

Transplant Times

NEWSLETTER OF THE TRANSPLANT AWARENESS ORGANIZATION OF GREATER ROCHESTER



www.tao-rochester.org

1-888-664-1463

January, February, 2007

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CALENDAR OF EVENTS

(Members and friends of TAO will receive phone calls about the upcoming programs.)

ALL TAO MEMBERSHIP MEETINGS ARE HELD

Third Wednesdays

NEW MEETING PLACE! SEE BELOW!

Wednesday, January 17, 7 pm Guest speaker will be Ann Finger from South Presbyterian Church. Ann will tell us about Rosemount House, a house that will be a 'home away from home' for transplant families. Rosemount House welcomed their first family during the last week of October. Ann will share the history of this endeavor and their hopes and dreams for the future. She is happy to have the opportunity to speak with us and establish some connections in the transplant community. We hope to find out some ways we can be of help to transplant recipients and their families.

Wednesday, February 21, 7 pm Elizabeth Keirstead, RD has been the dietitian for the Heart Transplant Program at Strong for the last 3 years and since Sept has been working with the Renal Transplant Program. Elizabeth will be available at the February meeting for an open discussion about healthy living choices. Please bring your questions and concerns to the meeting.

Deadline for March - April, 2007 *Transplant Times* - Wednesday, February 14

New Year = New Meeting Location

Happy 2007 to all our members. I hope everyone has had a very happy holiday and a healthy new year.

The TAO Board of Directors is pleased to announce that we have chosen a NEW meeting location. Starting January 17, 2007 it will be

Pinnacle Lutheran Church, located at **250 Pinnacle Road**.

The church meeting room is larger, has more seating and is conveniently close to the door and parking lot, and it is just down the road (on the other side) from our former meeting place at the Al Sigl Winton Road Annex. I encourage all our members to check it out at our first meeting of the year. As always, please let us know what topics, speakers and any information that would be of interest.

Many thanks to everyone involved in finding our new meeting space. I hope you will be happy with our choice.

Looking forward to seeing all current and new members on January 17th.

Thank you! *Dennis Stenshorn, President*

TRANSPLANT ANNIVERSARIES OF TAO MEMBERS - January - February

Charles Liberi -- 01-05-95 Kidney
Dawn Meschi -- 01-10-01 Kidney
Helen Cox -- 01-11-96 Kidney Pancreas
Patricia Stewart -- 01-23-94 Kidney
Frank Imburgia -- 01-30-02 Heart
Patricia Alexander -- 01-31-05 02-09-05 Liver
Patricia R. Legge -- 02-01-96 Kidney
Wayne A. Dickinson -- 02-02-97 Liver
David Beatson -- 02-07-01 Heart
Aisha O'Mally -- 02-09-04 Heart
Louis Mascaro -- 02-20-79 Kidney
Kevin Kain -- 02-22-02 Liver
Gerald Bluff -- 02-22-05 Lung
Peter Unbras -- 02-24-02 Liver
Ronald Barnard -- 02-26-90 Heart

*Congratulations! Did we miss yours? Get your date wrong? Please call the editor!
(Note: this list is members only)*

We missed Jerry Runion's anniversary last issue! He received a Kidney-Pancreas transplant November 4, 1994. Congratulations, Jerry!

Donate Life Awareness Bracelets Are Here!

The green "Donate Life/Done Vida" bracelets are here and will be available at the next meeting. The bracelets are individually wrapped. They are similar to the Lance Armstrong "Live Strong" bracelet. They are light weight, eye catching and a great way to start a conversation on organ and tissue donation. Don't forget to get one at the next meeting.

Karen Gledhill

Gift Ideas

A contribution to TAO in honor of or in memory of a loved one, a special person or a relative is always a thoughtful gift idea. It is a gift of caring that you can give on any occasion - a birthday, an anniversary or a special holiday. Send your check, made out to TAO, to our treasurer, Mike Stelljes, 5341 Booher Hill Rd., Geneseo NY 14454

TOPS never stops.....Helping TAO Raise Money
As one of the Tapesaver participants, (which Tops has discontinued), we have been given the opportunity to take part in their latest opportunity to raise funds for TAO. The Tops Gift Card Program allows our non-profit organization to earn a 5% return by selling Tops Cards. The more we sell, the more we earn.

The cards are available in denominations of \$5, \$10, \$20, \$50 and \$100. We have purchased \$1000 worth of cards and they will be available for you to purchase at our next meeting.

Donor Cards Campaign

If you would like to participate in the 12 weeks of giving campaign to raise the number of donor designations (number of new pledged organ and tissue donors) in our area as a part of a nationwide effort, please call Karen Guarino at (585) 272-7890 or 1-800-568-4321. The campaign runs until mid-February, so call today!

The number of new donor cards entered into the Regional Donor Pledge Registry of the Rochester/Finger Lakes Eye & Tissue Bank and Finger Lakes Donor Recovery Network from January to November is 1,420. Just over 20% of these are donor cards from health fairs and events! Thanks to all our volunteers who help staff the display throughout the year. Your efforts are making a difference!

Karen Guarino

Rochester/Finger Lakes Eye & Tissue Bank

The TAO Holiday Party at Strong December 13 was a big success. We had guests from the transplant floor, both patients and staff, as well as a nice turnout of members. Linda Hicks and Jerry Runion arranged everything, and thanks to Linda, Roche Pharmaceuticals picked up the tab. Many thanks!

Apologies!

The November/December issue of the Transplant Times got tangled in the mail, and was not received until after the November meeting. We tender our apologies, and will try to improve our mailing procedures.

Remember to check our website, www.tao-rochester.org if you have questions about our programs.

At our November meeting, Irene Freedman, Health Insurance Consultant for Lifespan, gave a very informative and complete discussion of the complexities of Medicare Part D. She handed out a packet of materials, and distributed her business card with the offer to help any of us on questions we may have. She can be reached at (585) 244-8400 ext.191, or ifreedman@lifespan-roch.org

Our Treasurer, Mike Stelljas, tells us that we have received donations beyond dues from the following:

Argie Mae Davis
Rochelle Whitney
Rochelle Whitney for the Transplant Games
David and Julie Davies for the Transplant Games
Macedon Center United Methodist church (Kidney Support Transplant Team)
Pharmacare Specialty Pharmacy (Transplant Games)
Bernice Eblövi (Transplant Games)
Betsy and Tom Helfrich (Transplant Games)

We have also received the following memorial gifts:
Odenbach Family Trust (in memory of Richard Odenbach)
Susan Saunders (in memory of Will Saunders)
Alan and Terrie Robbins (in memory of Roger Fisher)
Shirley Tuites (in memory of Dick Tuites)

We are grateful to you all!

ORGAN & TISSUE DONATION

Thousands wait for the gift of life!

Increase awareness of the need for donors,
and wear your ribbon with pride!





Members of Alpha Phi Omega from Brockport present poptops to TAO at the November meeting. Left to right, President Dennis Stensholm, Sarah Hunter, Sara Landon, and Ryan Brand. Their advisor Deb Birkins is not in photo.

ICE is an Acronym for In Case of Emergency

ICE is an entry in your cell phone memory that would give doctors an emergency contact number in case you are temporarily unable to communicate or advocate for yourself. The National Kidney Foundation recommends that all patients with kidney failure program an ICE entry into their cell phones in case of hospitalization or other medical emergencies.

See below for the entire New York Times article,

"Safety: ICE on Cellphones: An Acronym for Emergencies

By Eric Nagourney

A simple acronym entered into people's cell phone listings, ICE, can help emergency room doctors who are trying to track down a patient's family. It stands for In Case of Emergency, and a report presented at a recent gathering of the American College of Emergency Physicians said doctors should encourage their patients to start using it.

"We are always faced with situations where patients come into the emergency room and for one reason or another are not able to communicate with us," said the author of the report, Dr. Dennis McKenna of the Albany Medical Center. Traditionally, hospital workers have searched for a wallet and then tried to find relatives through the identification inside - a slow and not always successful method.

But with cellphones so common, Dr. McKenna said, hospitals now often search through cellphone address books for clues about whom to contact. While efforts to teach people to add an emergency contact listing have begun, doctors can do more to popularize the idea, he said.

For the study, researchers surveyed more than 400 emergency room patients and the people accompanying them and asked if they knew about ICE entries and if they would be willing to use them. Although about a sixth of those surveyed said they had heard of the idea, less than a tenth had the listing on their phones. When hospital staff members offered instructions or help, however, more than half of those who had phones with them agreed to put the listing in.

DON'T EAT GRAPEFRUIT After Changing the Cat Litter

By Jack Fassnacht, kidney recipient

From the Transplant Chronicles, National Kidney Foundation, Summer 2006

(Continued from the last issue)

6-11 Myths and Good Advice

1. "Transplant recipients should not donate blood."
 2. "Avoid touching doorknobs because they have germs."
 3. "Don't get flu shots because they can make you sick."
 4. "You can catch disease from changing cat litter without a box lining."
 5. "You shouldn't take all your medications at the same time."
 6. BONUS "ADVICE": "In addition to an organ, you might acquire some of the personality traits of your donor!"
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1. "*Transplant recipients should not donate blood.*" True. The American Red Cross and most blood centers have eligibility guidelines that prevent someone who is taking immunosuppressants from donating blood. These immunosuppressants could be harmful to the person who receives the blood.
 2. "*Avoid touching doorknobs because they have germs.*" This advice is more scary than practical. Every transplant recipient is at an increased risk for developing infections after transplantation because of immunosuppressant medications. The more immunosuppressant medications that you are currently taking, including those used to treat episodes of rejection, the greater the risk of developing an infection. With that said, *using common sense is the best policy. You did not have the transplant to live your life in a protective bubble.* Your hands can and will pick up germs from everywhere, not just doorknobs. Good hand washing with antibacterial soap or using a good hand sanitizer is the best policy. Many transplant families have developed the practice of carrying an alcohol-based hand sanitizer with them for those times when the environment is not the cleanest and traditional hand washing is not feasible.
 3. "*Don't get flu shots because they can make you sick.*" Two different formulations of the influenza vaccine are available; the influenza injection (flu shot) and the influenza nasal spray. While flu shots are considered safe for transplant recipients, flu sprays are not.
 4. "*You can catch disease from changing cat litter without a box lining.*" It is OK to dispose of litter if it is in a liner so that you are not touching any of the stool directly. Washing your hands often is also very important. The germs are in the cat stool, not the lining or box. Animals, even household pets, can sometimes carry diseases, and while few are likely to be life threatening, transplant patients who take immunosuppressants are at a greater risk of catching a disease. It is not recommended that a transplant recipient clean a cat's litter box if at all possible. Also, the litter and liner should be replaced frequently and the litter box should be cleaned at least every month with disinfectant soap or hot boiling water (by someone other than the transplant recipient, if possible).
 5. "*You shouldn't take all your medications at the same time.*" Transplant patients are usually on multiple medications. Many times it is perfectly okay to take your doses of multiple medications at the same time. For example, prednisone taken with cyclosporine is not likely to cause serious problems. However, there may be situations when two medicines should not be taken at the same time because they interact with one another. For example, any antacid and oral antibiotic should not be taken at the same time of the day because the antibiotic would be less well absorbed and the infection could go untreated. There are also examples of "grey" areas. For instance, the anti-rejection drugs cyclosporine

and sirolimus interact with each other if taken at the same time. The cyclosporine causes the concentration of sirolimus in the body to become higher than normal, leading to an increased chance that one will experience serious side effects from the sirolimus. Yet sometimes the doses of cyclosporine and sirolimus can be adjusted to maintain appropriate drug levels of each medication when taken together. Transplant centers are well aware of this drug interaction, and may choose to adjust medication dosages rather than separate the timing of the two medicines. Confused? Just remember the most important thing is to be consistent in when and how you take your medicines. Take your drugs the same way every day. Consistency helps your health care provider adjust your medications to your individual needs. Also, since medication regimens are individualized, check with your transplant center or pharmacist to find out which drugs can be taken at the same time, or whenever you have a drug related question.

6. **BONUS ADVICE: “In addition to an organ, you might acquire some of the personality traits of your donor!”** Alas, this is a myth. There are people who say that they feel closer to or even manifest the traits of their donor, but there is no scientific evidence that anything having to do with personality adheres to cells of a transplanted heart, liver, kidney or lung. Still, some transplant recipients may feel that they have indeed taken on some personality trait of their donor. The likely explanation for this is *when recipients know something about their donor, they feel grateful for the organ and may begin to identify psychologically with the donor’s best attributes, almost as a way to give thanks.* But, despite all the poets and novelists who wax on about the heart as the seat of the emotions, short of a brain transplant, you should not acquire any aspect of your donor’s personality or emotional or character traits after an organ transplant.

Be sure to always speak to your transplant team about any issues or questions you have.

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Gift of Life Hybrid Tea Roses from edmundsroses.com

(HARelan, Poetry in Motion) Soft golden yellow lightly tinged with light pink on long straight stems - perfect for cutting numerous bouquets of softly fragrant blooms. A bouquet of Gift of Life will brighten anyone’s day. Gift of Life was named to promote awareness of the need for organ donation through the National Kidney Foundation and the Organ Donor Program. A portion of the proceeds of the sale of Gift of Life is donated to these organizations.

Height 4-5 feet Petals: 25 Flower Size: 4-6 inches
Fragrance: moderate, rose Hybridizer: Harkness 1999
\$19.95 each, 2 for \$33.95 Item #23766 Order: call 1-800-347-7609.

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OTHERS NOT ON THE BOARD:

Laurie Packard	425-8034	kidtr0311@aol.com	Membership chair
James Grossman	295-4416		TAO attorney

TAO GOALS

1. To act as a support group for transplant candidates, transplant recipients and their families.
2. To provide education and information on transplantation and the issues that surround it.
3. To promote organ and tissue donation awareness.

All potential transplant recipients, candidates, family and friends are welcome. Meetings are held monthly and include programs of interest to the transplant community.

TAO/ROCHESTER MEMBERSHIP APPLICATION

Make checks payable to TAO/Rochester and mail to: Laurie Packard, Membership Chair,

228 Macedon-Center Rd., Macedon NY 14502

\$10 - Family \$10 - Institutional DATE _____

New Member Renewal

Extra contributions to help our organization are always welcome, and are tax-deductible.

NAME _____ PHONE _____

Spouse or companion _____

ADDRESS _____ E-Mail _____

CITY/STATE _____ ZIP _____

Please check here if you are unable to make a dues payment at this time. No one is denied membership because of financial considerations.

CANDIDATE RECIPIENT FAMILY MEMBER

HEALTH PROFESSIONAL FRIEND DONOR FAMILY

Candidate/Recipient Information

Number of Transplants _____ Dates(s) _____

Organ(s) _____

Where _____



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Transplant Times

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5 Sandpiper Lane
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