

www.tao-rochester.org

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March, April, 2007

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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

NEW MEETING PLACE! SEE BELOW!

Wednesday, March 21, 7 pm

Plans for the C-DOT float for the Lilac Day Parade.
Bring your best float ideas! The flat bed is 7x18 feet,
so we have some space to use.

Wednesday, April 18, 7 pm Rob Kochik, New
Executive Director of the Finger Lakes Donor
Recovery Network.

We also will have a brainstorming session on
increasing attendance at our meetings.

Deadline for May - June, 2007 *Transplant Times* - Wednesday, April 11

New Meeting Location

I hope all of our members find time in their busy schedules to stop by our new meeting location at

Pinnacle Lutheran Church, located at 250 Pinnacle Road corner of Stone Rd.

Go south on Winton Rd from Jefferson, past the Al Sigl Center where we used to meet. Winton becomes Pinnacle. Take Pinnacle to the light at Stone Road, turn left, the parking lot is behind the church.

The church meeting room is larger, has more seating and is conveniently close to the door and parking lot, and it is just down the road (on the other side) from our former meeting place at the Al Sigl Winton Road Annex. I encourage all our members to check it out. As always, please let us know what topics, speakers and any information that would be of interest.

Our March meeting will be a two part brainstorming meeting on the C-Dot float for this year's Lilac Parade and (if time allows) on how to get word out into the community to generate attendees at monthly meetings. Many of our members ride the float and it is only fitting that member ideas are used display. So please come with your ideas and thoughts on these matters. Looking forward to meeting and hearing from everyone.

Dennis Stenshorn, President

(Snow note: If the Rush-Henrietta schools are closed for the weather, the Pinnacle Church will be closed as well, and we will cancel our TAO meeting.)

TRANSPLANT ANNIVERSARIES OF TAO MEMBERS - March - April

Ralph Toscano -- 03-01-89 06-01-90 Cornea

Michael Gerchman -- 03-01-98 Liver

Jan Sharp -- 03-01-05 Kidney

Mary Lou Allocco -- 03-03-01 Lung

Laurie Packard -- 03-11-91 Kidney

Paula McKay -- 03-14-95 Kidney

Cynthia Boyer-Green -- 03-14-96 Kidney

Thomas Louer -- 03-22-04 Liver

Karen Gledhill -- 03-23-83 Kidney

Robert Hadsell -- 03-30-97 Liver

Kathy Friday -- 03-31-00 Kidney

Jake Robinson -- 04-05-04 Kidney

James Graczyk -- 04-06-02 Liver

Penny Sayles -- 04-09-98 Kidney

David Berndt -- 04-12-02 Liver

Linda Marie Serenka -- 04-14-01 Kidney

Asya Zarkhi -- 04-24-03 Kidney

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

(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

TAO Members Visit with Transplant Patients

The TAO Volunteer Transplant Visitation program is a program operated through the Friends Of Strong. TAO volunteer visitors are transplant recipients (and in some cases their care-givers) that visit with patients in the kidney/liver unit as well as the heart unit at Strong. The purpose of the program is to provide encouragement to transplant patients, those on the waiting list, and their family members as well as answer questions from the perspective of one who has been through the transplant process.

During the period April 1 through December 31 of 2006 the TAO volunteers visited with 331 patients at Strong. Some of these patients may have been visited more than once, depending on the length of their stay in the hospital. Unfortunately, the sign-in sheets for the period January 1 through March 30 "disappeared", so the actual number of patients

visited was probably over 400.

Dave Johnson

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.

In Memoriam - Ken Alt

Many of you remember Ken Alt who traveled to the Games with us - probably 3 games ago - with his wife Marilyn. Later, he joined the Central NY team, and we called him "The Traitor." This, he would get the biggest kick out of. He was a member of TAG (Syracuse) and volunteered for us in the Central NY area. I am sad to report that Ken passed away last week due to complications of Leukemia. He will be missed dearly.

Karen Guarino

Past President **Dave Johnson** was recently hospitalized for some surgery. He is recovering well, and hopes to be out and about soon. He says the pain medication is making him a bit goof(ier?)

Volunteers needed for RUN Committee

Strong Memorial has asked if anyone from our group would be interested in being on a committee that is forming for the 2007 River Run. The money collected from the Run will go to support transplant patients who have financial hardship. The event will be held August 25 and more information will follow.

If you are interested in being part of the steering committee please let Karen Gledhill know at 586-9252 (or kgledhill@rochester.rr.com). She will forward your name to the correct individuals.
Thanks

Karen Gledhill

BON-TON Community Day

On Saturday, March 3, BON-TON's is going to participate in the CARE TO SHARE COMMUNITY DAY. This will take place at ANY Bon Ton store all day long. Booklets are for sale for \$5.00. Each booklet contains a \$10 off coupon good on almost any merchandise item of \$10 or more. Also included are 8 coupons for 20% off and offers for 2 great bonus items available on Community Day only.

The National Kidney Foundation's Transplant Team (me) are selling these tickets as a fundraiser. If you are interested in receiving a booklet, please call Karen Gledhill (kgledhill@rochester.rr.com or 586-9252) to purchase the coupon books.

Small gifts in a big way!

Heart transplant recipient Frank Imburgia's children dropped in one weekend afternoon to find him popping tabs off over 300 soda cans in his garage. Frank was pretty excited over the number he had to turn into the TAO collection. But, his wife and family were impressed by his drive and started thinking where else they could collect them.

Daughter in law Jennifer mentioned her father had been saving them but had no place to turn them in. On her next trip home (Wyoming County), her father Tony Almeter was quick to donate his hefty bag of tabs. That spurred Tony on to thinking where else he might collect them.

Tony zealously put out the word to other family members and friends. Sunday, January 15, was Tony's 60th birthday party. Among the gifts, in addition to congratulations and good wishes, was the highlight of the day - 88lbs of pop tabs for the Strong Transplant fund.

Jennifer and Sal Imburgia were on hand to bring the tabs back to Rochester. "This is unbelievable! You just never know what might happen if you just ask. This is a birthday gift that will keep on giving," said Frank Imburgia.

NKF Touch-A-Thon

The National Kidney Foundation 2007 Subaru Touch-A-Thon will be held April 28, 2007 at the Marketplace Mall. There are three ways to enter this year. For more details, click on their website at <http://www.kidneynyup.org>. Volunteers are needed to run the event and sell tickets.

The Beat Goes On

"And the Beat Goes On" will be going again this year. This is a fund raiser for the transplant program to raise enough money to establish a house for transplant families from out of the area to stay while their family members are hospitalized awaiting transplants. The date is FRIDAY, MAY 18 starting at 6:00 P.M. It will be held at the Burgundy Basin Inn on Marsh Road in Pittsford. The evening includes a chicken barbeque and dancing to "Me-n-the Boyz " and "Second Chance" There will be raffle items and items for a silent auction as well as a 50-50 raffle. All this for only \$25.00 per person.

Toll-free Number for Patient Services from UNOS

The United Network for Organ Sharing (UNOS)* provides a toll-free patient services line to help transplant candidates, recipients and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services line number is: 1-888-894-6361.

*UNOS is a non-profit scientific and educational organization that administers the nation's only Organ Procurement and Transplantation Network (OPTN) established by the US Congress in 1984. Though the OPTN, UNOS:

- 1) collects and manages data about every transplant in the US
- 2) facilitates the organ matching and placement process
- 3) brings together medical professionals, transplant recipients and donor families to develop organ transplantation policy.

You can visit them at www.unos.org or www.transplantliving.org

An Invitation from Rosemount House - Our January Speakers

First off, I want to thank you all for inviting us to share our Rosemount House story with you at the January meeting. Being with all of you was a very affirming and energizing experience for us. We're looking forward to exploring the ideas you shared with us. Important ones you offered were potential connections with other agencies, services we might offer Rosemount House guests, and suggestions for future improvements to the facility.

Most importantly we are looking forward to more ways to get to know you and work together. In light of that, we'd like to invite you all to join us on **Saturday, March 31** at 3:30. We're holding a **Mission Fair and Game Fest**. This will be an opportunity for people to have fun together, learn about our church's mission activities, and do a little fund raising. A suggested donation of \$5.00 will get you in the door to play games, view the exhibits, and enjoy some light refreshments. We will have snacks and beverages available throughout the afternoon and evening, as well as a light dinner between 5:30 and 7 p.m. Proceeds of the event will be used to support two of our mission projects: Rosemount House (which desperately needs a new storm door) and helping to send South Presbyterian Church members on a Presbytery-led trip this May to help rebuild New Orleans.

If you plan to come, letting me know will help us plan how much food to prepare. If you have questions or wish to RSVP I can be reached at 244-6980 or afinger@library.rochester.edu. Our church is located at 4 E. Henrietta Rd. (near the McDonald's by Strong Hospital).

Ann Finger
South Presbyterian Church

In case you have misplaced your copy, here is the "Wish List" from Rosemount House:

Television, VCR, DVD Player
(and videos and DVDs)
New bed linens (twin, full, king)
Laundry baskets
Flashlights (and batteries)
Non-perishable food, grocery gift cards, local
restaurant gift certificates and coupons
Plastic Wrap, Aluminum foil, Ziploc bags
Paper goods, (tissues, paper towels, toilet paper)
Laundry detergent ad dryer sheets
Cleaning supplies
Toiletries and personal care items.

Ann Finger
afinger@library.rochester.edu
244-6890 (home) 275-9308 (work)

Shelly Carithers
Shellyjane@gmail.com
442-5139

Rev. Jamie Kenyon
revjkenyon@frontiernet.net
271-5078

Donations may be dropped off at the Church Office during its normal business hours, or you may call or email us to make special arrangements to deliver your donations to the Church.

Wonder organ transplant solution

Scientists and transplant surgeons in Edinburgh have developed a new preservative which should improve the success rate of organ transplants. They have produced a new solution which prevents blood clots inside the organ, making it more likely that the transplant will work. It is thought the liquid increases the length of time organs can be preserved. This could make it possible to transport organs long distances and improve the chances of a good match.

Using a chemical which contains nitric oxide, scientists have been monitoring the results of replacing the preserving liquid containing glutathione. Tests showed nitric oxide kept blood vessels open, which can also reduce clotting.

Cells lining blood vessels were also protected against harmful free radicals produced by oxygen in the recipient's blood after transplantation, they said. The scientists said preserving this layer of cells - the endothelium - is vital to making sure enough blood flows to the organ after transplantation.

The endothelium releases agents that relax blood vessels and prevent clots forming.

Professor Ian Megson, formerly a senior lecturer in cardiovascular science at the University of Edinburgh, said: "Our experiments so far have been based on analysing the effect of the solution on cultured cells and in isolated blood vessels, but we now hope to investigate the impact in the organs themselves.

"The results so far are extremely promising. Not only do they offer a greater chance of transplantation success, but they also suggest that organs might be able to be kept for longer prior to transplantation. This could facilitate transporting organs internationally for specific donors, improving the chances of a good tissue match."

BBC News 1/12/2007

FACTS ABOUT TRANSPLANTATION IN THE UNITED STATES

On February 9, 2007, the Organ Procurement and Transplantation Network (OPTN) national patient waiting list for organ transplant includes the following:

73,933	registrations for a <i>kidney</i> transplant.	241	registrations for an <i>intestine</i> transplant.
17,428	registrations for a <i>liver</i> transplant.	2,852	registrations for a <i>heart</i> transplant.
1,778	registrations for a <i>pancreas</i> transplant.	134	registrations for a <i>heart-lung</i> transplant.
294	registrations for a <i>pancreas islet cell</i> .	2,883	registrations for a <i>lung</i> transplant.
2,444	registrations for a <i>kidney-pancreas</i> transplant.	101,987	TOTAL REGISTRATIONS

NOTE: OPTN/UNOS policies allow patients to be listed with more than one transplant center (multiple-listing), and thus the number of registrations is greater than the actual number of patients.

* Some patients are waiting for more than one organ, therefore the total number of patients is less than the sum of patients waiting for each organ.

Numbers of Transplants Performed, 2005**

16,476	<i>kidney</i> alone transplants (6,562 were living donors)
6,444	<i>liver</i> transplants.
541	<i>pancreas</i> alone transplants.
903	<i>kidney-pancreas</i> transplant.
178	<i>intestine</i> transplants.
2,125	<i>heart</i> transplants.
35	<i>heart-lung</i> transplants.
1,406	<i>lung</i> transplants.
28,110	TOTAL

Number of Donors Recovered, 2005**

7,593	Deceased
6,896	Living
14,489	TOTAL

During 2005 6,342 patients were removed from the OPTN National patient waiting list for reason of death.**

Gallup Survey Finds Support for Organ Donation

HHS's Health Resources and Services Administration (HRSA) today announced the results of a 2005 Gallup Organization survey which indicates that Americans continue to strongly support the donation of organs and tissues for transplantation. More importantly, the survey also finds that far higher percentages of Americans have taken personal actions to become organ donors since a similar 1993 survey on donation.

The percentage of individuals who have granted permission to donate their organs or tissues on a driver's license or an organ donor card reached 53 percent in 2005, almost double the 28 percent who had done so in 1993. HRSA Administrator Elizabeth Duke urges anyone interested in becoming an organ donor to learn how at OrganDonor.gov. HRSA directs federal efforts to promote donation.

Nearly all of the survey respondents – 97 percent – said they would donate a family member's organs if they knew the person's wishes ahead of time. The 2005 survey reported that 71 percent of Americans had talked to a family member about their donation wishes, up from 52 percent in 1993.

“Make sure you tell your relatives about your intention to donate once you sign up. Sharing your intentions with family members is an important part of the donation process,” Duke added.

Donate Life America Announces New Website

Dear Donate Life America Colleagues and Partners:

It is with much excitement that Donate Life America announces the launch of the new donatelifenet.net and donevida.org web sites. These new and improved sites are designed to further the national brand of Donate Life and Done Vida, educate and inspire the public and parallel the creative direction of the new national campaigns.

Please take time to visit the sites at www.donatelifenet.net and www.donevida.org. We encourage you to notify us of any errors that may have avoided our quality check as we want to ensure that we immediately correct any oversights.

Now go help us put these sites to good use!
Sincerely, G. David Fleming, Executive Director

From Karen Guarino, for C-DOT

New “Compare Drug Plans” Packet from NKF

From the National Kidney Foundation, Beth Witten, Medicare Modernization Program Manager, writes:
The Kidney Medicare Drugs Awareness and Education Initiative updated its Compare Drug Plans packet on February 2, 2007. The current version of the packet includes the 2007 national Part D plans. You can view and print the full packet at www.kidneydrugcoverage.org/choose.htm. 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).

We have also uploaded a chart that lets you see how coverage has changed from month to month. The color green means that more plans cover that specific drug this month compared with last month. The color red means fewer plans cover that specific drug this month. No color means there was no change in the number of plans covering that specific drug from last month to this month. Look for other labor-saving tools, educational materials for patients and professionals, resources or links, and much more on www.kidneydrugcoverage.org. Links to internal pages in the site are underlined and hyperlinked.

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

