



TSO Transplant Support Organization

Serving the NY counties of Westchester, Bronx, Putnam, Dutchess, and southern Connecticut

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Transplant Support Organization
meets on the third Wednesday
of the month at
Congregation Sons of Israel,
1666 Pleasantville Rd.,
Briarcliff Manor, NY.
Please join us.

2009 Meeting Dates

- January 21, 2009
- February 18, 2009
- March 18, 2009
- April 22, 2009
- May 20, 2009
- June 17, 2009

And the Beat Goes On . . .

Dr. Veronica Delaney, medical director of kidney transplant at Westchester County Medical Center, spoke to us on October 29th about news in the world of transplants. She reminded us of how imperative it is to increase donation because of the extreme scarcity of donor organs. In the forefront of trends in transplantation is the move to give financial reward to a donor's family, and to living donors. This matter must be handled with great care because of the possibility of negative publicity.

There is a new agent on the immunosuppressant screen that does not affect the kidneys. Preliminary results are hopeful. It would be used with Cellcept and Prednisone. The hope for any new therapy is to achieve tolerance. We're not there yet and it's dangerous to stop immunosuppressants. The worry is that tolerance is nonsustaining; later rejection is difficult to control. The goal is to have minimal immunosuppressants.

Some good news is that the government and NIH are spending money on a tolerance schema. There is also more use of a monoclonal antibody, an induction agent given at time of transplant to prevent rejection. It's given during the first week and is an extremely powerful for repeat transplant.

There is a new type of rejection: antibody mediated rejection due to B lymphocyte. We are more aware of it now. Regular rejection is well handled now with a rejection rate of 10% now compared to 85% in 1983.

Side effects of immunosuppressant drugs:
bone disease – osteoporosis, osteopenia. Recommendations include regular exercise, adequate calcium, adequate Vitamin D, sunscreen. Vitamin D recommendation is 800 units per day. Steroids are the worst for bone disease but a necessary part of the antirejection medications.

Infections – keep up to date with vaccinations. Pneumococcal must now be given every five years. Diphtheria is coming back. Check CDC website for out of country travel suggestions. Wear a mask in airplanes since the air is recirculated.

Shingles – get to the doctor early for treatment. Acyclovir is a drug used to decrease the pain of post shingles. Transplant patients cannot have live virus vaccines and should not be around children with chicken pox.

Hospital acquired infections are especially dangerous. The worst place for a transplant patient is the hospital. There are new bugs which are antibiotic resistant. Stay out of hospitals as much as possible. Joint replacement surgery – if you can get by without operation, do so. The hospital bugs are getting worse. C- diff can also be acquired in the hospital.

Continued on page 3

With More to Come. . .

Schedule for monthly meetings

7:00 – 7:30 PM – Social time

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

Julia Rivera and Kathy Dwyer from NYODN will be our speakers at the January meeting. Please join us at 7 for refreshments and stay to hear our excellent speakers.

In order to help make our monthly meetings more meaningful, **TSO** suggests that anyone with a specific question for our guest speaker(s) submit it to us prior to the meeting. We will then provide our guest speaker(s) with these questions in advance, so they can be covered during their presentation.

Any question that is of general significance to our group will be printed, along with the response, in our next newsletter.

Questions may be submitted by mail to: TSO, 1154 Webster Avenue, New Rochelle, NY 10804; by phone: 914-576-6617; by email: tso97@optonline.net

The UNOS National Patient Waiting List

Type of Transplant Registrations as of 12/12/08

Kidney transplant	82,959
Liver transplant	16,565
Pancreas transplant	1,608
Kidney-pancreas transplant	2,326
Intestine transplant	217
Heart transplant	2,716
Heart-lung transplant	93
Lung transplant	<u>2,046</u>
Totals	108,527

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

Every 18 minutes a new name is added to the waiting list.

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Organization
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www.transplantsupport.org

And the Beat Goes On (continued)

All transplant patients must keep their blood pressure down to prevent kidney damage. Cholesterol must also be kept down. Pets – avoid feral cats and dogs. Do not pick up dog droppings, or clean cat’s litter box. Otherwise there is no evidence for transplant patients to not have pets, as long as the pets have received the recommended shots.



At our November meeting, **Lois Duke**, a nutritionist and registered dietitian from Westchester County Medical Center, spoke to us about nutritional issues after organ transplant. Due to the physical stress of surgery, calorie and protein needs are increased to promote healing and fight infection. The amount of additional calories and proteins are determined based on a patient’s weight. In order to control blood glucose, balanced meals, along with healthy snacks, are recommended. Some transplant patients experience hyperglycemia as a result of high doses of Prednisone administered immediately post transplant. This issue is usually resolved as the dose is tapered.

Some side effects of immunosuppressant medications, such as vomiting and diarrhea, can affect the nutritional status of the person. Food safety for the post transplant patient is very important since food borne illnesses may take an immunosuppressed patient longer to resolve. Grapefruit is to be avoided because it can increase or decrease a drug’s effect. Long term nutritional goals include maintaining a desirable weight, acceptable blood glucose levels, cholesterol levels ≤ 200 mg/DL. Maintain optimal bone density. Set achievable goals with physical activity. Do not use herbal supplements unless approved by your doctor. Some may affect the transplanted organ.

Finally, eat a healthy diet, engage in some form of physical activity, get adequate sleep and avoid stress. Yoga and meditation can help you maintain a healthy lifestyle.

We’re extremely grateful to Dr. Delany and Lois for giving of their time to talk with us. We’re all better informed because of them.

Happy Re-Birthday to you...

Warren Agatston	kidney	January 1991	Jack Powers	liver	January 2001
Robert Kuhn	kidney	February 1993	Ruth Konefal	lung	January 2003
Monique Eveillard	kidney	February 1993	Rudy Masry	kidney	January 2003
Helen Bellhouse	liver	January 1995	Theresa Mallon	liver	January 2004
Walter Greenberg	heart	January 1995	Meredith Laubin	kidney	January 2004
Stephen Arnold	kidney	February 1996	Charles Brown	liver	January 2004
Gerard Bushel	kidney	January 1997	Irene Sherman	kidney	February 2004
John Talbutt	liver	January 1998	Kathryn Kerpchar	liver	January 2005
Richard Marasco	kidney	January 1998	William Seery	liver	February 2005
Bill Williams	cornea	February 1998	Louis Hamway	kidney	January 2006
Sherinah Lugo	kidney	January 1999	Donald Simons	liver	February 2006
Ana Rosado	kidney	February 1999	Cornelia Bruno	lung	January 2007
Vicky Rebatta	kidney	February 2000	Angelo Stekardis	lung	February 2008
Betty Bottinelli	liver	January 2001			

Our best wishes to all for many more happy & healthy ones!

Healthy Lifestyle Tip: Simple and Sensible

By GLENNA EPPERSON SMITH, RD

Of course you know this stuff, but in the interest of limiting the pain of getting yourself into last year's swimsuit, here's a quick refresher course:

1. Change your definitions of full. After most meals, you should feel as if you could get up, go outside and take a brisk walk. Stop eating when you get to that point.
 2. Make a plan. Think about where you will be, who you will be with, what foods will be available, what foods are really special to you vs. those that you could probably do without, what are your personal triggers to overeat and how you can minimize them. Once you've thought about all of these things, make a plan of action.
 3. Quit judging yourself by the foods you eat. You're not necessarily "good" if you eat a salad or "bad" if you eat fudge. They're both just food. And all foods are allowed - it's the amount you eat that you have to watch. Don't rush through the experience.
 4. Forget "all or nothing." If you're feeling that you've already "blown it" with a doughnut in the morning, don't use that feeling as an excuse to raid the cookie jar at night. Instead, think of ways to be physically active 30 minutes a day.
 5. Get a move on. In addition to burning calories, exercise is a great way to deal with stress. Exercise is the fountain of youth and one of the best investments you can make for your health.
- Remember, you should enjoy good times with family and friends. The important thing to keep in mind is balance and moderation.

Volunteer Opportunities

Volunteers needed to man donor awareness table at the following events in 2009

Please contact **Helen Bellhouse**:
845-528-1782 or hmbellhouse@verizon.net

February 18th	CWA Blood Drive at Port Chester Fire House
March 18 th	CWA Blood Drive at the Westchester County Center
March 19 th	CWA Blood Drive at the Westchester County Center
April 22 nd	CWA Blood Drive at the Peekskill Fire House
June 24 th ,	CWA Blood Drive at Grace Baptist Church, Mt Vernon

TSO HAS FUN



Our Holiday Party at Antun's
Please join us at our meetings



You never know who you'll meet at one of our health fairs. Some of the characters seen at the PKD walk in Bedford Hills in September 2008

Classroom Questions

While presenting the program on organ and tissue donation to a health class at one of the local Westchester High Schools, students asked Jeff and George some interesting questions. Here are a few with the answers Jeff gave

Q. What if a person is in the donor registry, but does not have any family or friends for the hospital to ask?

A. Technically, the NYS Donate Life Registry is one of consent and the form that is filled out and signed states "I am giving legal consent ...". Therefore, the individual should end up becoming a donor.

Q. Can individuals who are under 18 years old become living donors if their parents allow them to (liver, kidneys, etc)?

A. From what I can determine there is not a legal restriction against someone under 18 being a living donor. According to statistical data from the United Network for Organ Sharing (UNOS - www.unos.org), in 2007 there were 3 living donors in the 11-17 age range (out of 6,313 living donors in 2007) and this year there have been 1 in the 6-10 year range and 1 in the 11-17 range (out of 4,149 living donors ytd). That being said, the vast majority of transplant centers will not consider anyone as a living donor who is under 18.

Q. Can parents decide to donate their deceased baby or small child's organs if they wish?

A. Yes they can. In looking at UNOS statistics, approximately 300 deceased donors each year in the U.S. are under the age of 5, which includes 75 to 125 infants under 1 year.

Q. One student said that her mother told her that organ donations are illegal in Japan, and that a friend of hers came here from Japan to get an organ transplant? (I doubted that it was illegal in Japan, do you know if that's true?)

A. Organ donation is not illegal, although there is some controversy surrounding brain death, in Japan. Here are 3 websites that provide some insight into their culture's perception of donation:

<http://www.miracosta.edu/home/lmoon/Japanorgans.html>

<http://www.jotnw.or.jp/english/index.html>

<http://www.medscape.com/viewarticle/408769>



We are always looking for articles of interest to our group.
If you have an article or item of interest to us, please call or email
Carol Johnson (914-946-5472) or carolj15s@optonline.net.
We look forward to hearing from you. Thanks.

The Vatican on Organ Donation

Vatican City, 7 November 2008

At midday today, the Holy Father received participants in an international congress entitled: "A Gift for Life. Considerations on Organ Donation". The meeting is being held in Rome from 6 to 8 November and has been organized by the Pontifical Academy for Life in collaboration with the International Federation of Catholic Medical Associations and the National Transplant Centre.

In his address the Pope affirmed that "tissue and organ transplants represent a great advance of medical science, and are certainly a sign of hope for many people suffering serious and at times critical illnesses".

"Unfortunately the problem of the availability of vital organs for transplant is not theoretical but dramatically real, as evinced in the long waiting lists of many sick people whose only hopes of survival are linked to a minimal supply which in no way corresponds to effective need".

Benedict XVI then recalled how "the body of each individual, along with the spirit which is given individually, constitutes an indivisible unit in which is impressed the image of God Himself". For this reason, "priority must be given to respect for the dignity of the person and protection of his or her individual identity".

Referring then to the technology of organ transplants, the Pope highlighted the fact that people can only donate "if the health and identity of the individual are never put at serious risk, and always for morally-valid and proportional reasons. Any logic of buying and selling of organs, or the adoption of discriminatory or utilitarian criteria ... is morally unacceptable.

"Abuses in the transplant and trafficking of organs, which often affect innocent people such as children, must find the scientific and medical community united in a joint refusal. These are unacceptable practices which must be con-

demned as abominable. The same ethical principle must be reiterated when it is suggested that human embryos be created and destroyed for therapeutic purposes. The very idea of considering the embryo as 'therapeutic material' contradicts the cultural, civil and ethical foundations upon which the dignity of the person rests".

After highlighting how "informed consent is a precondition of freedom" ensuring "that transplants have the nature of a gift and are not interpreted as acts of coercion or exploitation", the Holy Father recalled that "vital organs must not be removed save from a dead body, which also has a dignity that must be respected. Over recent years science has made further progress in ascertaining the death of a patient. ... In an area such as this, there must be no suspicion of arbitrariness, and where certainty has not been reached the principle of precaution must prevail".

Recipients of organs, Benedict XVI went on, "should be aware of the value of this gesture. They are recipients of a gift that goes beyond its therapeutic benefit. What they receive, in fact, ... is a testimony of love, and this must arouse an equally generous response so as to enhance the culture of giving and gratuity".

"Transplants which accord to this ethic of giving", the Pope concluded, "require all sides to invest every possible effort in formation and information, so as increasingly to awaken consciences to a problem that directly affects the lives of so many people. It is important, then, to avoid prejudices and misunderstandings, to overcome diffidence and fear replacing them with certainties and guarantees, so as to create in all people an ever-greater awareness of the great gift of life".

Ed. Note: Some of you may remember that it was in Italy that 7 year old Nicholas Green died after being shot, and his parents, Maggie and Reg Green donated his organs to save the lives several recipients .

DONATION AND TRANSPLANT FACTS

OPTN website

Researchers began experimenting with organ transplantation on animals and humans in the 18th century. Over the years, scientists have experienced many failures, but by the mid-20th century, they were performing successful organ transplants. Transplants of kidneys, livers, hearts, pancreas, intestine, lungs, and heart-lungs are now considered routine medical treatment.

In the last 20 years, important medical breakthroughs such as tissue typing and immunosuppressant drugs have allowed for a larger number of organ transplants and a longer survival rate for transplant recipients. The most notable development in this area was Jean Borel's discovery of an immunosuppressant drug called Cyclosporine in the mid-1970s. This drug was approved for commercial use in November 1983.

Unfortunately, the need for organ transplants continues to exceed the supply of organs. But as medical technology improves and more donors become available, the number of people who live longer and healthier lives continues to increase each year.

- 1954 First successful kidney transplant (first of its kind in the world)
- 1966 First successful pancreas/kidney transplant
- 1967 First successful liver transplant
- 1968 First isolated pancreas transplant
- 1968 First successful heart transplant
- 1981 First successful heart-lung transplant
- 1983 First successful single lung transplant
- 1986 First successful double lung transplant
- 1989 First successful related liver transplant
- 1990 First successful living related lung transplant

Donor Matching System

All patients accepted onto a transplant hospital's waiting list are registered with the UNOS Organ Center, where a centralized computer network links all organ procurement organizations (OPOs) and transplant centers. Staffed 24 hours a day throughout the year, the Organ Center assists with the matching, transporting, and sharing of organs throughout the U.S.

Transplant centers, tissue typing laboratories, and OPOs are involved in the organ sharing process. When donor organs are identified, the procuring organization typically accesses the UNOS computerized organ matching system, enters information about the donor organs, and runs the match program. At times, when requested or when there is a need to identify perfectly matched kidney donor/recipients, the matching process is handled by Organ Center personnel at UNOS headquarters in Richmond, Virginia.

For each organ that becomes available, the computer program generates a list of potential recipients ranked according to objective criteria (i.e. blood type, tissue type, size of the organ, medical urgency of the patient, time on the waiting list, and distance between donor and recipient). Each organ has its own specific criteria. Ethnicity, gender, religion, and financial status are **not** part of the computer matching system.

After printing the list of potential recipients, the procurement coordinator contacts the transplant surgeon caring for

the top-ranked patient (i.e. patient whose organ characteristics best match the donor organ and whose time on the waiting list, urgency status, and distance from the donor organ adhere to allocation policy) to offer the organ. Depending on various factors, such as the donor's medical history and the current health of the potential recipient, the transplant surgeon determines if the organ is suitable for the patient. If the organ is turned down, the next listed individual's transplant center is contacted, and so on, until the organ is placed.

Once the organ is accepted for a potential recipient, transportation arrangements are made for the surgical teams to come to the donor hospital and surgery is scheduled. For heart, lung, or liver transplantation, the recipient of the organ is identified prior to the organ recovery and called into the hospital where the transplant will occur to prepare for the surgery.

The recovered organs are stored in a cold organ preservation solution and transported from the donor to the recipient hospital. For heart and lung recipients, it is best to transplant the organ within six hours of organ recovery. Livers can be preserved up to 24 hours after recovery. For kidneys and typically the pancreas, laboratory tests designed to measure the compatibility between the donor organ and recipient are performed. A surgeon will not accept the organ if these tests show that the patient's immune system will reject the organ. Therefore, the recipient is usually not identified until after these organs are recovered.

Donate Life Registry

By enrolling in the Donate Life Registry, you are giving legal consent for the recovery of your organs, tissues and eyes for the purposes of transplantation and research at the time of your death. Registry information is kept strictly confidential and can only be accessed by a) Department of Health employees when required for the performance of their official duties, b) federally regulated organ procurement organizations, c) New York State licensed tissue and eye banks and d) other entities formally approved by the Commissioner. Such access can only be for the purpose of identifying potential organ and tissue donors at or near the time of death.

NYS Donate Life Organ and Tissue Donor Registry Enrollment Form

Please Print (* required)

Prefix: _____(Dr., Fr., etc)

*First Name: _____

Middle Init: _____

*Last Name: _____

Suffix: _____(Jr, Sr, II, etc)

*Address: _____

*City: _____ *State: _____ *Zip: _____

Phone: (____) _____ - _____

*Date of Birth: ____/____/____ *Gender: ____Male____Female

*Height: ____feet____inches *Eye Color: _____

9- digit Motor Vehicle license or non-driver license DMV issued ID number: _____

* I offer the donation of:

All Organs, Tissues and Eyes

Limited Organs, Tissues and Eyes as specified below

Please CHECK the box of the organs and tissues that YOU WISH TO DONATE:

- Bone and Connective Tissue
- Corneas
- Eyes
- Heart (For Valves)
- Heart with Connective Tissue
- Kidneys
- Liver/Iliac Vessels
- Lungs
- Pancreas (with Iliac Vessel)
- Skin
- Small Intestine
- Veins

* I wish to donate the organs and or tissues specified above for:

- Transplantation and Research
- Transplantation only
- Research only

I wish to enroll in the New York State Donate Life Organ and Tissue Donor Registry maintained by the State Department of Health. I understand that by enrolling in the registry I am giving legal consent to the donation of my organs tissues and eyes (as specified above) in the event of my death. I authorize the State Department of Health to access this information as needed in administration of the registry, and to share this information at or near the time of my death with federally regulated organ procurement organizations, New York State licensed tissue and eye banks and entities formally approved by the Commissioner.

Signature

_____/_____/_____
Date

Mail to: **New York Organ Donor Network**
132 West 31st Street, 11th Floor
New York, New York 10001

TRANSPLANT SUPPORT ORGANIZATION

*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 2 Top: Miracle Maker
Bottom: Kidney Donor

LPF 7 Top: Transplantation Works
Bottom: Lung Recipient

LPF 4 Top: Organ / Tissue
Bottom: Donor Family

LPF 9 Top: Transplantation Works
Bottom: Heart Recipient

LPF 8 Top: Transplantation Works
Bottom: Liver 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.



T S O Transplant Support Organization

Participant Application: New Renewal

Please fill out this form and mail it with your tax-deductible contribution to:

T S O, 1154 Webster Avenue, New Rochelle, NY 10804

NAME(S) _____

Mailing Address: _____

Telephone #'s: Daytime: _____ Evening: _____

Email address _____

PERSONAL INFORMATION (optional)

Date of Birth _____ Sex _____ Marital Status _____

Occupation _____

CANDIDATE / RECIPIENT INFORMATION - Please circle appropriate description

Transplant Recipient _____ Transplant Candidate _____ Family Member _____

Donor Family Member _____ Interested Individual _____ Professional _____

Have you already had a transplant? Yes No

Number of Transplants _____ Type of Transplant(s) _____

Date(s) of Transplant(s) _____ 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** (two members at same address) \$ 35.00
- Additional participants** at same address \$ 10.00 each additional
- Additional participants** at different address \$ 15.00 (first) \$ 10.00 (additional)

Professional (*Surgeon, Physician, Clinical Coordinator, Nurse, Social Worker, Other*) \$ 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
- _____ Hospital Visitor
- _____ Clerical
- _____ Contributor
- _____ Patient & Family Support
- _____ Newsletter
- _____ Data Processing
- _____ Other
- _____ Sorry, too busy

6007, January 21, 2009 — NEXT MEETING

1. *Keep only cheerful friends.*
2. *Keep learning: Learn more about the computer, crafts, gardening, whatever. Never let the brain get idle.*
3. *Enjoy the simple things.*
4. *Laugh often, long and loud. Laugh until you gasp for breath. And if you have a friend who makes you laugh, spend lots and lots of time with him/her.*
5. *The tears happen: Endure, grieve, and move on. The only person who is with us our entire life, is ourselves. LIVE while you are alive.*
6. *Surround yourself with what you love: Whether it's family, pets, keepsakes, music, plants, hobbies.*
7. *Cherish your health: If it is good, preserve it. If it is unstable, improve it. If it is beyond what you can improve, get help.*
8. *Don't take guilt trips. Take a trip to the mall, even to the next county, to a foreign country, but NOT to where the guilt is.*
9. *Tell the people you love that you love them, at every opportunity.*
10. *Forgive now those who made you angry or made you cry. You might not get a second time*

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.