

www.tao-rochester.org

1-888-664-1463

May, June 2004

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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

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, May 19, 7 pm. A FAVORITE RETURNS

Please join us for our May meeting as we welcome back a favorite. Dr. Mark Nickels MD, from the Consultation Psychiatry Program at Strong Memorial Hospital will be speaking. Dr. Nickels' practice concentrates on the transplant population at Strong Memorial Hospital, although he does serve other chronic illness groups. He will speak to the group about the psychological aspects of living with a transplant, medications and ways to cope. There will be a short presentation and member driven questions.

Wednesday, June 16, 6pm ATTENTION SPORTS FANS!

Celebrate the beginning (we hope) of summer, say good-bye to fellow TAO members for the summer and meet the members of the UPSTATE NEW YORK TRANSPLANT TEAM! Our June meeting is going to be FABULOUS! It will be a picnic in honor of the Transplant team and a thanks to all the members for their support this year. We will have subs and beverages. PLEASE BRING A DISH TO PASS. We will have games and outdoor fun for all. How about a game of "pin the organ on the correct body position" and other games still to be invented!

I am going to need a count so that we know what to order so please let me know by e-mail or phone. Karen Gledhill, President, H (585) 586-9252, W (585) 246-3364, kgledhill@aol.com

Elections to Be Held in June

It is that time again. In the by-laws established by TAO, our group needs to hold elections before the summer. This allows TAO to start the new year with a new slate of officers to better serve the group. Because our April meeting ran so far over I did not get a chance to announce that we are looking for people to serve on the board. If there is anyone that would like to run for any of the offices (president, vice president, treasurer or secretary) please let Karen Gledhill (see above) know before the MAY meeting

The Board has a monthly meeting the Wednesday before the membership meeting to plan the agenda, the speakers and address issues. There is a good chance that the Board meetings will be held every other month, starting in the fall.

We have spoken to Dan Newhouse who has indicated that he would like to be on the board this year. We are

asking several other people who have expressed interest and we will talk about candidates at the May meeting. **Saturday, May 15, will be the Lilac Parade.** Every year we develop a float and carry transplant recipients with signs which state their organ and date of transplant. The crowds always have a positive response, and it is a fulfilling experience. Plan now to sign up to ride the float 9am to noon. WE NEED YOU ON THE LFOAT. Call karen Guarino at the Rochester Eye and Tissue Bank, 272-7890.

Deadline for next Transplant Times - Wednesday, August 4

September Meeting - Wednesday, September 15 or 22, check the website www.tao-rochester.org

**TRANSPLANT ANNIVERSARIES OF
TAO MEMBERS -May, June, July,
August**

Roger Duryea -- 05-01-95 Kidney
Vaughn Palmieri -- 05-05-95 Kidney
Nancy Ross -- 05-06-95 Liver
Bonnie Gottorff -- 05-07-95 Kidney
Leo Bianchi -- 05-16-02 Liver
Nancy Thompson -- 05-18-93 Liver
Barbara Robida -- 05-18-02 Liver
Patricia Terra -- 05-20-02 Liver
Bonnie Patten -- 05-21-95 Liver
Richard Orczyk -- 05-23-91 Heart
Benjamin Franklin, Jr. -- 05-23-02 Liver
Jean McDade -- 05-31-00 Kidney
Ralph Toscano -- 03-01-89 06-01-90 Cornea
Shelley Stone -- 06-05-95 Lung
Joseph Loggalbo -- 06-07-03 Kidney
Rosa Dratsch -- 06-08-93 Kidney Donor
Ethel Jean Schrader -- 06-15-02 Liver
Otto Schuster -- 06-23-01 Liver
Don Kennedy -- 07-12-02 Kidney
Phillip Ronzo -- 07-19-96 Liver
Patricia A. Johnson -- 07-26-97 Kidney
Pancreas
Sherry Rogers -- 07-27-95 Heart
Giulio Verde -- 07-30-98 Heart
David Spiro -- 08-01-97 Liver
Patricia Rankin -- 08-10-98 Kidney
Roger(Bud) Robinson -- 08-12-92 Heart
Sharon Resch -- 08-14-97 Liver
Michael Kerins -- 08-23-95 07-09-02 Kidney
Pancreas
Joseph Yahn -- 08-27-94 Heart
David Watts -- 08-30-90 Kidney
Rebecca Snyder -- 08-31-98 Heart

Congratulations! Did we miss yours? Get your date wrong? Please call!

(Note: this list is members only)

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

The following people have recently made donations to TAO:

Nancy Thompson
Ernst Baier
Dennis Kovel
Mary and Leland Erickson
Shirley Tuites
Vonnie Stowell and Paula Durgola to honor their friend Patricia Bianchi on her birthday in April

Welcome to New Member

Mary Singh (Heart Lung Candidate)

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 at 436-9032.

Saving Tops Tapes and Pop Tabs

Please remember to save the cash register tapes when you go shopping at Tops Friendly Markets. Linda Barnard collects and counts them and turns them in periodically. A nice portion of our budget comes from this source. Linda is collecting pop tabs from aluminum cans. Bring tapes and tabs to the meeting, or mail them to Linda Barnard at 281 Guinevere Dr. Rochester NY 14626.

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, donors, family and friends are welcome. Meetings are held monthly and include programs of interest to the transplant community.

Reimbursing Organ Donors

WASHINGTON (AP) - The House, hoping to spur more lifesaving organ donations, voted Wednesday (3-24-04) to reimburse organ donors for travel and other nonmedical expenses involved in transplant surgery. The legislation is an "important move to ensure that those who want to give the gift of life are not swayed by financial constraints," said Rep. Edolphus Towns, D-N.Y. It would authorize the Department of Health and Human Services to spend \$5 million a year, beginning Oct. 1, to reimburse qualified donors. On Thursday, March 25, the Senate approved the legislation by a voice vote and sent it to the president.

Living donors now outnumber the traditional source of organs - cadavers. Of the 6,808 living donors in 2003, the vast majority gave a kidney, according to the Organ Procurement and Transplant Network. Segments of the liver, lungs, pancreas and, rarely, the intestine, also can be taken from a live donor. The bill authorizes an additional \$15 million in 2005 for grants to states, public awareness efforts and studies on how to increase recovery and donation rates. It also would finance new programs at hospitals and organ procurement organizations to coordinate organ donations.

More than 84,000 people nationwide are currently awaiting donations, the organ procurement group said. Every day, 68 people receive organ transplants, but another 18 die while waiting for a donor match, according to HHS. "This is a life-or-death legislation for thousands of people on waiting lists," said Rep. Jay Inslee, D-Wash., a sponsor of the legislation. A key to closing the gap is getting family members to discuss organ donation. "Sadly, while most Americans indicate that they support organ donation, only about 50 percent of families who are asked to donate a loved one's organs agree to do so," Towns said, citing a study by the National Academy of Sciences' Institute of Medicine.



The Cost of Organ Transplants

Estimated charges, first year following transplant

	Evaluation	Procurement ¹	Hospital	Physician	Follow-up	Immune-suppressing drugs	Total
Heart	\$16,800	\$57,000	\$210,000	\$29,300	\$68,100	\$10,200	\$391,800
Lung	17,400	58,200	170,000	27,100	57,100	12,800	343,000
Liver	17,200	54,100	131,800	42,700	58,400	9,400	313,600
Kidney	9,500	45,700	32,800	13,500	31,200	10,600	143,300
Pancreas	9,500	43,900	40,200	15,200	31,200	8,900	148,900
Intestine	31,000	69,600	593,100	55,100	58,400	6,900	814,500

¹Procurement includes donated organ or tissue recovery services, which may include preservation, transportation and other acquisition costs. Source USA Today, thanks to Michael Stelljes

Library

The TAO organization has a lending library that has not been used recently but we are once again making it available. It has a temporary home with Carol Roberts and you can arrange with Carol to borrow a book or tape from the collection by calling her at (585)225-7845. She will bring your selection to a membership meeting or you can make arrangements to pick it up. For a complete listing of all the items in the library check out our website at tao-rochester.org. If anyone would like to donate anything to the library we'd love to expand and update it. Also it is looking for a permanent home - if someone would like to store it or even be able to transport it to our meetings please let us know. It is a lovely bookcase on wheels that was made by Fran Begy and his son.

Walk on the Wild Side

Saturday May 22nd at the Seneca Park Zoo - the Western NY Chapter of the American Liver Foundation's fifth annual 5K Walk. Please help us to fight liver disease by: **Walking** -preregister and receive a bonus prize, **Honor** a loved one with a personalized sign on the walk route, or **Sponsor** another walker. For more information visit www.liverfoundation.org or call (585)271-2859

Primary Biliary Cirrohsis

The Western NY American Liver Foundation, Axcan Pharma, and the Western NY PBC Support Group are hosting an educational meeting on Primary Biliary Cirrohsis at the Holiday Inn Select in Niagara Falls, NY on July 14-15. For the full details go to www.liverfoundation.org. There will be several speakers including Linie Moore from the PBCers Organization and Dr Thomas Shaw-Stiffell. The hotel is offering discounted rooms - continental breakfast and lunch are included in the meeting fee of \$30. Any questions contact Carol Roberts at (585)225-7845.

Support for Transplant Patients

The following is reprinted from the **Volunteer Update**, the *Friends of Strong* newsletter: "Some of Strong's heart transplant patients are in the hospital for months at a time waiting for a heart and then for recovery from surgery. The *Friends of Strong* are looking for new or very gently used televisions, VCR's, DVD players, or combination of TV/VCR or TV/DVD. They are also accepting donations towards purchase of new TV's, VCR's or DVD players. For more information please call Joan Clancey at the Friends of Strong at 275-2420. Thank you!"