

www.tao-rochester.org

1-888-664-1463

May, June, 2006

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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 Sigl 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!

Wednesday, May 17- 7 pm Dr. Mark Nickels, Transplant Psychiatrist will be at the May meeting. Dr. Nickels has been a frequent contributor to TAO meetings and we look forward to another opportunity to hear him. Dr. Nickels is available to Pre and Post transplant patients and has been working with the transplant population for many years. This will be an informal meeting with opportunity to ask questions.

Here's an interesting item for recipients on Medicaid:

On-Line Drug Comparison Tool from the NKF

The Kidney Medicare Drugs Awareness and Education Initiative has developed a Compare Drug Plans packet (www.kidneydrugcoverage.org/choose.htm), which will update its formularies monthly. Medicare updates the Drug Plan Finder and Formulary Finder at www.medicare.gov on the first Monday of each month. The current version of the Compare Drug Plans packet is available on www.kidneydrugcoverage.org and was updated on Wednesday, March 15, 2006. This packet includes a FAQ on how drugs and plans were chosen, search tips, and two charts that allow you to search for what drugs a specific plan covers (by plan) and what plans cover a specific drug (by drug).

Wednesday, June 14- 6:30 PM TAO June Picnic

The June TAO meeting will be one week early, on Wednesday June 14th at 6:30pm at the Al Sigl Center Annex. This meeting will be a picnic sponsored by TAO to send off the Transplant Athletes to the 2006 US Transplant Games in Louisville, KY. All TAO members and family are invited, as are all team members. Submarine sandwiches and beverages will be provided. TAO members are asked to sign up to bring a salad, chips, dessert, or side dish to pass. Sign up sheets will be passed around at the April and May TAO meetings.

If the weather permits (this is Rochester after all) we'll have volleyball and other outside activities. So bring your volleyball shoes to give the team some practice.

If you're unable to sign up at one of the meetings but would like to attend the picnic, please call Dave Johnson at 889-1346 or email davejohn@rochester.rr.com.

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

Roger Duryea -- 05-01-95 Kidney
Phil Sinaguglia -- 05-04-04 Kidney
Shelley Whitney -- 05-09-03 Lung
Leo Bianchi -- 05-16-02 Liver
Barbara Robida -- 05-18-02 Liver
Nancy Thompson -- 05-18-93 Liver
Patricia Terra -- 05-20-02 Liver
Bonnie Patten -- 05-21-95 Liver
Richard Orczyk -- 05-23-91 Heart
Ralph Toscano -- 03-01-89 06-01-90 Cornea
Shelley Stone -- 06-05-95 Lung
Joseph Logalbo -- 06-07-03 Kidney
Rosa Dratsch -- 06-08-93 Kidney Donor
Ethel Jean Schrader -- 06-15-02 Liver
Otto Schuster -- 06-23-01 Liver
Bernice Eblovi -- 06-27-02 Liver
Phillip Ronzo -- 07-19-96 Liver
James Blake -- 07-24-04 Liver
Giulio Verde -- 07-30-98 Heart
David Spiro -- 08-01-97 Liver
Donna Christy -- 08-05-00 Liver
Patricia Rankin -- 08-10-98 Kidney
Roger(Bud) Robinson -- 08-12-92 Heart
Maira Miller -- 08-17-05 Liver
Joseph Yahn -- 08-27-94 Heart
David Watts -- 08-30-90 Kidney

Last issue we missed Penny Sayles - 04-08-98 Kidney. Sorry Penny!

*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

Best wishes to **Ron Barnard** as he goes through chemotherapy. He appreciates your cards and letters.

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

Telephone Committee Needs Help

We are continuing to add members, and that means we need more people to make reminder calls. Sandy McNitt and Paula McKay coordinate this responsibility. They say that callers spend about ten minutes each month on their reminder calls. Contact Paula pmckay73@rochester.rr.com or 436-9032 or Sandy at sdmcnittot@aol.com or 359-8015.

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.

check our website www.tao-rochester.org

Euchre Tournament

There were 16 tables of four players each and probably ten more who just came to support the team at the Euchre Tournament Fund Raiser on Monday, February 27, at the Village Pub in Chili. Throughout the day door prizes were given out and a "Chinese Raffle" held. There were some great prizes donated, as well as the restaurant space, food and drink. Teri Morganti was the team leader for the event, and Karen McKissock, Linda Barnard, Bonnie Haefner, Mike Swete, Jerry Runion, Karen Gledhill and Ernst Baier all helped. The event netted over \$2000 for the Transplant Games Team.

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.

ELECTIONS ARE COMING: MAY 17th

The election committee is happy to announce the following candidates for our up coming elections. The offices that need replacements are President, Vice-President, Secretary, and three Board Members.

The nominees are:

President:	Dennis Stenshorn
Vice President	Karen Gledhill
Secretary	Shelley Whitney
Board Members	Joanne Schum Jerry Runion Rita Lesnick

Dave Johnson will be rotating off the board as President but will continue to serve as a board member, required by the TAO by-laws.

Dennis Stenshorn is running for President. He has been a board member for the past two years and joined TAO in 2003, with his wife as his support. He is also a volunteer for the Eye and Tissue Bank .

Karen Gledhill will be running for re-election as Vice-President. She served for two years and was our President prior to that term. She volunteers for the Eye and Tissue Bank and The Kidney Foundation. She has been a TAO member for over ten years.

Shelley Whitney volunteered to run for Secretary at the April Membership meeting. Shelley is a single lung transplant, May 2003, from Cleveland Clinic.

Joanne Schum is running for re-election for board member. She has been a TAO member since 1998.

She is an active volunteer for the Eye and Tissue Bank and Cystic Fibrosis Foundation.

Jerry Runion is running for board member. He has been a board member for The Kidney Foundation and plans to rotate off this position in Spring 2006. He has been a TAO member since 2002.

Rita Lesnick served as our secretary for the past year but feels the board member position is her preference. She has been a TAO member since 2004 and is a support person for her daughter.

The term for these offices is two years. The Board of Directors meets the second Wednesday of each month at the Rochester Eye and Tissue Office. We will have additional descriptions of these positions at the April meeting. Please read and ask questions to current officers. Let **Karen Gledhill 586-9252** or **Sandy McNitt 359-8015** know if you would like to run for election before the May 17th meeting.

Please help us to continue to achieve our mission and to improve how we serve our members and our community.

10,000th Cornea for Transplant Provided by Local Tissue Bank

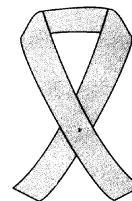
(We recently received this press release with a note from Karen Guarino saying “We are very proud of this milestone, and wish to thank all our volunteers for helping make this possible through their efforts in increasing awareness of the need for eye, tissue and organ donation.”

March 14, 2006 - Rochester NY - The Rochester/Finger Lakes Eye & Tissue Bank (R/FLETB) provided its 10,000th cornea for transplant at the end of February. “This milestone affirms our community’s generous nature. Those who have made the decision to become eye donors at the time of death, and those family members who consent to donation, are to be honored,” said Linda Fraser, R/FLETB executive director. “It is especially poignant that R/FLETB reached this milestone now, as March is National Eye Donor Month,” she adds.

Since 1952, R/FLETB has been providing ocular tissue for transplant, medical education and research. “Approximately 200 people every year in our region need corneal transplants due to disease, injury or infection,” states Fraser. “The only positive alternative for many is a transplant.” Nationally, over 32,000 individuals receive sight-restoring transplants each year.

ORGAN & TISSUE DONATION
Thousands wait for the gift of life!
Increase awareness of the need for donors,
and wear your ribbon with pride!

corneal
corneal



National Patient waiting list as of April 14, 2006

All Organs	98,471
Kidney	69,956
Liver	17,692
Pancreas	1,770
Kidney/Pancreas	2,598
Heart	3,005
Lung	3,102
Heart/Lung	150
Intestine	198

Lilac Parade Saturday, May 13

The Council for Donation of Organs and Tissues (C-COT), of which we (TAO) are a member, will be sponsoring a float in the Lilac parade again this year. All transplant recipients are urgently invited to ride on the float, wearing transplant t-shirts and carrying signs with your date and organ prominently displayed. We have a lot of fun singing and chanting and waving at the crowd. We always get cheers.

Interested? Contact Karen Guarino at the Eye Bank (585) 272-7890.

How Are Things Going?

In the last issue of *Transplant Times* I put in a request for people who are not able to attend meetings to send in a note telling us how things are going for them. I am pleased to report that we have messages from three members.

When Linda Marie Serenka sent in her dues she included her new address. With her permission we are publishing it here so you may contact Linda. She and her spouse Robert moved to Albany in May 2005. **Linda Marie Serenka**, 229 Jay Street, Albany NY 12210-1807 .

We also heard from **Nancy Thompson**, who provided and served refreshments at the meetings as long as I can remember. "Hello friends. I miss seeing all of you but my family commitments have not permitted me to attend meetings. I am doing well, keeping busy caring for all my grandchildren. My husband is now able to be back to work full time. I hope everyone is doing fine. Sincerely, Nancy"

Ron and Betty Goehle sent this message: "Sorry we have missed so many meetings of TAO. Miss you all!!!! I have been feeling quite well. I'm still on the list for another liver transplant. My MEL score is 20, however, I am in no hurry for a replacement. I'm quite happy with the quality of life I have. Both Betty and I are again involved in community theater with our son and his family. We just helped Spencerport High School do "ANYTHING GOES." I designed the set and Betty did publicity. This activity helped me focus on something other than my medical problems. We are now working on a Dinner Theater for the PORT OF CALL COMMUNITY PLAYERS. Hope to see you all when things calm down." Ron and Betty Goehle

It is a pleasure to hear from members of our transplant community. We hope to hear from you soon. Send messages to:
Sally Stelljes, 5341 Booher Hill Road Geneseo NY 14454 (585) 245 9579 salstell@rochester.rr.com

And the Beat Goes On!

On August 13, 2005, Tom Arcara was looking forward to playing drums with his band for his street picnic. Instead, he ended up in critical care at Strong Memorial Hospital after suffering a massive heart attack. Tom's heart did not survive and Tom was kept alive on a ventricular assist device until he had a heart transplant 6 weeks later. He was able to return home in October.

Tom and his wife Christine were so grateful to the doctors and nurses and the entire transplant team at Strong, that they felt they had to thank them and try to help other patients waiting for heart transplants. Tom is doing great and he is playing with the band again. The fact that he is able to play gave them the idea to use music as a fundraiser. They have organized a benefit called, "**And the Beat Goes On**" that will be held on Saturday June 3rd at Burgundy Basin Inn from 4:00 PM to midnight. Funds raised from this event will go directly to support the patients and immediate families on the Heart Transplant Unit. There will be a total of 4 bands playing (Buster Rocks, 2nd Chance, 585, and Brass Taxi). There will be a BBQ (Beef and Chicken) and full picnic buffet with salt potatoes, baked beans and salads. There is an outside deck if it is a nice day and an inside and outside cash bar. There will be many raffle items (the guys may bid on the golf or the ladies on a trip to the spa). We want as many people to come out and have fun with us as possible – to celebrate life and 2nd chances!

Sound like fun? Tickets will be going on sale at the end of April. Give Tom or Chris a call at 349-0686 or send an email to CARCARA@rochester.rr.com if you would like to join us.

Thank you from the bottom of Tom's (NEW) heart!

New Volunteer Opportunities at Strong

Note: Both of these volunteer positions are through the Friends of Strong and require you to go through the normal volunteer orientation and medical screening. The medical screening is to make sure all your immunizations are up to date and you have to have a yearly TB test. The screening and any needed immunizations are given for free. In addition, you received free parking in the ramp garage whenever you volunteer, an invitation to the annual volunteer appreciation dinner, and a 20% off coupon at the giftshop on your birthday!!

Solid Organ Transplant Unit Volunteers

A new Friends of Strong volunteer position will be opening soon. Allen Erway, the Nurse Manager on 6-1600 is setting up a volunteer cadre to work on the transplant unit. Allen is looking to staff the unit, to start, from 9am to 5pm weekdays. Eventually this may be expanded to include weekends and evenings up to 8pm. It's not necessary to work a full 8 hours, split shifts are fine. Duties will include greeting new patients, taking patients for walks, visiting with patients, getting them water, books magazines, etc. You'll also be answering the call buttons and will receive training to do so.

Transplant recipients and their caregivers are preferred, but this position is open to any interested parties. If anyone is interested, you can contact Allen directly at Allen_Erway@URMC.Rochester.edu or contact Dave Johnson at (585) 889-1346, davejohn@rochester.rr.com.

New Patient Support Program

If you were at the January meeting you probably recall me telling a little about a support program that Mike and I are interested in developing at Strong. Our idea is to develop a program to provide support and encouragement to transplant patients and their families before, during and after surgery. We feel it is important to give people the opportunity to develop connections in the transplant community The following info will bring you up to date about our progress.

On Tuesday, March 7 we traveled to Upstate Medical Center in Syracuse to spend time with volunteers and others in the kidney transplant department. Paul Meigs of the Syracuse Transplant Awareness Group and the lead volunteer in the transplant unit spent about six

hours with us. The day began with them meeting a transplant candidate in the lobby of the hospital , chatting for awhile and then escorting candidate to transplant area for day of evaluation.

We observed part of the time that hospital personnel spent with the candidate. The remainder of the time was spent with the volunteers explaining how their program works. In addition we met with Ann Roman, the head transplant coordinator at the Syracuse Hospital. They shared their enthusiasm for the support that the volunteer program provides.

Since our day in Syracuse we have met with Nancy Metzler, administrator in the transplant department at Strong along with Linda Hicks, and Frank Cannizzaro, transplant social workers. All three were supportive of our proposal to start a program similar to what we observed in Syracuse.

The next step will be to work with FRIENDS OF STRONG to outline the volunteer position with regard to purpose, tasks, required skills, and training required.

We will keep you apprised of our progress. If you are interested in learning more about our proposal , please contact me by phone, (585) 245 9579 or e-mail salstell@rochester.rr.com

Sally Stelljes

TAO-Rochester Board of Directors 2005/2006

Name	Phone	Email	Office	Term Exp.
Ron Barnard	227-2887	barnardr@peoplepc.com	Board Member	2007
Lisa Faucz	671-3914	lfaucz@rochester.rr.com	Secretary	2007
Karen Gledhill	586-9252	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
Robyn Miller	272-4936	robyn_miller@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/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!

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Transplant Times

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Pittsford NY 14534

