



Transplant Support Organization meetings are held at 7 pm on the third Wednesday of the month (with some exceptions) at Congregation Sons of Israel, 1666 Pleasantville Road, Briarcliff Manor, NY.

### Schedule for monthly meetings

7:00 – 7:30 PM – Social time

7:30 – 9:00 PM – Meeting and program for the evening.

Our speaker at the November meeting is Dr. Lewis Teperman, Director of Transplantation, NYU Langone Medical Center.

This year our **Holiday Party** will be held at Antun's of Westchester on **December 6, 2010**. Invitations will be sent out in early November. Please join us in celebration of the holidays.

Please join our meetings for support, information and new friendships.

For directions to our meeting, donor registration form, and further information, please check our website:

**[www.transplantsupport.org](http://www.transplantsupport.org)**

To contact us by mail please write to TSO, 1154 Webster Ave., New Rochelle, NY 10804

### **Transplant Support Organization Officers**

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**Rudy Masry**

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#### Vice-Presidents

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**TSO website:**

[www.transplantsupport.org](http://www.transplantsupport.org)

To all recipients of this newsletter. Please send your email address so we may notify you of any last minute changes to our meetings. If you have changed your address recently please let us know so we can update our records.  
Contact Janet Ocasio at GKJP@aol.com

### **The UNOS National Patient Waiting List**

Candidates as of 10/8/2010

**86,481** patients waiting for a kidney transplant.

**16,057** patients waiting for a liver transplant.

**1,425** patients waiting for a pancreas transplant.

**2,214** patients waiting for a kidney-pancreas transplant.

**260** patients waiting for an intestine transplant.

**3,158** patients waiting for a heart transplant.

**78** patients waiting for a heart-lung transplant.

**1,829** patients waiting for a lung transplant.

**108,891** TOTAL PATIENTS\*

**Every 12 minutes a new name is added to the waiting list.**

## *And the Beat Goes On (continued from p. 1)*

the incurable disease, which renders her legally blind. Although she has some vision, her first symptom was night blindness. It is an inherited disease, and manifests itself in different ways with different people. In her case she has many blind spots in the center of her vision. She now uses a cane for two reasons: it helps her with her vision loss, and alerts other people that she is blind.

Judith is always “reinventing herself” and trying to bring order to her life. When her grandchildren visit they know they must leave the house in the same condition in which they found it. As a docent at the Jewish Museum for over 35 years, an advocate for the disabled, and guide at the MOMA, Whitney Museum and the Guggenheim, she found her skill of talking to people even though as a child she was always shy.



Judith ran the NYC marathon with sighted guides and proudly wears the medal proving she finished the race. As a teacher in the Brooklyn schools for many years, she believes she had guardian angels watching over her as she traveled to her job. She now makes use of any tool available to help her and asks for help when needed.

We were all inspired by this amazing lady.

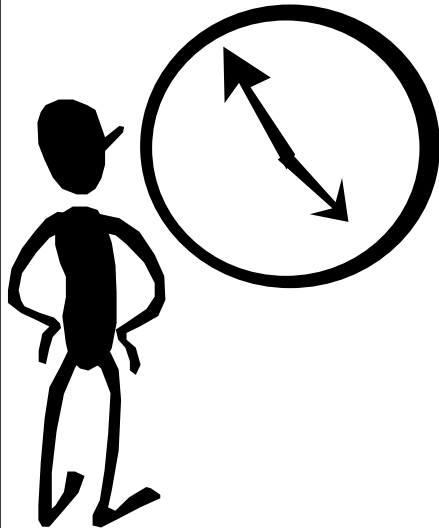
## *Happy Rebirthday to You*

Jeff Graham	Nov-96	Liver	Ali-Jean Christman	Nov-06	Liver
Frank Carbonaro	Nov-98	Liver	Carmen Camacho	Nov-06	Kidney
Imelda Arbeely	Nov-99	Kidney	Regina Kalinowski	Nov-07	Liver
Sandra Brennan	Nov-00	Kidney	Ann Marie Farrell	Dec-82	Kidney
Matthew Moshen	Nov-01	Heart	Bob Winters	Dec-89	Kidney
Mel Kaplan	Nov-02	Kidney	Richard Knizeski	Dec-93	Kidney
Aruna Mansaray	Nov-03	Liver	Helen Manz	Dec-97	Liver
Ascher Sellner	Nov-03	Liver	Janice Powers	Dec-98	Kidney
Peter Sarno	Nov-03	Liver	Joseph Cannizzaro	Dec-98	Liver
Robin Zencheck	Nov-03	Heart	Patricia Davey	Dec-00	Lung
Sarah Fontanez	Nov-04	Liver	Jacinth Heyliger	Dec-01	Lung
James Dwy	Nov-04	Kidney	Donna Hogben	Dec-05	Lung
Debbie Vega	Nov-05	Liver	Steven Lowy	Dec-06	Kidn/Liver
Brian Wynne	Nov-06	Kidney	Thomas LaSorsa	Dec-08	Kidney

*Our best wishes to all for many more happy and healthy years to come*

## Coordinator's Corner While You Wait . . .

KAREN FARKAS, RN  
MPH, RENAL TRANSPLANT COORDINATOR



Waiting for anything is often frustrating and can be quite stressful - like waiting to see your doctor when there is a room full of patients ahead of you; waiting for your meal in a busy restaurant when you are hungry or waiting on a long line at the Motor Vehicle Department to renew your license. The waiting seems endless especially for those that are very impatient like me.

While I have never waited on a transplant list, I certainly have listened to and shared in my patient's frustrations as they wait for a transplant. Because of the shortage of deceased donor organs, patients are waiting much longer on the list than ever before. My advice has always been and continues to be the following - live life to the fullest, stay as healthy as you can possibly be, try to forget about the wait but be mindful that you need to be ready for the surgery when you get the call.

One can wait for a deceased donor organ for a few days or for many years. Since you never know when an organ will become available, it is imperative that you are prepared. These are a few things that you can do while you wait for the call.

- ✓ Have transportation ready to get you to the transplant center.
- ✓ Plan for the care of your children and pets.
- ✓ Make a list of the items to bring to the hospital - list of medications, personal care items, insurance cards, etc.
- ✓ It is vital that the transplant team be able to reach you 24/7 - notify your transplant center of any changes in phone numbers, address or if you will be unavailable for any period of time. Don't assume that your doctor or dialysis center has communicated with the transplant team. They often do not.
- ✓ If you are on a kidney waiting list, make sure your routine blood samples for cross matching are getting to your transplant center as requested.

## *Coordinator's Corner (continued)*

### *While You Wait . . .*

- ✓ Keep all prescribed testing up to date - your Transplant Coordinator will prompt you when tests are due. Keep up with your routine health maintenance such as seeing your dentist regularly.
- ✓ Visit the transplant center for follow up appointments as scheduled so as not to risk missing an opportunity for a transplant when the call comes, always notify the transplant team if you have been hospitalized or if your health has changed. It is much easier to obtain updates from your doctor during business hours than it is in the middle of the night or on a weekend.
- ✓ Take medications as prescribed, exercise, eat balanced meals, and maintain a healthy weight. Work with your Dietitian, if you have been told you need lose or gain weight. If still smoking, quit
- ✓ Attend transplant support groups such as TSO or TRIO. Your center may also have a support group of their own. Attendance may be beneficial for both you and your caregiver or other family members for both education and support.
- ✓ Continue to educate yourself about transplant - attend seminars or workshops, read articles or research the Web.
- ✓ Volunteer to educate others about transplant and organ donation.
- ✓ Let your family, friends, work associates, church & social groups know that you are on a waiting list for a kidney. You never know, someone may wish to be a living donor for you.
- ✓ If you are having a hard time emotionally, ask to speak with your Social Worker or Transplant Coordinator.

Just remember one thing. Your turn will come eventually. I wish you all the best of luck and hope that you get the call very soon.....maybe tonight!

Stay healthy!

If you plan to get books, CD's or DVD's for your Holiday Gifts, you can help us raise money for TSO at the same time. **Borders/Walden Books** is partnering with TSO in a unique Fundraising Event. All you need to do is shop in one of their stores or buy online using the voucher or the voucher code, and TSO will receive a percentage of the profits. (Voucher below may be duplicated.) Use of this voucher is in addition to any coupons you may have.

**The dates for the fundraiser are:**

**11/27 AND 11/28**

**Remember to share this information with your family and friends**

**Borders** has also invited us to participate at their in-store gift-wrapping station. They will provide the table and supplies and we provide the manpower. We can also display donor registry information at the wrapping table.

We get to keep any donations made by the customers at the wrapping station. The date(s) and location(s) for this will be announced shortly. If you would like to volunteer to help wrap, please call Carole Graham at 914-576-6617

## Valuable voucher to benefit the Transplant Support Organization

Benefit Days – our way of giving back

Excludes previous purchases, gift cards, newspapers, magazines, coupon books, digital downloads, comics, special orders, video games, Smartbox products, Rosetta Stone software, and shipping. Void where prohibited by law. Any other use constitutes fraud. Cash value .01¢. Not redeemable for cash. Valid on [dates].

**Cashiers:** Ring items, select S3, select S4, scan or enter barcode #, select S1, enter \$0.01, and Total.

Note: if a customer presents a Total Purchase coupon, such as "\$5 off Total Purchase" or "10% off Total Purchase", use this barcode to ring that discount. Follow the instructions on the original coupon, but scan the barcode on the Benefits Day voucher. The register will only accept one barcode for Total Purchase coupons.

**Borders Online Code: TRSP1128P**

a percentage of the net sales raised from this coupon will be donated to the Transplant Support Organization



valid 11/27–11/28/10

**BORDERS®** **Waldenbooks®**

## *Transplant in the News*

### Generic vs. Brand Name Drugs

The issue of brand name versus generic prescription drugs has intensified in recent years to become a common topic of discussion. The information below will help you find just what you need to understand more about this topic.

#### **Safety Concerns**

Although generics may look different, they use the same active ingredients and have the same intended use, quality, risks and benefits as their brand name counterparts.

The FDA requires that all drugs be safe and effective, and both brand name and generic drug facilities meet the same standards of good manufacturing practices. In fact, brand name companies are linked to an estimated 50 percent of generic drug production--they frequently make copies of their own or other brand name drugs but sell them without the brand name.

However, it is important to consider that generic drugs are not necessarily formulated in an identical manner to their brand name counterparts, therefore affecting absorption into the patient's bloodstream. This absorption may cause occasional differences in individual response and side effects.

#### **Cost Issues**

Generic drugs are less expensive because generic manufacturers do not incur the investment costs of the development of a new drug. New drugs are developed under patent protection, which protects the investment--including research, marketing and promotion--by giving the company the sole right to sell the drug while it is in effect. When the patent expires, other drug companies can apply to the FDA to sell competitive generic versions, but only after the drug has been thoroughly tested by the manufacturer and approved by the FDA. Because generic manufacturers don't have the same development costs, they can sell their product at substantial discounts. Also, once generic drugs are approved, there is greater competition, which keeps the price down. Today, almost half of all prescriptions are filled with generic drugs.

#### **Naming Conventions**

A generic drug is called by its chemical name, while a manufacturer assigns a brand name.

## TSO School Program reaches new heights!

Jeff Graham reported that the high school team has spoken to 889 students this year. They have presented the program to 48,606 since the inception of the program. 158 classes are scheduled through mid-January 2011. On November 4<sup>th</sup>, the program will reach 50,000 students. Congratulations!!



## *Transplant in the News*

### Ossining kidney recipient champions organ donation

LOHUD.COM, SEPTEMBER 5, 2010

With one kidney transplant she received at age 6 having failed, and the prospect of a second transplanted kidney also not working, 12-year-old Mary Wu looked solemnly at her father from her hospital bed and asked if she should prepare a will.

Wu recalled how the color drained from her father's face, and his immediate reply.

"No! What are you talking about? You are too young to be thinking of those things!" Joseph Wu said sternly.

Thanks to anti-rejection drugs, her body accepted the second kidney.

Sixteen years later, Wu, who grew up in Thornwood and graduated from Manhattanville College, is a vibrant 28-year-old woman full of life and optimism, and with a purpose: To educate people on the importance of organ donation.

"Over 110,000 people are waiting for life-saving organs in the United States, yet New York has the lowest rate of registered donors at only 11 percent of the population," she said. "My mission is to find a way to increase the percentage in New York. There are so many misconceptions about organ donation that it boggles my mind."

For example, getting an organ transplant does not mean the recipient will no longer be sick.

"People think it's a cure, but there are so many side effects," she said. "My body rejected the first kidney and it was only because of the medicine I received that my body accepted the second transplant."

Another misconception, she said, is the belief that indicating on your driver's license that you'd like to be an organ donor is enough. It's not, Wu said.

"While it's important to let your loved ones know your wishes to be an organ donor, that's not enough. In New York, you must sign up with the donate life registry. That way, if your family doesn't know your wishes, it will be on the registry," Wu said.

Wu, who works for Memorial Sloan-Kettering at Phelps Memorial Hospital in Tarrytown, has been involved with the National Kidney Foundation, the New York Organ Donor Network and the Transplant Support Organization, where she counsels parents of children slated to get a donated organ. The support organization serves people in Westchester, Putnam and Dutchess counties, the Bronx, Staten Island and southern Connecticut.

"When I counsel families, I just speak from my own experience," Wu said. "The number one thing you tell people is that they're not alone. I've been there and nearly 110,000 people are still there."

Wu's donor was a 4-year-old girl who died in an accident at home. Wu said she tried to contact her donor's family, but understands why they did not want a relationship with her. Still, she says, that family's selflessness allows her to enjoy each day.

"I try to always be optimistic as a way to give back to my organ-donor family," she said. "They literally gave me a new lease on life, so I feel obligated to always focus on the positive."

Briarcliff Manor resident Rudy Masry, president of the Transplant Support Organization, said he never ceases to be amazed by Wu's positive outlook.

"She has a smile on her face all the time when, if you stop to think what she's been through, she should be in the corner crying," said Masry, also a kidney recipient. "She is truly amazing."

## *Transplant in the News*

### *Kidney Paired Donation Pilot Program to Begin Matching in October*

The national Organ Procurement and Transplantation Network (OPTN), operated under federal contract by United Network for Organ Sharing (UNOS), will soon perform the first match run of a national pilot program to facilitate kidney paired donation (KPD) transplants. The match run is intended to identify medically compatible pairs of potential living kidney donors and candidates, in cases where the potential donor was not able to match with his or her original intended recipient. "In the last three years, kidney paired donation has made possible more than 700 transplants nationwide that otherwise wouldn't have taken place," said OPTN/UNOS President Charles Alexander, RN, M.S.N., M.B.A. "We believe many more transplants are possible. Through this national pilot program, we want to see whether having a national pool of potential donors and candidates will provide more opportunities for lives to be saved and enhanced."

A total of 77 living kidney donor transplant programs will participate in the initial pilot phase. Each program is affiliated with one of four coordinating centers, which will work directly with UNOS on administrative issues such as donor/recipient applications, logistical arrangements and data submission. The coordinating centers are listed below.

Alliance for Paired Donation

Johns Hopkins Hospital

New England Program for Kidney Exchange

University of California at Los Angeles Medical Center/California Pacific Medical Center

Match runs will be conducted every four to five weeks with information on potential living donors and candidates supplied by participating transplant programs. Each transplant program must document that potential donors have completed a rigorous medical screening and evaluation process, and that they have provided detailed informed consent for donation and for potential participation in a national match run. Each transplant program will make individual medical decisions about accepting living donors or candidates or whether they are appropriate for matching through the pilot program. Additional resource information about the pilot program is available on the OPTN website: <http://optn.transplant.hrsa.gov/resources/KPDPP.asp>

## **New York Organ Donor Network Notice**

**WESTCHESTER** Watch for a kick off advertising campaign in Westchester county this month. Ads featuring real New Yorkers will be on Posters, bus tails, radio, and at DMV's, hospitals, Village Halls, Libraries, Veterans groups, churches and Post Offices (thank you Rudy for this great idea!) Please contact Miriam Perez [mperez@nyodn.org](mailto:mperez@nyodn.org) if you can help educate first time drivers and those renewing licenses at Department of Motor Vehicles along with David Holt. The campaign will run through December.

October 7 was the second meeting at Westchester Medical Center for "Viviendo con su Transplante" (Living with your Transplant) support group. All are invited as this bi-lingual group continues to grow and evolve. It is open to all transplant patients, families and friends whether they are WMC patients or not. Miriam Perez (NYODN), Mimi Greenman (WCMC), Janet Ocasio, NYODN and TSO Volunteers are spearheading. For info call the WCMC Social Work Department: 914/493-7641

Jeff Graham is spearheading a High School Education volunteer training. Train with Jeff and take it back to your county. [cpaykin@nyodn.org](mailto:cpaykin@nyodn.org) for more information. Thank you team leads Rudy and Jeff!

# Help Promote Donor Awareness License Plate Frames For Sale

\$ 10.00 each 2 for \$ 18.00 3 for \$ 25.00



LPF 1 Top: Make a Miracle  
Bottom: Be an Organ Donor

LPF 7 Top: Transplantation Works  
Bottom: Lung Recipient

LPF 2 Top: Miracle Maker  
Bottom: Kidney Donor

LPF 8 Top: Transplantation Works  
Bottom: Liver Recipient

LPF 4 Top: Organ / Tissue  
Bottom: Donor Family

LPF 9 Top: Transplantation Works  
Bottom: Heart Recipient

LPF 10 Top: Transplantation Works  
Bottom: Kidney Recipient

Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_

Phone \_\_\_\_\_

Frame(s) desired \_\_\_\_\_

(add \$2.00 for postage and handling)

Send order with payment to: TSO, 1154 Webster Ave. New Rochelle, NY 10804

## Directions to the Monthly Meeting

Congregation Sons of Israel  
1666 Pleasantville Rd.  
Briarcliff Manor, NY

### From New York City, George Washington Bridge

Take Henry Hudson Parkway North to Saw Mill Parkway North. Continue to interchange with Taconic Parkway North. Bear RIGHT onto Taconic Parkway. Exit RIGHT at Route 9A/100. Stay on Route 9A. Make a LEFT at the second traffic light (Chappaqua Road). Road will bear right and become Pleasantville Road. Get into the LEFT turning lane to make a LEFT turn into CSI.

### From Tappan Zee Bridge

Cross bridge, stay to right, follow signs for Saw Mill River Parkway North (Exit 8A) and follow directions above.

### From Long Island, Connecticut, Southern Westchester

Take Cross Westchester Expressway(287) West to Exit 3 ("Sprain Parkway North, New York City, to Taconic Parkway"). Take this exit and continue straight up the ramp to Sprain Parkway North. DO NOT make a quick right, marked to New York City. Follow Parkway North approximately 5 miles to interchange with Taconic Parkway and follow directions above.

### From Upstate New York

Take Taconic Parkway South to Routes 100/133, Briarcliff exit. Cross over Route 100 and follow Route 133 to second traffic light (about 3 miles). Make a left onto Pleasantville Road. Continue approximately one mile to CSI on RIGHT.



# TSO Transplant Support Organization

Participant Application:                      New                      Renewal

Please fill out this form and mail it with your tax-deductible contribution to:  
TSO, 1154 Webster Ave., New Rochelle, NY 10804

NAME(s) \_\_\_\_\_

Mailing Address: \_\_\_\_\_  
\_\_\_\_\_

Phone #: Daytime: \_\_\_\_\_ Evening: \_\_\_\_\_ Cell: \_\_\_\_\_

Email: \_\_\_\_\_

**PERSONAL INFORMATION** (optional)

Birthdate: \_\_\_\_\_ Sex: \_\_\_\_\_ Marital Status: \_\_\_\_\_

Occupation: \_\_\_\_\_

**CANDIDATE / RECIPIENT INFORMATION — Please check appropriate description**

Transplant Recipient \_\_\_\_\_ Transplant Candidate \_\_\_\_\_ Family Member \_\_\_\_\_

Donor Family Member \_\_\_\_\_ Interested Individual \_\_\_\_\_ Professional \_\_\_\_\_

Have you already had a transplant?      Yes \_\_\_\_\_      No \_\_\_\_\_

Type of Transplant(s) \_\_\_\_\_

Date of Transplant \_\_\_\_\_ Time waited (or waiting) \_\_\_\_\_

Where did you (will you) have your transplant? \_\_\_\_\_

**PARTICIPANT CATEGORIES & SUGGESTED CONTRIBUTIONS**

**Regular**      (Transplant recipient, transplant candidate, family member, donor family)

**Individual Participant** \$25.00

**Family Participant** (2 members, same address) \$35.00

**Additional participants** at same address \$10.00 each

**Professional** (Surgeon, Physician, Clinical Coordinator, Nurse, Social Worker, etc.) \$25.00

**Additional optional voluntary contribution** (at your discretion) \$ \_\_\_\_\_

I would like to take an active role within TSO (please check all areas of interest):

Speaker \_\_\_\_\_      Membership Drive \_\_\_\_\_      Fund Raiser \_\_\_\_\_

Clerical \_\_\_\_\_      Contributor \_\_\_\_\_      Patient & Family Support \_\_\_\_\_

Newsletter \_\_\_\_\_      Data Processing \_\_\_\_\_      Other \_\_\_\_\_

**TSO**  
Transplant Support Organization  
1154 Webster Ave.  
New Rochelle, NY 10804

## NEXT MEETING — November 17, 2010

### Volunteer Opportunities

Thursday, November 4<sup>th</sup> – Bedford community Response Team, Bedford Hills Community House, 7 Church Street, Bedford Hill, NY, 12:00-5:00

Saturday, November 6<sup>th</sup> – Star of Bethlehem Church, 304 Spring Street, Ossining, NY, 10:00-3:00

Monday, November 15<sup>th</sup> – Mahopac High School, 421 Baldwin Place Road, Mahopac, NY, 8:00-2:00

Wednesday, November 17<sup>th</sup> - Pace University, 861 Bedford Road, Pleasantville, NY 11:30-4:30

Wednesday, November 17<sup>th</sup> – Greenberg Public Library, 300 Tarrytown Road, Elmsford, NY, 2:00-7:00

Friday, November 19<sup>th</sup>- North Salem Firehouse 2-7

Tuesday, November 23<sup>rd</sup> – Eastchester High School and community, Middle School Gym, 2:00 (3:00?)-7:00

Call Helen Bellhouse if you can help: (845) 528-1782 or email at [hmbellhouse@verizon.net](mailto:hmbellhouse@verizon.net)

### Transplant Support Organization's Mission

#### *To help save lives by:*

- **Providing** education relating to organ donation and transplantation;
- **Promoting** organ and tissue donation as an important social responsibility;
- **Giving** support to transplant candidates, recipients, their families and donor families;
- **Effectively** communicating to government bodies and the general public, the concerns and needs that affect the welfare of those individuals impacted by the transplant process.