

www.tao-rochester.org

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November, December, 2006

Dennis Stenshorn, President, 585-323-1392

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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

Cafeteria, Cerebral Palsy Center, Al Sigi Winton Rd. Annex
3399 S. Winton Rd., south of Jefferson Rd.

New instructions: Park on Winton Rd. Side near the flagpole and use the Winton Rd. Entrance.

The rear door we have been using will be locked!

It is a long walk to the cafeteria in the rear. Wheelchairs will be available near the front door.

Wednesday, November 15, 7 pm

Irene Freedman from Lifespan is a HIICAP (Health Insurance Information Counseling Assistance Program) Coordinator and specializes in Medicare. She will review Medicare coverage and Medicare Part D prescription plans. Now is your chance to get your questions answered, so don't miss this meeting!

Wednesday, December 13, 7 pm

Holiday Party at Strong Memorial Hospital, 6th floor Transplant Unit, conference room. Supper and music provided. We will invite staff and patients from the Unit. Parking stickers will be provided. RSVP to Dennis 323-1392, dstensh1@rochester.rr.com

Deadline for Jan. - Feb. 2007 *Transplant Times* - Wednesday, December 12

From the President - Dennis Stenshorn

Participate in a Research Study for Kidney Transplant Recipients

A research study exploring what the experience of kidney transplant is like for participants is currently taking place. The study asks questions about any stress recipients may be experiencing and how they are currently feeling, both mentally and physically. Participants are also asked to journal about their experience with transplant for three 15 minute sessions, over a one week period. Finally, three months later participants are asked to answer a few more questions about how they feel. Answers, journal writing and contact information will be kept private and confidential.

All kidney transplant recipients who are now 18 years old or older are eligible to participate in the study, regardless of when they received their transplant. There are two ways to participate. Interested individuals can complete the entire study online at www.pages.drexel.edu/~akp26 or receive a paper and

pencil version in the mail to complete at home.

The goal of this study is to identify an intervention that may decrease stress and improve kidney transplant recipients' quality of life. Similar interventions have been found to have many positive outcomes for both healthy and medically ill individuals.

If you would like to participate or learn more about the study please contact the project coordinator, Kyle Possemato by email (akp26@drexel.edu) or by phone 315-558-0517. Kyle will also be present at the TAO meeting on November 15th to discuss this research study and distribute study materials.

TRANSPLANT ANNIVERSARIES OF TAO
MEMBERS - November - December

James Spaeth -- 11-02-99 Kidney Pancreas
Michael Stelljes -- 11-06-01 Liver
Richard Orrvick -- 11-09-93 Kidney
Alice Sceusa -- 11-11-02 Liver
Dean A. Bush -- 11-11-03 Liver
Peter Davis -- 11-16-96 Liver
Daniel Newhouse -- 10-30-90 11-17-95 Kidney
Donna Crosby -- 11-19-03 Liver
Ronald Goehle -- 11-22-01 Liver
Ruth Maines -- 12-01-90 Liver
Larry Buck -- 12-06-00 Kidney
Elaine Kimber -- 12-06-05 Kidney
Ricardo Juskiewicz -- 12-09-96 Kidney
Susan Moody -- 12-14-92 Bone Marrow & Kidney
Beverly Shank -- 12-14-05 Liver
Bonnie Haefner -- 12-25-01 12-14-05 Kidney
Stephen Odai -- 12-15-01 Liver
Richard Greene -- 12-25-00 Liver

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

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

Bonnie Haefner has been in and out of the hospital since our last Membership meeting. Diagnosis uncertain at press time. We wish her well.

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.

Membership Dues

Our Membership Chair, Laurie Packard, is laid up with a broken leg. She is presently living in her (finished) basement, with all amenities except her computer! She arranged to have the 2007 Dues notices sent to those whose e-mail addresses we have, and the snail mail notices will be coming soon. If you have not paid your 2007 dues, you may use the form on the back of this newsletter. If you receive a notice even though you have paid, just ignore it.

Phone calls and notes are welcome.

Joanne Schum receives Heroes of Hope Award

On October 19, Joanne Schum received a Heroes of Hope Award from the Cystic Fibrosis Foundation and Genentech, Inc.

“Who is a Hero?

A hero is a role model who portrays hope and strength.

A hero takes initiative and pursues goals and dreams.

A hero is motivated to live life to the fullest.

A hero has a positive approach to life.

A hero uses his/her skills to help others as well as themselves.

A hero contributes to the community.”

Congratulations to Joanne, a double lung transplant recipient, 1997, University of North Carolina, Chapel Hill, and a TAO Board Member.

“MEET AND GREET” Volunteer Program

Since its inception on July 31, 2006 transplant recipient volunteers have met with five to ten liver transplant candidates per week. Each Monday and Thursday morning between the hours of eight and eleven, volunteers “meet and greet” the candidates and their families in the clinic area on the second floor of Strong.

Our group of volunteers is growing and I would like to take this opportunity to recognize the people who are involved : Ernst Baier, Bernice Eblövi, Karen Gledhill, Bonnie Haefner, Frank Imburgia, Ray Lyman, Rich Perez, Jan Sharp, Mike Stelljes, and Shelley Whitney. Some others have expressed interest and are currently being processed through FRIENDS OF STRONG.

Since Eval Day can present much stress and anxiety the candidates and their families are most appreciative of the opportunity to talk with a transplant recipient.

We have hopes of expanding our program. More volunteers are encouraged and welcomed. If you are interested please call Jane Walsh in FRIENDS OF STRONG (275-2420) concerning the job description and qualifications. When you call tell the receptionist that you are interested in volunteering in the transplant clinic program. If you are already certified through FRIENDS OF STRONG as a volunteer, contact me directly.

Please feel free to call or e-mail us with any questions or concerns:
Sally and Mike Stelljes, (585) 245 9579 (h), (585) 519 2753 (cell), salstell@rochester.rr.com
Submitted by Sally Stelljes

Holiday Gift Wrapping for TAO

Karen Gledhill, has once again contacted our friends at Barnes & Noble, Pittsford Plaza, for us to do gift wrapping on their premises. This is a fund raising event for the Transplant Awareness Organization, this year, but, more importantly, it is an outstanding opportunity for us to share with the public the continued need for donors and the success achieved through transplantation. If you are interested in taking a shift (or two) please contact Karen either by e-mail (KGledhill@rochester.rr.com) or via phone 586-9252. Here are some details:

Dates: **Saturday Dec. 9 and Sunday, December 10th**
Shift: 10 am to 2 pm, 2 pm to 6 pm, 6 pm to 9 pm.

Date: **Tuesday, December 19**
Shift: 10 am to 2pm, 2 pm to 6 pm, 6 pm to 10 pm.

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DON'T EAT GRAPEFRUIT After Changing the Cat Litter

By Jack Fassnacht, kidney recipient
From the Transplant Chronicles, National Kidney Foundation, Summer 2006
(Continued in the next issue)

As a two-time kidney transplant recipient, the more I talk to other solid organ transplant recipients, the more confused I get about what to do and what not to do to keep myself healthy. It's bad enough that no one seems to be taking the same combination of medicines as me. What's worse is that I'm not sure whether to believe all the well-intentioned advice I receive from my fellow recipients. To try to get the right answers for once and for all, I asked some transplant and medical specialists to comment on the following 10 pieces of “advice” I have received over the years. Before reading their responses **below**, why not test your own knowledge of post-transplant care by deciding for yourself whether each of the following statements is good advice or a myth. If you get all 10 correct, you can give me advice any time. (But I may still check with my transplant office—always good advice for any transplant-related question!)

1. “Transplant recipients should avoid eating raw seafood.”
2. “It is safer to drink bottled water than tap water on airplanes.”
3. “Avoid grapefruit and grapefruit juice, but oranges and orange juice are OK.”
4. “Take Tylenol® (acetaminophen) when needed, but not aspirin.”
5. “You should pre-medicate before every visit to the dentist.”

1. *“Transplant recipients should avoid eating raw seafood.”* Good advice. Transplant recipients have weakened immune systems, so the risk of food poisoning which can lead to an infection is greater. It is good advice to avoid raw fish, oysters, shrimp, sushi and refrigerated smoked seafood unless it is an ingredient in a cooked dish such as a casserole. Canned fish such as tuna or salmon can be eaten safely.
2. *“It is safer to drink bottled water than tap water on airplanes.”* It can’t hurt, and might help, to follow this advice. While there is some evidence that tap water on airplanes can contain bacteria which may be harmful, there have been no reported cases of anyone getting sick from drinking airplane “tap” water. However, to be on the safe side, drinking bottled rather than tap water when you fly is a good idea.
3. *“Avoid grapefruit and grapefruit juice, but oranges and orange juice are OK.”* Transplant recipients taking cyclosporine, tacrolimus, or sirolimus are advised to avoid grapefruit and grapefruit juice. Research shows that grapefruit juice (but not orange juice) can block an enzyme in the intestines that is responsible for the breakdown and absorption of these medications, leading to increased amounts of these medications in the body, which may hurt the kidneys. In addition, because absorption of other medicines may also be affected by grapefruit juice, it is a good idea to ask your pharmacist whether grapefruit juice will interact with any of your other prescribed medicines.
4. *“Take Tylenol® (acetaminophen) when needed, but not aspirin.”* In general, this is good advice. Tylenol® (acetaminophen) is the over-the-counter drug of choice for aches, pains and fever for solid organ transplant recipients. Acetaminophen is relatively safe with few side effects *when taken as directed*. While aspirin may work well for aches, pains and fevers, the unwanted effects, such as increased bleeding or stomach irritation, may be too much for some transplant recipients. This does not mean that all aspirin use should be avoided. For some patients the risks of bleeding or stomach irritation are far outweighed by the benefit of taking aspirin. A good example of this is taking a daily dose of aspirin (80–325 mg) to protect the heart. Use of NSAIDs (non-steroidal antiinflammatory drugs) such as ibuprofen, naproxen, and ketoprofen should also be avoided. This class of medications increases the risk of harm to the kidney in patients taking cyclosporine or tacrolimus. In most cases, using NSAIDs to relieve aches, pains, or fever is not worth the potential harm to the kidney.
5. *“You should pre-medicate before every visit to the dentist.”* Good dental care is recommended for everyone, but because transplant recipients take immunosuppressant (anti-rejection) medications, they are at an increased risk for developing mouth infections that could lead to serious complications. Every transplant center has a protocol for dental prophylaxis after transplantation. You should consult with your transplant coordinator to ask about the protocol recommended by your physicians. Also, let your dentist know that you are taking immunosuppressants; he or she may recommend pre-medicating before each visit.

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

Reaching Out to the Community

Thanks to the support and commitment of our volunteers during January - September 2006:

1,005 new donor cards were entered into the Regional Donor Pledge Registry	90 classrooms visited
57 health fairs were attended	1,611 students reached
9 presentations were given reaching 106 individuals	7 college visits
28 school visits	7 college classes presented to
	105 college students reached

If you are interested in staffing the display at health fairs or sharing your personal transplant/donation story at group presentations or school programs, please contact Karen Guarino (Rochester Eye & Tissue Bank/Finger Lakes Donor Recovery Network) at (585) 272-7890 for more information.

TAO-Rochester Board of Directors 2006/2007

Name	Phone	Email	Office	Term Exp.
Ron Barnard	227-2887	barnardr1@peoplepc.com	Board Member	2007
Karen Gledhill	586-9252	kgledhill@rochester.rr.com	Vice President	2008
Karen Guarino	272-7890	kguarino@rehpb.org	Rep. Rochester Eye and Tissue Bank	
Linda Hicks	275-8306	linda_hicks@urmc.rochester.edu	Rep. Dept. of Transplantation, SMH	
David Johnson	889-1346	davejohn@rochester.rr.com	Board member	2008
Suzanne McNamara	385-3144	shawmcn@aol.com	Board member (<i>Times</i> editor)	2007
Sandy McNitt	359-8015	sdmcnittot@aol.com	Board member	2007
Janice Odenbach	216-9856	janiceodenbach@aol.com	Board member	2007
Richard Padula	272-4936	Richard_Padula@urmc.rochester.edu	Rep. Finger Lakes Donor Recovery Network	
Jerry Runion	865-7461	jgrunion@rochester.rr.com	Board member	2008
Joanne Schum	671-7635	twoluckylungs@juno.com	Board member	2008
Mike Stelljes	245-9579	mstellje@rochester.rr.com	Treasurer	2007
Dennis Stenshorn	323-1392	dstensh1@rochester.rr.com	President	2008
Shelley Whitney	334-8267	whitney618@aol.com	Secretary	2008

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 _____



Transplantation Works!

Ask Us!

Transplant Times

TAO/Rochester
5 Sandpiper Lane
Pittsford NY 14534

