatin), a cholesterol-lowering drug. A one-month supply of Lipitor costs twice as much in the US as in Canada (\$124.99 versus \$60.78).

Pfizer earned \$12.4 billion in sales last year from Lipitor. Obviously, the new bill could hurt the pharmaceutical industry. However, a little friendly competition is a good thing, and may force drug companies to lower their costs, which is definitely a good thing for the American people.

Source: http://news.healthguru.com/story/article/id/4158/New_Law_May_Allow_Americans_to_Purchase_Imported_Drugs

Celebrating the New York Organ Donor Network's 30th Anniversary

The following is a reprinted excerpt from "The Beat" A New York Organ Donor Network publication Vol. 12 Issue 2

The New York Organ Donor Network is able to accomplish its life-saving work in large measure because of the dedication of our many partners.

For example, it is the transplant support groups that help us on a consistent basis to get the word out about donation to every corner, every county of the greater New York metropolitan area—a region of 13 million people. We couldn't do it without the commitment of these volunteers, transplant recipients who are giving back by supporting the Donor Network and our life-saving mission.

Of course, they support donation while offering essential and invaluable support and resources for transplant recipients and those on the waiting list, as well as their families.

On the Beat is pleased to share with our readers these 30th anniversary messages from the presidents of the support groups, on behalf of their members. It is also an ideal opportu-

nity for you to get to know who these dedicated people are.

These Transplant Recipients, Leaders of New York's Transplant Support Groups explain why they give back and send 30th anniversary greetings:

Mike Sosna, President of Transplant Recipients International Organization (TRIO), Long Island Chapter; Chairman, Public Policy, TRIO International

"I was very lucky to receive the generous 'Gift of Life' on July 18, 1995. Both of my parents offered to donate and my father was a perfect Match. He gave me one of his Kidneys and saved my life. I am deeply grateful for this gift and I'm so pleased to offer peer support to hundreds of Long Island TRIO members. We partner with the Donor Network during events throughout the year to promote the "Donate Life" organ donor registry. I send my best wishes and sincere thanks on this special anniversary. Here's to the next 30 years saving many, many more lives. Keep up the great work."

Health Insurance Questions Answered

Tom Bush will help you with health insurance questions and issues you might have including questions about Medicare, Medicaid, private insurance carriers, coordination of benefits, Medicare Advantage Plans, billing practices, appeals, and Medigap plan options. In Tom's words, he is LI TRIO's "Amateur Social Worker" and spends a great deal of time and effort helping people with questions about health insurance.

Many LI TRIO members have provided feedback and stated that Tom presented them with a great deal of solutions and options as well as specific answers to health insurance questions. If he doesn't have an answer on hand, Tom will take the time to seek counsel and find answers to questions and resolutions to issues. The world of health insurance is more complicated today than ever so LI TRIO members are urged to utilize the services of our

experienced health insurance "guru" who will help you navigate through the choppy waters of the health care system.

Please call the LI TRIO hotline at 516.942.4940 and leave a message for Tom. He will return your call promptly.

Protocol Improves ABO-Incompatible Transplants

Long-term patient and graft survival similar to that of compatible live donor renal transplants.

By: John Schieszer
March 06 2009

MARCO ISLAND, Fla.—A brief escalation in immunosuppression without long-term B-cell depletion may provide excellent long-term patient and graft survival after ABO-incompatible (ABOi) kidney transplantation, data show.

The study findings suggest that a relatively simple therapeutic regimen could facilitate widespread application of ABOi kidney transplantation. Findings suggest that blood-type incompatibility should no longer be viewed as a barrier to kidney transplantation.

ABOi kidney transplantation is a rare procedure, but if protocols were implemented to transplant across blood-group barriers, it is estimated that an additional 1,500 live donor kidney transplants could be performed each year in the United States alone. Until now, there have been significant barriers to adopting this approach because of the requirements for potent immunosuppression and splenectomy coupled with the formidable risk of irreversible antibody-mediated rejection (AMR).

Researchers at Johns Hopkins Medical Institutions in Baltimore retrospectively reviewed their single-center experience with 60 consecutive ABOi kidney transplants. Over the past several years, they have developed a treatment protocol that includes only a brief escalation in immunosuppression and no long-term B-cell depletion. Among these 60 consecutive patients, the one- and three-year survival rates were the same: 96.3%. The five-year survival rate was 89.4%. The one- and three-year death-censored graft

survival rates were 98.3% and 92.9%, respectively. The five-year death-censored graft survival was 88.7%. These survival rates are comparable to United Network for Organ Sharing data for compatible live donor transplants.

No cases of hyperacute rejection were reported, and no grafts were lost secondary to AMR. In addition, fewer than 17% of patients experienced a clinical episode of AMR. Elimination of B-cell ablative therapies did not result in an increased incidence of AMR.

"The perception when incompatible transplantation started was that the blood-type barrier was going to be harder to cross than HLA barriers," said study investigator Dorry Segev, MD, assistant professor of surgery and director of clinical research for transplant surgery at Johns Hopkins. "What we have shown in the past 10 years with our program is that you can achieve great outcomes with ABO-incompatible transplantation, with very minimal intervention in the recipient in terms of desensitization."

Dr. Segev, who presented findings here at the American Society of Transplant Surgeons 9th Annual State of the Art Winter Symposium, added: "This is a demonstration that our recent change in paradigm is durable. We now feel comfortable that this is a very safe modality."

At one-year post-transplant, most patients had chronicity scores similar to those of compatible kidney transplant recipients. Only patients who experienced an AMR episode had significant elevation in chronicity scores at one year. Excellent graft function persists, the investigators report, with patients having a median creatinine clearance of 60 mL/min.

Source: renalandurologynews.com

Three Sisters Find Kidney Donor for Dad Using Craigslist

LI TRIO is not endorsing craigslist in any way and also not endorsing the act of placing ads like this on craigslist. Please note that there are more scams and fraudulent responses to ads like

this than legitimate responses on craigslist. This article was suggested for our newsletter by Tom Bush.

Jennifer Flood, 30, and her sisters (her twin Cynthia and older sibling Heather, 32) posted the message on Craigslist in a desperate attempt to find a someone willing to make the ultimate sacrifice: donate a kidney to a complete stranger without asking anything in return.

That ad launched a chain of events that eventually led the Pleasantville, N.Y.-based family to find such a person—a 48-year-old California woman named Dawn Verdick—who was willing to donate a kidney to their father, Daniel Flood, 68. The kidney transplant took place December 12, and the family is beyond grateful.

The journey was incredible, but it was also difficult, Flood says, and Craigslist isn't the easiest way to find an unrelated organ donor. "We're not recommending people to post ads on Craigslist, just because there's a lot of loopholes, a lot of scammers. Like many parents, her father had tried to protect his children from the bad news for as long as possible.

Although Flood, her two sisters, and their brother, Christopher, knew their father had hypertension and was taking blood pressure-lowering drugs, they didn't know his kidney damage was so bad that he needed dialysis—or a kidney transplant—soon.

"He kind of kept it a secret; he was trying to protect us from his illness," says Flood. Immediately, the family members had themselves tested to see if they could donate a kidney, but no dice. (Although kidney transplants do require tissue matching, having a matching blood type is even more important.)

Flood, a psychiatric nurse, knew that the statistics weren't encouraging. Roughly 17 people in the U.S. die each day while on waiting lists (which are managed by the United Network for Organ Sharing (UNOS)), and about 100,000 people are currently on the waiting list. Patients can wait anywhere from two to six years for an organ. Flood also knew that sometimes these organs, which come from

cadavers, don't function as well as those from a living donor.

Their desperate solution? Put an ad on Craigslist. The family was already using the site for just about everything—to find jobs, childcare, and to buy and sell items. "We all just came together and said, 'Why not use Craigslist to find a living donor for dad?'" she says. "Even though it's a shot in the dark, why not try?"

They posted an ad in August 2007 and not much happened. But then a local journalist saw their post and mentioned it on a radio show; the responses started streaming in. Overall, there were more than 100 replies to the ad within a few months.

Posting the ad turned out to be the easy part. "It was tons of work," says Flood. She and her sisters had to wade through the responses to find an appropriate donor.

They interviewed all the candidates and sent likely candidates a kit for a blood donation. They ended up with five possible donors, and after tissue matching were left with three. Two were ruled out due to other medical conditions, leaving Verdick, a children's book publisher, who ended up donating a kidney to their father.

Part of the screening process included steering clear of people who wanted to sell a kidney, which is illegal.

In fact, finding a kidney donor on the Internet is a controversial practice because of the potential for abuse, says Flood.

Typically, the organ recipient's health insurance covers the donor's surgery to have the organ removed. By law, the recipient can also pay for the donor's lost wages, travel expenses, accommodations, and other transplant-related expenses, but that's it. (Which is what the Flood family covered for Verdick.)

Had Craigslist not worked out, the Flood family could have pursued paired kidney donation, which helps people who have a friend or a family member willing to donate but unable due to a blood-type mismatch. Donor A and recipient B are paired to donor C and recipient D; donor A gives a kidney to recipient D, and donor C gives

one to recipient B.

"Exchange programs are a way that these people who don't match to their family and friends can actually donate a kidney and get more people transplanted in the bargain," says Hanto.

The first paired donation in the U.S. took place in 2000, and the practice started to pick up speed in 2004, when computer optimization programs were developed. There are now several networks in the country doing paired donations.

One big advantage of paired exchanges is that people who want to volunteer to donate a kidney to anyone in the network can help two or more people get a kidney—the person they match and a person who is a good match for that individual's family or friend who is willing to donate (and so on).

Paired donation programs have been such a success that UNOS is launching a pilot program in the spring of 2010 to have a more national system, she says.

Editor's note: We also have the National Kidney Registry in our region. Please see www.kidneyregistry.org.

Upcoming LI Walks

◆ **NKF- Kidney Walk at Hofstra University Long Island- May 31, 2009.** For more information please contact Lindsay Gilman, lindsayg@kidney.org or 212-889-2210. Please let them know you are walking with or for the Long island TRIO Team

◆ **Kidney and Urology Foundation - Kidney Walk at Eisenhower Park- May 17, 2009.** Parking Lot 5, Cherry Picnic Area. Please let them know you are walking with the LI TRIO team. For more information contact info@kidneyurology.org.

◆ **ALF Liver Walk Long Island - May 17, 2009.** For more information call 212.943.1059.

WELCOME NEW LI TRIO MEMBERS!

Michael Keane

HAPPY RE-BIRTHDAYS!

Joseph Behar	March 2, 2005	Kidney
Ed Burki	March 28, 2000	Kidney/Pancreas
Rosalie Collura	March 28, 1992	Heart
Gerard Eichhorn	March 6, 1991	Kidney
Richard Johnson	March 6, 2003	Liver
Irene Kolodny	March 9, 2006	Kidney
Al Lange	March 6, 2007	Kidney
Milton Marcus	March 2, 2004	Liver
Michael Marscovetera	March 22, 2005	Kidney
Robert Seebach	March 17, 1996	Heart
Steven Taibbi	March 27, 2001	Heart
Kathy Vliet	March 30, 2006	Pancreas

SUBCOMMITTEE CHAIRPERSON CONTACT LIST

LI TRIO Main Number/Voicemail—

Jerry Sosna 516-942-4940

Welcome Committee—Tom Bush 516-942-4940

E-Mail Tree—Joe LaBarbera litrio@gmail.com

Corresponding Secretary—

Jo Michaels 516-798-8411

Social Secretary—Ruth Pohl 631-884-0482

Treasurer—Walter Ruzek 516.328.4381

Website Design/Legislative Initiatives

& Guest Speakers—Mike Sosna mike@sosproductions.com

Special Projects—Ed Burki 516-620-3700

Rose Garden Ceremony—Jo Michaels 516-798-8411

Rose Garden Logistics—Dave Rodgers 516-449-1421

Data Base Manager—Howard Pohl 631-884-0482

Donor Families & Social Secretary—

Barbara Musto 516-671-5793

Singers and School Speakers—

Sue Tietjen and George Tietjen 516-746-0693

The Ways and Means Committee/

Holiday Party Chairpersons—

Florence & Jerry Sosna 516-482-2908

Meeting Hospitality—Frank Feltkamp 516-599-2273

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LI TRIO

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Long Island Chapter

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