

www.tao-rochester.org
1-888-664-1463

November, December, 2005
Guest editor: Penny Sayles

Dave Johnson, President, 585.899.1346
davejohn@rochester.rr.com

CALENDAR OF EVENTS

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

ALL TAO MEMBERSHIP MEETINGS ARE HELD

Third Wednesdays

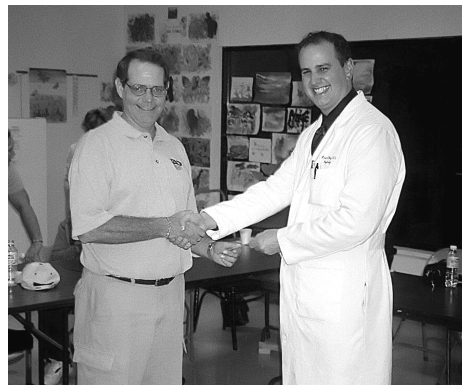
Cerebral Palsy Center, Al Sigl Winton Rd. Annex
3399 S. Winton Rd., south of Jefferson Rd.

Enter from the back parking lot - go to the cafeteria

Wednesday, November 16, 2005, 7:00 PM. James Quetschenbach, Manager, Clinical Services, Finger Lakes Donor Recovery Network, will speak on the HRSA (Health Resources and Services Administration) Collaboratives on increasing organ donation and also organ yield.

Wednesday, December 14, 2005, 6:30PM
Holiday Party: Strong Memorial Hospital 6th floor Transplant Unit, conference room.
RSVP Karen Gledhill at kgledhill@rochester.rr.com or 585-582-9252.

NOTE: This is the 2nd Wednesday and the meeting is at Strong.



TAO President, Dave Johnson and TAO Guest presenter, Dr. Richard Wing, Nephrology Fellow from Strong Memorial Hospital. Dr. Wing presented "The Effect of Prescription Coverage on Kidney Allograft Survival," a research project partially funded by TAO. Dr. Wing, the second investigator of the research project spoke at the September, 2005 TAO meeting.

Deadline for Jan.Feb.06. 2005 Transplant Times - Wednesday, December 14

**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
- Michael J. Swete -- 11-12-95 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
- Fred A. Gilman -- 12-08-96 Kidney
- Vene (Skeeter) Todd -- 12-09-96 Liver
- Ricardo Juskiewicz -- 12-09-96 Kidney
- Susan Moody -- 12-14-92 Bone Marrow &
Kidney
- Stephen Odai -- 12-15-01 Liver
- Richard Greene -- 12-25-00 Liver
- Bonnie Haefner -- 12-25-01 Kidney
- June Vargo -- 12-27-95 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, payable to TAO, to our treasurer, Mike Stelljes, 5341 Booher Hill Rd., Geneseo NY 14454

Telephone Committee Needs Help

We are continuing to add members, and that means we need more people to make reminder calls. Paula McKay coordinates this responsibility. She says that callers spend about ten minutes each month on their reminder calls. Contact Paula pmckay73@rochester.rr.com or 436-9032.

TOPS never stops.....Helping TAO Raise Money

As one of the Tapes saver 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.

UNOS Transplant Waiting List - October, 2005

Kidney.....	63,365	Heart.....	3,071
Liver.....	17,408	Lung.....	3,326
Pancreas.....	1,685	Heart/Lung...	154
Kidney/Pancreas.	2,472	Intestine.....	189

Total Candidates on Waiting List.....89,569

Check Out:

Our website www.tao-rochester.org

Attention Medicare Participants:

Though geared more towards professionals, these teleconferences may be of interest to recipients and patients.
You are welcome to join the calls.

Please note the information about the second of six half-hour teleconferences from the community-wide Kidney Medicare Drugs Awareness and Education Initiative that will begin on Tuesday, September 20 at noon, EDT.

Many people with kidney disease have drug coverage from other sources. This teleconference will address how Medicare prescription drug coverage coordinates with other coverage, which patients may or may not need a Medicare prescription drug plan, and which patients might lose their current healthcare coverage by joining a Medicare prescription drug plan.

Medicare: How It's Changing To Help More People

Kidney Community Initiative to Host Teleconference Series for Professionals

This teleconference series is brought to you by the Kidney Medicare Drugs Awareness and Education Initiative, an alliance of over three dozen organizations, whose goal is to help people with kidney disease and the health care professionals who care for them understand the new Medicare drug benefit.

There will be a series of free 30-minute monthly teleconferences on Medicare prescription drug coverage (Part D). The objective is to share key messages and kidney-specific information to answer questions health care professionals or patients may have.

Any healthcare professional or person with kidney disease who wants to learn more about Medicare prescription drug coverage may participate one of two ways:

1. Register and listen to the live teleconference at noon, Eastern time, by calling 1-877-707-9628 and using the code: 44919. Call in a few minutes in advance. Music lets you know you're connected. Download the slides. starting the Monday prior to the event.

OR

2. Listen to the recorded teleconference and download the transcript and slides later at
www.kidneydrugcoverage.org
<http://www.kidneydrugcoverage.org/>
(<http://www.kidneydrugcoverage.org/>) >

E-mail your questions to [_info@kidneydrugcoverage.org_](mailto:info@kidneydrugcoverage.org) (mailto:info@kidneydrugcoverage.org) . Please type "question" in the subject line. Questions about the teleconference topic may be answered during the call. Other questions will be answered and posted on the website FAQ page.

Visit [_www.kidneydrugcoverage.org_](http://www.kidneydrugcoverage.org) (<http://www.kidneydrugcoverage.org>) for more information about the teleconference, community initiative, and kidney-specific materials. If you do not have Internet access, ask your library or someone else to help you get this information.

Attention Medicare Participants: *(continued)*

Tuesday, November 15

Medicare - How It's Changing to Help More People: Exceptions and Coverage Determinations

Tuesday, December 20

Medicare - How It's Changing to Help More People: Grievances and Appeals

Tuesday, January 17

Medicare - How It's Changing to Help More People: Helping to Fill the Coverage Gap.

-Carol Roberts

It's Time to Think About the Holiday Season

TAO has again been approached by Barnes and Noble in Pittsford to wrap gifts during the holiday season. This year, we are scheduled for the following days:

Thursday, December 1, 10 a.m. – 10 p.m.

Wednesday, December 21, 10 a.m. – 10 p.m.

Thursday, December 22, 10 a.m. – 3 p.m.

It is a fundraising and public awareness event for TAO. Any money donated to us during our shifts, is ours to keep. You do not have to be a good wrapper; most of the items that we wrap are books! To volunteer for a shift or two, contact Karen Gledhill at 586-9252 or via e-mail at kgledhill@rochester.rr.com.

National Donor Sabbath, November 11-13

The 10th anniversary of the celebration of National Donor Sabbath is a time the religious community formally commemorates organ donation in an effort to increase organ donation awareness. Please contact your church, spiritual leader, etc., to suggest ways in which your faith can do this, for example, offering to present during a service, attaching a donor card information in your newsletter or bulletin, offering donor awareness pins after service, etc. Pins and materials can be obtained from Karen Guarino, C-DOT representative, at 272-7890 or e-mail at kguarino@rehp.org.

Volunteers Needed

With your help, 255 new donor cards have been entered into the Regional Registry during the months of July, August, and September. Also during this time period, volunteers helped educate the public in our service area through participation at 23 health fairs/events and in 19 class presentations from grades 7-college level.

Volunteers are needed to staff displays at the following Health Fairs and Presentations:

School of the Arts, Monday, 11/14, 8:30-1:30

Rochester Women's Network, Wednesday, 11/16
5 p.m. – 8 p.m.

MCC Class, Wednesday, 11/23, 9-10 a.m.

Contact: Karen Guarino at 272-7890 or
via e-mail at kguarino@rehp.org.

Subject: **Donate Life Rose Parade for 2006 and Chance to Join the Circle**

Date: 10/6/2005 12:08:32 PM Eastern Daylight Time

From: pmeigs@Twenvy.rr.com

Paul G. Meigs-Membership and Communication Director Transplant Awareness Group of Central NY

Instead of another sweater or pair of socks this holiday season, we invite you to give your family a unique and meaningful gift by joining the **The Family Circle** and sponsoring a rose to ride on the **2006 Donate Life Rose Parade Float** in the name of organ and tissue donors, recipients, candidate for transplant or those whom have passed away while waiting.

Initiated by donor sister, Laurel Wolowic, the Family Circle both extend the magical experience of the Donate Life Float to families across the nation and give the float itself greater meaning and purpose by hosting this special tribute to the lives that have been transformed through organ and tissue donation.

This year's sponsorship dollars will go toward building a web site the media will use to direct millions of parade viewers to information on organ and tissue donation. This site will be launched soon! Each year Family Circle projects will have the goal of both honoring families and raising awareness about organ and tissue donation.

For any questions about the project, please contact Tenaya at (213) 401-1011 from Family Circle committee.

Kidney Foundation Working for Support from Local Legislators on New Bill

The National Kidney Foundation is urging ALL to write your member of Congress in support of this legislation!

Rep. Dave Camp (R-MI) introduced into Congress H.R. 1298 (The Kidney Care Quality and Improvement Act of 2005). This legislation seeks to address long standing goals of the NKF that include improving how Medicare provides services to Americans with ESRD, End Stage Renal Disease. Medicare has failed to keep pace with some of the medical advances since the inception of the ESRD Program (1972) that ensure that patients with kidney failure receive high quality care.

H.R. 1298 seeks to improve the ESRD Program by:

- Creating public and patient education initiatives to increase about Chronic Kidney Disease
- Providing Medicare coverage for Chronic Kidney Disease education services for Medicare-eligible patients.
- Establishing an outcomes-based quality demonstration project to study how to best structure incentives for providers.
- Ensuring quality through improvements in the ESRD payment system, including phasing in an annual update mechanism for dialysis providers that, unlike all other Medicare providers, do not have an update mechanism for payments to account for real changes in price and inflation.
- Aligning incentives for physician surgical reimbursement for dialysis access to promote quality and lower costs.
- Establishing a uniform training for patient care dialysis technicians.
- Improving ESRD Coverage by removing barriers to home dialysis and creating an ESRD Advisory Committee.
- *To find your member of congress: Go to www.capwiz.com/c-span/dbq/officials, then enter your 9-digit zip code and find your Representative.*

TAO-Rochester Board of Directors 2005/2006

Name	Phone	Email	Office	Term Exp.
Ron Barnard	227-2887	barnardr1@peoplepc.com	Board Member	2007
Lisa Faucz	671-3914	lfaucz@rochester.rr.com	Secretary	2007
Karen Gledhill	582-9252	ksgledhill@rochester.rr.com	Vice President	2006
Karen Guarino	272-7890	kguarino@rehpb.org	Rep. Rochester Eye and Tissue Bank	N/A
Linda Hicks	275-8306	linda_hicks@urmc.rochester.edu	Rep. Dept. of Transplantation, SMH	N/A
David Johnson	889-1346	davejohn@rochester.rr.com	President	2006
Suzanne McNamara	385-3144	shawmcn@aol.com	Board member (<i>Times</i> editor)	2006
Sandy McNitt	359-8015	sdmcnittot@aol.com	Board member	2007
Dan Newhouse	663-4508	tatmandan@aol.com	Board member	2006
Janice Odenbach	216-9856	janiceodenbach@aol.com	Board member	2007
Jim Quetchenbach	272-4950	james_quetschenbach@urmc.rochester.edu	Rep. Finger Lakes Donor Recovery Network	N/A
Penny Sayles	624-4126	psayles@brockport.edu	Board member	2006
Joanne Schum	671-7635	twoluckylungs@juno.com	Board member	2006
Mike Stelljes	245-9579	mstellje@rochester.rr.com	Treasurer	2007
Dennis Stenshorn	323-1392	dstensh1@rochester.rr.com	Board member	2006

OTHERS NOT ON THE BOARD:

Laurie Packard	425-8034	kidtr0311@aol.com	Membership chair
James Grossman	325-2112		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.

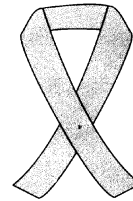
Exercises that do no good

Climbing the walls
Dragging your heels
Grasping at straws
Tilting at windmills
Spinning your wheels
Jumping the gun
Passing the buck
Pushing your luck
Stretching the truth
Running amok

ORGAN & TISSUE DONATION

Thousands wait for the gift of life!

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



Wear Our Green Ribbon

Donate your car to TAO

Like an old friend, your "slightly used" car can be considered part of the family. As such, you want to ensure that when its days are near the end, it is taken care of. Your old car, boat or trailer can help TAO and our efforts. May we contact Insurance 585-426-1030. arrange pick up, vehicle and send TAO their portion. It sounds simple. It is. Keep it in mind!



Your trailer can fund raising suggest you Auto Action, They will auction the

“Life - Pass It On” License Plate

The Department of Motor Vehicles Commissioner offers a custom license plate “Life - Pass It On” to benefit organ and tissue donation and research.



This plate is available to anyone who has a passenger or commercial vehicle registered in New York State. To order your “Life - Pass It On” license plate, visit any DMV issuing office, DMV’s website at www.nvsdmv.com or call the DMV Custom Plates office at 518-402-4838, Monday thru Friday, 8-4:30 pm.

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 they 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