

www.tao-rochester.org

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September, October, 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 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!

Wednesday, September 20, 7 pm

This will be our "WELCOME BACK" meeting - a time to see friends you have not seen all summer and share ideas for upcoming meetings. The members of the Transplant Team will also share their experiences at the Transplant Games in Louisville this summer. We will congratulate Dan Newhouse on winning the Mickey Mantle Courage Award. See Page 4 for a list of medal winners.

Wednesday, October 18, 7 pm

Michelle Lester of the Donor Family Network

Deadline for Nov. - Dec. 2006 *Transplant Times* - Wednesday, October 11

From the President

I would like to welcome everyone back from a very nice summer to 2006/2007 TAO meetings. As your new president I would like to welcome our newest members of board of directors, **Shelley Whitney** as secretary and **Jerry Runion** as board member. I also would like to welcome back returning members of the board of directors and thank **Rita Lesnick** acting for **Lisa Faucz** as secretary and **Penny Sayles** and **Dan Newhouse** as board members for their time on TAO board.

One of Tao's goals is to provide support, information to members, recipients, candidates and their families. We hope to bring useful and a variety of information to our monthly meetings, but we need your input. All members should feel free to contact myself or any board member about speakers or topics that they feel would benefit our membership.

I would like to meet as many members as I can and look forward to seeing you soon.

Dennis Stenshorn

TRANSPLANT ANNIVERSARIES OF TAO
MEMBERS - **September, October**

Ivan Tzontchev -- 09-05-00 Kidney
Ernst Baier -- 09-05-00 Kidney
Joanne Schum -- 09-13-97 Lung
Suzanne McNamara -- 10-01-93 Heart
Carrie Rodriguez -- 10-02-05 Kidney Pancreas
Michelle Halloran -- 10-09-97 Kidney
Claudia Ciresi -- 10-18-94 Liver
Susan Bennett -- 10-19-98 Kidney
Keith Oliver -- 10-28-02 Liver
Dennis Kovey -- 10-30-01 Kidney
Daniel Newhouse -- 10-30-90 11-17-95 Kidney
David Johnson -- 10-31-00 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

Best wishes to **Ron Barnard** as he goes through radiation following 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

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

NEW MEMBERS THIS SUMMER

Patricia Terra, (Liver 5/20/02), Thomas Louer (Liver, 3/22/04), Patricia Alexander, (Liver, 1/13/05, 2/9/05), Beverly Shank (Liver, 12/14/05), Dan and Marilla Gardner, DONOR FAMILY

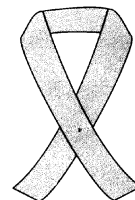
WELCOME!

From our Membership Chair, Laurie Packard: "The 2007 TAO dues date is fast approaching. If I have your e-mail address, be on the lookout for your 2007 dues notice around the end of September. I will be mailing all others around the second week of October." TAO dues are \$10/year. See back page of this newsletter for details.

ORGAN & TISSUE DONATION

Thousands wait for the gift of life!

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



A Unique Volunteer Opportunity

Perhaps you remember reading in the May-June 2006 issue of TRANSPLANT TIMES about some new volunteer opportunities. Mike and I are happy to announce that on Monday, July 31 we launched a new program at Strong. The program is designed to provide support and encouragement to transplant candidates on the day of his/her evaluation. Our long range goal is to provide transplant candidates and their families the opportunity to develop connections in the transplant community.

On the first day we greeted five liver transplant candidates along with their support person(s). We then found out where their first stop would be, such as lab, clinic, testing appt. etc. and escorted the people to that location. We attempted to touch base with the candidates as the morning progressed to show them where the cafeteria is located and answer questions they may have.

We have already received positive feedback from FRIENDS OF STRONG and one of the transplant social workers. The candidates themselves were very appreciative of our efforts.

As I write this on August 2 we have four transplant recipients and one support person who have committed to helping with this program. At this time we are in need of more volunteers to help on Monday and Thursday mornings. If you are interested please see Jane Walsh in FRIENDS OF STRONG concerning the job description and qualifications.

Please feel free to call or e-mail us with any questions or concerns:

Sally and Mike Stelljes
(585) 245-9579 (home)
(585) 519-2753 (cell)

Six Transplant Surgeons at Strong

While Mike and I were working on developing and implementing our new volunteer program we had the opportunity to meet with Nancy Metzler who is a transplant administrator at Strong Memorial Hospital. Nancy provided us with the following information on the transplant surgeons at Strong. These surgeons handle transplants for kidney, pancreas and liver. The heart transplant unit is entirely separate.

Program Director : Dr. Adel Bozorgzadeh
Surgeons: Peter Abt, MD, Mark Orloff, MD, Ashok Jain, MD

New Surgeons now on board:
Georgios Tsoulfas, MD, Completed his fellowship at Massachusetts General in Boston and did his general surgery residence at the University of Iowa.

Randeep Kashyap, MD, Completed his fellowship at the University of Rochester Medical Center/Strong Memorial Hospital and also trained at the University of Pittsburgh.

Submitted by Sally Stelljes

Report from the Transplant Games website: www.teamupstateny.org

We're back from a very successful games. Everyone was tired and sore but healthy. The team won 10 medals!

A surprise announcement was made at the closing ceremonies. The **2008 US Transplant Games** will be held in **Pittsburgh in July**. That's pretty darn close, and no conflicts with school.

Team Results - 2006 US Transplant Games

Karen Gledhill - 50m Breaststroke - Silver
Karen Gledhill - 50m Backstroke - Silver

Tom Jansen - 5K Race for Organ & Tissue - Bronze
Tom Jansen - 1500m Run - Silver

Kevin McCorry - Individual Golf (Gross) - Bronze
Kevin McCorry - 5K Cycling - Silver
Kevin McCorry - 20K Cycling - Silver

Mike Swete - Individual Golf (Net) - Bronze

Ryan Yaple - High Jump - Bronze
Ryan Yaple - 200m Run - Bronze

In a pleasant surprise to the entire team, **Dan Newhouse** was selected to receive the **Mickey Mantle Courage Award** for the 2006 Transplant Games. The Mickey Mantle Courage Award recognizes a transplant athlete who has overcome great challenges to participate in the Games

Congratulations to all the athletes of Team Upstate NY. Considering that we only had 12 athletes, 10 medals is a pretty impressive showing!

Hear all about the games at the September meeting.

Five Points of Life

Every year there is a national bicycle ride to promote the "Five Points of Life." The five are Blood, Apheresis, Marrow, Organ/Tissue, and Cord Blood.

This year the ride starts in Ottawa, Canada and travels to South Beach, Florida and biking through 10 States and hitting 38 cities on the way.

The cycling team consists of amateur cyclists who have a personal connection to one or more of the five points as donors, recipients, or in some cases both. They act as messengers for the program sharing their experiences and the reason why it is so important to donate.

As they travel the route, they will stop at events arranged by local donor or transplant organizations. They will arrive in Rochester on Monday September 11 at Johnson & Johnson in Greece

C-DOT = Council for the Donation of Organs and Tissues in our area is organizing the event at each stop point. We encourage all TAO Members, Friends, Professionals, Candidates, Donors and Recipients to encourage the riders on to spread the word on Donation.

The direct contact for CDOT is Karen Guarino in Rochester (Email is kguarino@rehpb.org)

Monthly Record Number of Organ Donors Reported

More lives were saved by organ transplantation in the month of May than in any month ever before! According to data from the nation's Organ Procurement and Transplantation Network (OPTN), operated by United Network for Organ Sharing (UNOS), there were 725 deceased organ donors in the United States in May, 2006.

Transplant community meets the challenge

The number of deceased donors increased rapidly in the last two years. This is attributed in part to the Organ Donation Breakthrough Collaborative, the federal government's initiative to save or enhance the lives of thousands each year by sharing and implementing known best practices in organ donation with the nation's largest hospitals to achieve organ donation rates of 75 percent or higher.

Collaborative participants were challenged in September 2004 to strive for a new record of 700 donors recovered in a single month.

Monthly records for deceased organ donors:

- More than 400 deceased organ donors reported for the first time in July, 1990
- 500 donors reported eight years later in April, 1998
- In May 2004, 600 donors reported
- Another benchmark reached in less than two years with 725 donors reported in May, 2006

More lives to save, decisions to record

Even with the increase in donation, there still remains a great need with more than 92,000 patients waiting for an organ transplant in the United States. The transplant community has set the goal of registering 100 million donors in state organ and tissue donor registries throughout the country. Visit Donate Life America's Web site, www.donatelife.net to find out how to make sure your wishes are carried out where you live.

The Organ Procurement and Transplantation Network (OPTN) is operated under contract with the U.S. Department of Health and Human Services, Health Resources and Services Administration, Division of Transplantation by the United Network for Organ Sharing (UNOS). The OPTN brings together medical professionals, transplant recipients and donor families to develop organ transplantation policy.

Overall by Organ Current U.S. Waiting List
Based on OPTN data as of August 11, 2006

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Heart / Lung	Intestine
Registrations	99,033	70,983	17,569	1,768	2,514	2,877	2,940	151	231

(From the OPTN Website.)

Regional Donor Pledge Registry - a joint collaborative between the Rochester/Finger Lakes Eye & Tissue Bank and the Finger Lakes Donor Recovery Network

700 organ and tissue donor cards entered into the registry from January 1, 2006 to July 31, 2006.
Total donor cards in the registry since inception = 89,498

And the Beat Goes On

On Saturday, June 3rd, the first fundraiser to benefit the heart transplant unit at Strong Memorial Hospital was held at the Burgundy Basin Inn. The event – “*And The Beat Goes On*” – was attended by approximately 550 people who enjoyed a chicken and beef barbeque, as well as listening to three local, "live" bands. Over 150 items were donated for the raffle and 10 items were in the Silent Auction, which included an autographed football from Jim Kelly, an electric guitar, and a golf outing at Oak Hill Country Club with Dr. Hicks. This exciting event raised more than \$13,000 after expenses. The funds will pay for computers and DVD players for patients on 7-3400 who are waiting for heart transplants. We are happy to report there will be a second "*And the Beat Goes On*" event next year on Friday, May 18th, at the Burgundy Basin Inn.

Countless Additional New Yorkers to Receive the “Gift of Life”

Governor George E. Pataki, on August 18, 2006, announced he had signed into law a series of bills that will encourage organ and tissue donation in New York State, ensuring that countless additional New Yorkers receive the “Gift of Life.”

The bills will:

Require a driver’s license or renewal to prominently display the words “Organ Donor” in cases where the person has consented to donate. ·

Require a license application or renewal form to include a box for a voluntary one dollar donation to the “Life Pass It On” Fund. ·

Require the Department of Health to inform New Yorkers about the need and importance of organ and tissue donation through Health Care and Wellness Education and Outreach Program. ·

Direct the Transplant Council to issue a report on the issues surrounding presumed consent for organ donation, with a focus on “presumed consent” systems set forth in other nations. In a system of presumed consent, the person is presumed to consent to donation unless he or she specifies otherwise. ·

Transform the New York State Organ and Tissue Donor Registry to one of intent to one of consent. ·

Rename the New York State Organ and Tissue Donor Registry to the “Donate Life” Registry to further encourage organ and tissue donation. ·

Provide up to \$10,000 subtracted from federal adjusted gross income for certain unreimbursed expenses incurred by living organ donor, including travel, lodging or lost wages. ·

Several TAO members have traveled to Albany with the Rochester/Finger Lakes Eye & Tissue Bank and Finger Lakes Donor Recovery Network staff to assist in educating our Senate and Assembly members about the need for more organ and tissue donors. These efforts do make a difference!

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 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	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	N/A
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

