

November, December - 2007

[www.tao-rochester.org](http://www.tao-rochester.org)

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## MEMBERSHIP MEETINGS

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

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. Use the Office entrance.

**Deadline for January, February, 2008 *Transplant Times* - Wednesday, December 12, 2007**

**DUE TO A CONFLICT WITH PINNACLE LUTHERAN CHURCH, THE FEBRUARY 20, 2008 AND MARCH 19, 2008 TAO MEETING WILL NOT START UNTIL 7:30PM AND END AT 9PM**

**Wednesday, November 14<sup>th</sup> – 7:00pm**

Please join us Nov. 14 at Pinnacle Lutheran

Church to hear a speaker from H&R Block discuss the NY State 2007 changes affecting the estimated tax. A new subtraction from Federal is available to taxpayers who, while living, donate one or more human organs to another person for organ transplantation. The new subtraction is equal to the cost incurred by the taxpayer, or \$10,000, whichever is less, relating to the taxpayer's organ donation for lodging expenses, lost wages and travel expenses. If you itemize your deductions, you may be able to deduct expenses you paid in 2007 for medical care. You can include any expense you pay for medical care you receive because you are a donor or a possible donor of a human organ. Transportation is included.

**Wednesday, December 5<sup>th</sup> – 3:00 – 6:00pm**

Holiday Party!!!! The Party will be held on the 6<sup>th</sup> floor conference room. This is for both patients and staff. PLEASE ATTEND – WE ALWAYS HAVE A GREAT TIME. ROOM 6-2546

A reminder from the membership chair.....The 2008 Dues notices will be sent out in the next month. Please fill out the dues notice with all information, even if nothing has changed, as I like to make sure I have the correct information. Also, I am resigning as Membership Chair as of June 30, 2008. Please let me know or one of the Board members if you are interested in taking this position over. Please email me at [kidtr0311@aol.com](mailto:kidtr0311@aol.com) or call me if you would like to know more about the responsibilities. Thank you. Laurie Packard

**TRANSPLANT ANNIVERSARIES OF TAO MEMBERS – November, December 2007**

James Spaeth – 11-02-99 Kidney Pancreas  
Jerry Runion – 11-04-94 Kidney Pancreas  
Eric Wright – 11-05-06 Lungs  
Michael Stelljes – 11-06-01 Liver  
Richard Orrvick – 11-09-93 Kidney  
Alice Sceusa – 11-11-03 Liver  
Dean A. Bush – 11-11-03 Liver  
Peter Davis – 11-16-96 Liver  
Donna Crosby – 11-19-03 Liver  
Ronald Goehle – 11-22-01 Liver  
Daniel Newhouse – 11-30-95 Kidney  
Ruth Maines – 12-01-90 Liver  
Larry Buck – 12-06-05 Kidney  
Elaine Kimber – 12-06-05 Kidney  
Ricardo Juswkiewicz – 12-09-96 Kidney  
Beverly Shank – 12-14-05 Liver  
Stephen Odai – 12-15-01 Liver  
Richard Greene – 12-25-00 Liver  
Bonnie Haefner – 12-25-01, 12-14-05 Kidney

*Congratulations! Did we miss yours? Get your date wrong? Please call the editor!  
(Note: this list is members only)*

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**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, Transplant Awareness Organization of Greater Rochester, PO Box 23552, Rochester, NY 14692-3552

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**Keeping in Touch**

Two new members: Maria A. Fiorille, Tom Brown Welcome!!

Ray Riker received his double lung transplant on September 11<sup>th</sup> at Univ. of Pittsburgh. Congrats!

Fundraiser for Heart Patient- A spaghetti dinner will be held as a fundraiser for heart patient Mary Crowley. The dinner will be served at the American Legion in Shortsville on November 9<sup>th</sup>, at 6:30pm. Tickets are \$15 each and may be obtained by calling either Mary's two aunts; their numbers are: 585-289-6871 OR 585-289-6609.

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TOPS never stops.....Helping TAO Raise Money -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 \$25, \$50 and \$100.

### Johnson Wins Award

Our very own David Johnson was presented with the VOLUNTEER SUPERVISOR AWARD at the FRIENDS OF STRONG annual Volunteer Recognition Dinner. The event was held on September 26 in the Sarah Flaum Atrium at University of Rochester Medical Center. The person receiving the award is selected for his/her exceptional skills in training, recognizing and including volunteers as a member of the "team." In 2001, Dave became supervisor of the volunteers in the Visitor/Transplant Program. All of the volunteers in this program have had a transplant and visit patients having the same experience. As supervisor, Dave meets with new volunteers to orient them to the program. He coordinates a volunteer visitation schedule for the ten volunteers in the program. Dave also volunteers on the pediatric inpatient unit, facilitating Bingo for the children. He has been a member of the FRIENDS OF STRONG COUNCIL since 2004. Dave has logged in approximately 1,785 hours of volunteer work at Strong. CONGRATULATIONS, DAVE!!!!Submitted by Sally Stelljes

### Joanne Schum receives the Mary Jane Taylor Distinguished Contributor Award

Joanne is a double lung transplant recipient who was diagnosed with Cystic Fibrosis at age 4, and is now 44 years old. She serves on the Board of Directors for the Rochester Chapter of the Cystic Fibrosis Foundation, The Transplant Awareness Organization, and Lungs for Life. She was the recipient of the 2006 Heroes of Hope award and has written a book titled: Taking Flight: Inspirational Stories of Lung Transplantation. Joanne was honored on October 20<sup>th</sup> at the Crowne Plaza Hotel for the "Roses of Hope" Gala – she was honored for her accomplishments and her never ending spirit of hope. Congratulations Joanne!

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### TRANSPLANT GAMES

WOULD YOU POSSIBLY LIKE TO ATTEND THE GAMES? GET TOGETHER – LEARN ABOUT THE GAMES AND CHECK OUT WHAT IS IN STORE FOR THE TEAM!! PLEASE INVITE EVERYONE YOU KNOW WHO HAD A TRANSPLANT TO LEARN MORE.

On Saturday Nov. 17 we are having a meeting/information seminar at the Bagel Bin on Monroe Avenue to talk to transplant patients about the 2008 Transplant Games. The event is being held 10:30 until ? and we are trying to find people who might be interested in forming a team. If you could pass this along to your groups, it would be very helpful. Any questions can come to me. THANKS SO MUCH Karen Gledhill

National Kidney Foundation U. S. Transplant Games – July 11-16, 2008, Pittsburgh, PA  
The U.S. Transplant Games is a four day athletic competition among recipients of organ transplants. Bone marrow recipients are also eligible to participate. Organ donor families will be in attendance also. For further details, attend the Nov 17<sup>th</sup> gathering.

## Good Morning.

Below is the link to let your Congressperson know how you feel about proposed legislation to extend Medicare funding for immunosuppressive drugs coverage for kidney transplant patients.

1. Current Medicare coverage is for 36 months post transplant.
2. The proposed legislation would provide coverage for the life of the transplant.
3. We are seeking many Congressional co-sponsors to this legislation, to ensure that it has the best chance of moving out of committee. You may forward this link to friends and family living throughout the US to enlist their representatives' support.

Thank you!

Jan Miller

<http://capwiz.com/kidney/issues/alert/?alertid=10141476>

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## BON TON "CARE TO SHARE" day

Bon Ton is having its annual "care to Share" day Saturday, November 10. Doors open at 6 a.m.

Please help the Kidney Foundation's Transplant Team and purchase a coupon book. The books cost \$5.00 For that you get a \$10.00 coupon good for \$10. off anything \$10. or more You also get 8 20% coupons good on anything thru out the store.

Help the Transplant Team raise funds to go to the 2008 Transplant Games next year.

For more information or for coupon books, please call: Bonnie Haefner at 334-7034 or Karen Gledhill at 586-9252

THANK YOU!

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## Thought you Like to Know....

A total of 1,664 new donor designations were entered into the regional registry from January through August 2007. (For 2006 Jan – Dec we had a total of 1563). 45% of these due to health fair attendance and presentations given. Thanks to everyone for making this possible.

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## VOLUNTEER PROGRAM

The volunteer program in transplant clinic celebrated its first anniversary on July 31, 2007. At this time volunteers have seen close to 500 potential transplant candidates. On each patient's evaluation day, he/she is greeted by a volunteer who presents a folder of information containing suggested questions to ask, a directory of websites, info about TAO, an organ donor card, a coupon to be used in the cafeteria and a pen and pad. In addition to Pharmacare, many individuals have made donations of pens and pads to be used in the folders. On clinic days volunteers also have the opportunity to see many transplant recipients as they return for check ups. Many of us have experienced the joy of seeing a patient pre and post transplant and a real connection is made through these contacts. At this time I would like to recognize our very faithful volunteers. They are: Jerry Bluff, Bernice Eblövi, Karen Gledhill, Bonnie Haefner, Frank Imburgia, Ray Lyman, Janice Odenbach, Rich Perez, Bev Shank, Jan Sharp. My husband Mike and I both volunteer in the program also and are very proud to be part of this group of dedicated people who are part of our transplant community. Submitte by: Sally Stelljes.

## TAO-Rochester Board of Directors 2007/2008

Name	Phone	Email	Office	Term Exp.
Karen Gledhill	586-9252	<a href="mailto:kgledhill@rochester.rr.com">kgledhill@rochester.rr.com</a>	Vice President	2008
Karen Guarino	272-7890	<a href="mailto:kguarino@rehpb.org">kguarino@rehpb.org</a>	Rep. Rochester Eye and Tissue Bank	
Bonnie Haefner	334-7034		Board Member	2009
Linda Hicks	275-8306	<a href="mailto:linda_hicks@urmc.rochester.edu">linda_hicks@urmc.rochester.edu</a>	Rep. Dept. of Transplantation, SMH	
David Johnson	889-1346	<a href="mailto:davejohn@rochester.rr.com">davejohn@rochester.rr.com</a>	Treasurer	2008
Sandy McNitt	359-8015	<a href="mailto:sdmcnittot@aol.com">sdmcnittot@aol.com</a>	Board Member	2009
Janice Odenbach	216-9856	<a href="mailto:janiceodenbach@aol.com">janiceodenbach@aol.com</a>	Board Member	2009
Rob Kochik	272-4930	<a href="mailto:rob_kochik@urmc.rochester.edu">rob_kochik@urmc.rochester.edu</a>	Board Member	2009
Jerry Runion	733-3422	<a href="mailto:jgrunion@rochester.rr.com">jgrunion@rochester.rr.com</a>	Board Member	2008
Joanne Schum	671-7635	<a href="mailto:twoluckylungs@juno.com">twoluckylungs@juno.com</a>	Board Member(Times Editor)	2008
Sally Stelljes	245-9579	<a href="mailto:salstell@rochester.rr.com">salstell@rochester.rr.com</a>	Board Member	2009
Dennis Stenshorn	323-1392	<a href="mailto:dstensh1@rochester.rr.com">dstensh1@rochester.rr.com</a>	President	2008
Shelley Whitney	334-8267	<a href="mailto:whitney618@aol.com">whitney618@aol.com</a>	Secretary(Times Editor)	2008
Debbie Yendrzski	377-6028	<a href="mailto:auggieday@aol.com">auggieday@aol.com</a>	Board Member	2009
<b>OTHERS NOT ON THE BOARD:</b>				
Laurie Packard	425-8034	<a href="mailto:kidtr0311@aol.com">kidtr0311@aol.com</a>	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 of Greater Rochester, PO Box 23552, Rochester, NY 14692-3552

- \$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

1104 Bay Road

Webster, NY 14580

