

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 March meeting is Dr. Daniel Cameron who will speak about ticks and Lyme disease

Future speakers are:

4/21/10, Dr. Gerald Zaidman, Ophthalmic and Cornea Surgeon, Westchester Medical Center

5/12/10, Dr. Devon John, NYU Hospital Transplant Surgeon

6/16/10, Roberta Billman, RN, Rogosin Institute Post Transplant Nurse.

Please join us for support, information and new friendships.

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

www.transplantsupport.org

To contact us by mail please write to TSO, PO Box 2712, Briarcliff

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 2/12/2010

83,321	patients waiting for a <i>kidney</i> transplant.
15,806	patients waiting for a liver transplant.
1,492	patients waiting for a pancreas transplant.
206	patients waiting for a pancreas islet cell.
2,212	patients waiting for a kidney-pancreas transplant.
233	patients waiting for an intestine transplant.
3,101	patients waiting for a heart transplant.
72	patients waiting for a heart-lung transplant.
1,865	patients waiting for a lung transplant.
105,760	TOTAL PATIENTS*

All candidates will be less than the sum due to candidates waiting for multiple organs.

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

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TSO website:

www.transplantsupport.org

It is with deep sadness that we announce the passing of two of our long time members,
 who also served on the TSO Board.:

Cori Maass, who for several years offered group counseling to any of our members who
 needed help dealing with their transplant issues.

Jim Dowd, with the big smile, was our treasurer for many years, and up until the end
 helped get the newsletters out to members.

We love you both and will miss you so very much.
 We're blessed to have known you.
 Rest in peace.



Happy Rebirthday to You

Wayne Grossman	Mar-96	Kidney	Janice Maron	Apr-97	Kidney
Yvette Sharrow	Mar-97	Liver	Joan Ploschke	Apr-00	Kidney
Trinidad Fernandez	Mar-00	Kidney	Hermenegildo Correia	Apr-00	Kidney
Barbara Mattioli	Mar-02	Kidney	Nader Elnimri	Apr-01	Kidney
Joseph Ramos	Mar-02	Kidney	Gerhard Freyer	Apr-02	Kidney
David Juliano	Mar-03	Kidney	Angela Chebetar	Apr-02	Liver
Bobby laboni	Mar-05	Kidney/Liver	Efrain Roman	Apr-04	Liver
Michael Murphy	Mar-06	Kidney	Marilyn Heideman	Apr-04	Liver
Helen Harper	Mar-07	Kidney	George Belezair	Apr-05	Kidney
William Becker	Mar-08	Kidney	Frank Ryan	Apr-05	Kidney
Anne Landisi	Apr-94	Kidney	Sara Marshall	Apr-06	Kidney
Pearl Herson	Apr-96	Kidney	David Holt	Apr-08	Heart

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

Transplant Recipient's Story – Rudy Masry

About 20 years ago, on a visit to my doctor, I was told my latest test results indicated a gradual decline in my kidney functions which will culminate in a need for a kidney transplant. In 1997 I reached what is called End Stage Renal Failure. I was prescribed a diuretic medication to reduce the edema in my legs.

In 2000, my kidney functions got worse. The doctor prescribed a second diuretic to be taken in conjunction with the first. Subsequently I went on dialysis.

Two months later I was registered to get on the transplant waiting list. Then, the waiting time was estimated to be up to 5 years. Today, it is up to 8 years or more.

The dialysis went well. I was very lucky: I was free of a lot of the side effects such as weakness and fatigue. The diet was very difficult to manage though. There is a long list of foods to avoid. Even liquids such as water and soda had to be taken in very small quantities. New medications were added to the mix that I was already taking.

My son volunteered to be tested for compatibility. I was very reluctant to subject him to such a procedure at the age of 28. He was compatible up to a degree; however, the transplant doctor advised against him being the donor.

My wife, all along insisted on being tested. At the time she was disqualified because she was over 60. However, due to the extreme shortage of donated organ the surgeons decided to waive the age limitation and the slight high blood pressure that she also suffered.

She was a match for blood type, a match for compatibility and not a match for the protein markers. One's blood carries 6 protein markers. Ideally, a perfect match is when both donor and recipient have 6 out of 6 markers. We had zero markers. The surgeons assured us that there were advances in the immunosuppressant drugs today that will compensate for that and not to worry about it.

The surgery took place on January 15th, 2003. All went very well. My wife's surgery was done laparoscopically and she was released from the hospital less than 48 hours after surgery. Two days later she felt as if she did not have any procedure.

Please register to be an organ donor. Be sure to discuss your decision with your next of kin. People are dying needlessly waiting their turn on the transplant list.

There are 105,000 plus Americans on the waiting list, Every 12 minutes 1 individual is added and 18 die each day due to lack of an organ.

Coordinator's Corner

Deep Vein Thrombosis (DVT) Part One

KAREN FARKAS, RN, Renal Transplant Coordinator,
Westchester Medical Center

Deep vein thrombosis is a condition where a blood clot forms and lodges in a deep vein. They are usually found in the legs but can occur in other areas of the body. With treatment, most disappear without further problems, however they can recur. Pulmonary embolism (PE) is one of the most serious complications of DVT. A PE can occur when a piece of the clot breaks off and travels to the lungs blocking one of the blood vessels. This is a life threatening condition.

There are a few reasons why clots form. They can occur if blood flow has slowed; a blood vessel has been irritated, or injured; or blood is thicker than usual. These risks are as follows:

- Prolonged bed rest as in a long hospitalization or paralysis
- Sitting for long periods of time in a wheel chair or while traveling long distances
- Family history of DVT or PE or previous occurrence of DVT
- Inherited blood clotting disorders such as Factor V disease
- Surgery or injury to veins during trauma or after a broken bone
- Certain infections, cancers or cancer treatments
- Heart failure – a damaged heart may not pump blood efficiently
- Heart irregularities – arrhythmias such as Atrial fibrillation
- Indwelling catheter – can irritate the blood vessel wall and slow blood flow
- Medications such as erythropoietin or estrogens found in birth control pills or hormone replacement therapy – can cause blood to thicken
- Older age – can occur at any age but is less common in children
- Smoking – affects blood clotting and circulation
- Pregnancy – pressure increases in the veins of the pelvis and legs in the later months
- Obesity

If a DVT develops there may be no symptoms at all. More commonly one may experience pain, swelling, or redness in the affected area. It may be warm to touch. If any of these symptoms occur, notify your doctor. Unexplained, sudden shortness of breath, pain during a deep breath or coughing up blood can be symptoms of a pulmonary embolism especially if a diagnosis of DVT has already been made. This is a medical emergency and requires immediate attention.

If DVT is suspected, your doctor will examine the area and may order certain blood tests. A Doppler ultrasound will show the presence or absence of a clot. Once treatment nears completion a repeat ultrasound will confirm that it was successful or if the clot remains, treatment will continue. Less frequently a CT scan, MRI or Venography is done. If a PE is suspected, a VQ scan is performed.

The treatment for DVT is most often anticoagulant medications, know as blood thinners. They do not dissolve clots (they eventually resolve on their own) but rather reduce the body's ability to clot blood. They prevent the clot from enlarging, breaking loose, and may prevent the clot from happening again. Heparin is usually the first medication to be administered. It may be in the form of an injection but if given intravenously, admission to the hospital is necessary. After a few days, warfarin (Coumadin) is started orally. Warfarin is usually needed for 3 to 6 months. If a person has had more than one incidence of DVT, lifelong therapy may be required. In rare cases surgery may be necessary to insert a filter in the body's largest vein (Vena cava) to prevent clots from traveling to the lungs. This is generally reserved for those who cannot take blood thinners or those with a higher risk for PE.

Karen has asked for suggestions, requests of items you would like her to discuss . Please contact her at:
farkask@wmc.com

Community Views

What was the most significant change, positive or negative, in you life after your transplant. If you are a caregiver, what was the most significant change that you observed regarding your recipient's life.

As a donee, the one fundamental change in my life was my attitude toward life. Prior, feeling doom and gloom. After, uplifting, aggressive and desirous of positive change. The feeling of giving back, helping more, joining groups for positive change. **Frank Cimino, Kidney Recipient**

In answer to your question of the month: The most significant positive change for me after my liver transplant which was 3 and 1/2 years ago is to truly appreciate each and every precious moment given to me. I prayed for health and I received this gift from an unknown angel donor, which has given me the energy and courage to continue the work that God had assigned to me. I am among the most blessed to have a wonderful support system that nurtures and sustains me but it is the true acknowledgement that we are merely instruments in the hands of the Lord that I put my trust. **Carole Baral, Liver Recipient**

It is a pleasure to answer your inquiry. The fact that I am alive is fantastic. The most significant change in my life was the fact that I had taken many things for granted...that my broken leg would heal, a cut would heal, my skin would recover from sun burn, etc. I took for granted the fact that I had a good education, that I had a job, that I had a wonderful wife and friends, that I could smell the flowers. Now each day I thank the Lord for all my blessings and am much more sensitive to people and things around me. I have become much more tolerant of other peoples' thoughts, likes and dislikes and attitudes towards everything. I adapted very well, first, to a heart pump (LVAD) that kept my heart pumping on a regular basis for 14 months while I moved up the transplant list. Then, when I got a heart transplant, I recovered quickly and adapted to the regimen of pills taken twice each day. I asked my physical therapist from the heart transplant team at Columbia to come to the apartment to help me set up an exercise program both on a tread mill and using weight lifting machines. Today I am healthier than at any time in the last 10 years and enjoying traveling and eating out and visiting with family and friends. **Ted Lawson, Heart Recipient**

The most significant change after my transplant was my attitude or outlook of life. The mind and body are so extremely connected. In general, I've always tried to maintain a positive attitude, but to do that in the midst of being so sick is such a challenge. After my transplant, I was so much more and genuinely positive, hopeful, and happy from my health improving significantly from the second kidney transplant. Before the transplant, I was so sick and sickness led to a negative and sad attitude. Thanks to my transplant, I was finally able to physically do more and fully enjoy my daily activities and time with my family and friends. All of this has made me the positive and upbeat person that I am, appreciating life and all my loved ones. **Mary H. Wu, Kidney Recipient**

Due to the side effects of my medications it was necessary for me to retire. **Bill Becker, Kidney Recipient**

The thing I recall most was the ability to travel without limitations!! We no longer had to limit our destinations to areas that had dialysis centers or have to make arrangements for dialysis weeks in advance. We both felt like birds out of a cage!! **Glenna Epperson, Caregiver**

After my simultaneous kidney/pancreas transplant, the most positively significant change to my life was that I no longer had to live with Type 1 diabetes! I was diagnosed with it when I was 15. Although I'd tried to live within the confines of a strict diet and in the later years up to 8 insulin shots a day, my kidneys began to fail about 25 years in. I managed with medication and an even more strict diet to keep those kidneys functioning for another 14 years. I was lucky enough to receive my transplant, at NY Presbyterian Hospital/Cornell, shortly before having to go on dialysis. 10 years have passed now without the huge weight of that insidious disease on my (and my husband's) shoulders. I thank my unknown donor every day of my life for this amazing gift and for my freedom.

Glenda Daggert, Kidney/Pancreas Recipient

**Thank you for your responses. Please share your opinions so we can continue this column.
If you would like to suggest a question please contact Helen Bellhouse or Janet Ocasio.**

E-Mail Addresses

To all recipients of this newsletter. Please send us your e-mail 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

Volunteer Opportunities

- March 10th** Pace University, Pleasantville 11:30 AM-4:30 PM (Wednesday)
- March 11th** NY Sports Club, 14 Saw Mill Rive Road, Hawthorne 11:30 AM-6:00 PM (Thursday)
- March 20th** Global Health Fair at the White Plains High School from 9 AM-2 PM (Saturday)
- April 13th** Town of Harrison 1 PM-6:00 PM (Tuesday)
- May 12th** Pace University, Pleasantville (time to be announced) (Wednesday)

Please contact Helen Bellhouse if you would like to volunteer for any of the above events: 845-528-1782 or hmbellhouse@verizon.net

April 14th-16th Mount Sinai Hospital all day Donor Education Awareness Events. Anyone interested in volunteering please contact: *Sharyn Kreitzer at SharynKreitzer@mountsinai.org*

Please let us know if you would be interested in serving on the TSO Board. Please contact anyone on the present board See page 2 of this publication for names and phone numbers. We usually meet once a month a week prior to the general meeting.

Transplant News

Flags Across America

Flags Across America 2010 is a program sponsored by Donate Life America which continues to build momentum as hospitals, procurement organizations and the public continue to share new ways to use Donate Life flags to honor donors and recipients and help increase donation. Check their website <http://donatelifenet.net/faa/faa.php>

· **Customize Your Donate Life House Flag** – Volunteers, donor families and recipients can use the Donate Life flag at home and in their community to honor donors and recipients, as well as increase donor designations. Check the Flags Across America page on the Donate Life America public site for a list of ideas and ways to promote FAA 2010, including instructions on how to customize a home flag. Visit the Donate Life store for a variety of FAA items such as house flags, garden flags, personal flags, car flags and more!

· **Stick Flags Now Available** – Smaller sized stick flags and bases to display them (each ordered separately) can now be ordered from the Donate Life store. These make an excellent addition to one's work space, reception area, conference rooms, break areas, etc.

· **Using a Donate Life Card to Complement Ceremonies** – Thanks to Jana Lacera at The Community Hospital in Munster, IN, all donor families from the area Community Hospital system received a specially designed Thank You card and a Donate Life garden flag to honor their loved one in 2009. Cards can be easily printed in-house on card stock (see the .pdf file at <http://www.box.net/shared/12bvan19mh>) and Jana would like to share this with other hospitals, encouraging them to honor their donors in a similar fashion with their own custom designed card. Contact Jana (219-836-6862) for more details on using the card.

· **Other Ways to Display the Donate Life Flag** – Flags given by hospitals to donor families have been displayed at funeral homes during visitations and at memorial services for the deceased donor, either on display, as a casket cover or altar cloth

Inner Peace:

If you can start the day without caffeine,

If you can always be cheerful, ignoring aches and pains,

If you can resist complaining and boring people with your troubles,

If you can eat the same food every day and be grateful for it,

If you can understand when your loved ones are too busy to give you any time,

If you can take criticism and blame without resentment ,

If you can conquer tension without medical help,

If you can relax without liquor,

If you can sleep without the aid of drugs,

**Then You Are Probably
The Family Dog!**

Transplant News

New Technique for preserving pre-transplant livers

Health & Medicine, January 25, 2010

Preserving organs on ice prior to transplantation, an approach known as cold storage or CS, has been the standard practice in liver transplant for 20 years. Now there is new evidence that a technique called hypothermic machine perfusion (HMP) may offer an improvement, according to the first-ever study comparing the impact of the two techniques on transplant outcomes. The phase I study was carried out by Dr. James V. Guarrera and his colleagues at New York-Presbyterian Hospital/Columbia University Medical Center. The researchers found that HMP is at least as good as CS in preserving donor livers -- and that it most likely constitutes an advance over the traditional method. Improving preservation, they emphasize, could expand the availability of organs for transplantation.

Unlike cold storage, which Dr. Guarrera describes as a static technique, HMP dynamically simulates "aliveness" by providing a continuous flow of oxygen and key nutrients to the liver while diluting and removing toxins and waste products.

"Cold storage is the easy way to preserve vital organs for transplant. Generally, it has been a fairly effective way to keep a liver healthy en route to transplant surgery. But today, we have the technology to do better," says Dr. Guarrera, surgical director of adult liver transplantation at New York-Presbyterian Hospital/Columbia University Medical Center and assistant professor of surgery at Columbia University College of Physicians and Surgeons. "And by better preserving donor livers and reducing preservation-related injury, we may be able to expand the pool of available organs, making liver transplantation available to more patients who need it."

The study compared 20 transplant patients who received HMP-preserved livers with 20 patients with CS-preserved livers, finding the first group experienced shorter hospital stays and fewer long-term complications. The HMP group also had lower levels of blood markers indicating injury to the liver that may have occurred during the preservation interval.

The findings are currently reported online in *The American Journal of Transplantation* and will be featured in the journal's February issue. The study was supported by a grant from the Health Resources and Services Administration, Division of Transplantation. A second grant is funding a phase II study.

Molecular and mechanistic studies also are under way. Establishing the benefits of HMP over CS will depend on the results of larger clinical studies, says Dr. Guarrera, but it is equally important to clarify the way the two techniques play out at a cellular and molecular level.

"We aim to show that even imperfect livers can be maintained in peak condition via HMP during the critical period when they are in transit from donor to recipient. It's the kind of 'quality improvement' that will translate into long-term benefits for patients."

Source: New York- Presbyterian Hospital/Weill Cornell Medical Center

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, PO Box 2712, Briarcliff Manor, NY 10510-2712

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 _____ Date Processing _____ Other _____

TSO
Transplant Support Organization
PO Box 2712
Briarcliff Manor, New York 10510

NEXT MEETING — March 17, 2010

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.*