

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

1-888-664-1463

November December 2004

Dave Johnson, President, 585.899.1346

Suzanne McNamara, Editor 585.385.3144

## 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, November 17, 7 pm. Get Your Creative Juices Flowing and Your Body Parts Ready!

The November meeting is almost here and, as usual, it is our membership's favorite. **BODY PARTS!** We have invited members of TAG, our Syracuse counterpart, to join us for this meeting. To add to the fun, we are offering **prizes for the most original transplant/donor awareness t-shirt.** We are looking for a unique design, slogan or phrase.

Design a shirt and wear it, or wear one of your favorites from times past. Enlist your family and friends to come up with a slogan or design. Magic marker your way to "fame and fortune."

As is usually the case, we will separate into groups according to the type of transplant received. Sharing your experiences and talking about your transplant with others who have gone thru the same thing is a great way to learn and realize that you are not alone. We can learn from each other. Medication, side effects, stress, no subject is left out.

TAG, (Transplant Awareness Group), is a group like ourselves formed in Syracuse after separating from TRIO. This group meets on the first Tuesday of each month at 7 p.m. in the Log Cabin Bldg on the NY State Fair Grounds near Syracuse.

### Wednesday, December 8, HO HO HO! It is the TAO HOLIDAY PARTY!

Please join the members of TAO on December 8, starting at **6:30** (please note the earlier beginning) for the annual Holiday Party. As in the past the party will be held at the **Strong Hospital**, in the 6th floor conference room. Take the red elevators to the 6th floor, go toward the 1600 unit and you will see the conference room on your right.

We will be inviting the staff, patients and patients' families to come and enjoy some holiday cheer, as a break from their hospital stay. For those of you who do visitation, please mention it when you are on the floor.

Food and beverages will be provided. We do ask that you again bring a gift consisting of a music CD, cassette tape or AA batteries that we will donate to the transplant unit. New or used CD's are fine. They will be used by the patients in the coming year. TAO, in the past, has donated CD and tape players to the unit.

Park in the ramp and see Dave Johnson at the party for a parking sticker validation.

*Karen Gledhill*

Deadline for January-February 2005 *Transplant Times* - Wednesday, December 8

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

## **TRANSPLANT ANNIVERSARIES OF TAO MEMBERS -November-December**

James Spaeth -- 11-02-99 Kidney  
Pancreas  
Michael Stelljes -- 11-06-01 Liver  
Nicole Seagrave -- 11-08-00 Kidney  
Alice Sceusa -- 11-11-02 Liver  
Dean A. Bush -- 11-11-03 Liver  
Michael J. Swete -- 11-12-95 Liver  
Peter Davis -- 11-16-96 Liver  
Daniel Newhouse -- 10-30-90 11-17-95  
Kidney  
Donna Crosby -- 11-19-03 Liver  
Ronald Goehle -- 11-22-01 Liver  
Ruth Maines -- 12-01-90 Liver  
Larry Buck -- 12-06-00 Kidney  
Fred A. Gilman -- 12-08-96 Kidney  
Vene(Skeeter) Todd -- 12-09-96 Liver  
Ricardo Juszkiwicz -- 12-09-96  
Kidney  
Susan Moody -- 12-14-92 Bone  
Marrow & Kidney  
Stephen Odai -- 12-15-01 Liver  
Richard Greene -- 12-25-00 Liver  
Bonnie Haefner -- 12-25-01 Kidney  
June Vargo -- 12-27-95 Liver  
*Congratulations! Did we miss yours?  
Get your date wrong? Please call!  
(Note: this list is members only)*

### **In Memoriam**

We have lost two members this fall. Word has been received that Bill Finney and Charles Lochner have died. Our sympathy to their families.

We will miss them both.

### **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

**Correction:** Donna Crosby **received** part of her liver **from** her son, Patrick.

### **Welcome to New Members**

Rita Lesnick, Family member  
Keith Oliver, Liver  
Jerry Runion, Kidney  
Welcome!

### **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.

### **Tops Discontinues Tapesaver Program**

Tops Supermarkets has announced a new program for non-profits to raise funds. As a result of their new program they are discontinuing the tapesaver program. They will no longer accept tapes after January 1, 2005. Linda Barnard will continue to accept tapes until December 15, 2004, as she needs time to collate the tapes and turn them in. If anyone has tapes lying around please get them to Linda ASAP.

Tops' new Gift Card Program for non profits will be discussed at the next board meeting to see if it is something TAO wants to do. Checks have been received this year from Tops receipts and aluminum tabs for a total of \$390.

### **GRANTS FROM TAO**

Each calendar year TAO makes a donation between \$500 and \$1000 to a worthy cause. The donation alternates between a research cause and the Transplant Games. Since 2004 was the Transplant Games it is time to decide on a research cause for 2005 of interest to our group. The last research donation was to U of R for kidney research. Please bring your ideas to the next meeting or make your thoughts known to one of the board members.

*sally/mike stelljes*

## Attention Transplant Athletes!

The Fifteenth WORLD Transplant Games will be held July 16-24, 2005, in London Ontario, Canada. For more information, go to [www.2005wtg.london.ca](http://www.2005wtg.london.ca)  
From the website:

“The competitors are unique in that each one of them is alive as a result of a successful organ transplant. Competitors must be medically fit with no significant complications of chronic organ failure or immunosuppressive therapy. World Transplant Games’ competitors demonstrate the level of health and vitality that can be achieved after transplantation. The Games embrace all ages, anyone from 4 - 80 years old who have received a life-support organ transplant more than one year before the Games.”

## About the Games

The World Transplant Games have been in existence for over 25 years when the first 'Transplant Olympics' were held in 1978. At that time, these Games were an international event and included teams from France, Germany, Greece, and the United States. Since the first Games that included slightly less than 100 competitors the Games have grown exponentially. The International Summer Games are held every two years. In Nancy, France in 2003 there were some 1,500 competitors from 55 countries taking part.

There is a group of Upstate NY Transplant Team Members and other recipients and donor families in the area that are interested in attending these games.... .please email or call Joanne Schum to get your name on the mailing list for details as they formulate. phone: 585-671-7635

## Health Fair and Presentation Schedule

Volunteers are needed to help staff the public education display, or to accompany an agency representative to schools / other group meetings.

If you are interested in volunteering, please contact Karen Guarino or Julie E. Ward-Roth at (585) 272-7890 or 1-800-568-4321.

On Friday, Nov. 5th the Annual Wellness Fair sponsored by the **Brighton Central School District** & the Town of Brighton will be held at the Brighton HS Gymnasium. This Health Fair will run from 10am - 1:30pm.

On Saturday, Nov. 6th **Red Creek School** is hosting a PTA Community Health Fair from 9am - 1pm. It will be held in the Community Center (which is attached to the school). Red Creek is East of Wolcott.

Another Health Fair on Saturday Nov. 6th is the Sector 9 Neighborhoods Wellness Project. This is the first annual Health Fair in this community. It will be held at the **Carter St. Recreation Center** at 5002 Carter St. They expect about 500 people. This fair will run from 11am - 3pm.

**SUNY Brockport REOC Student Health Fair, Fri. Dec. 3, 9 am - 1 pm**

### Presentations

Schools are beginning to call to schedule class presentations. If you are interested in sharing your personal story with students from grades 5 through college level, we need you! Time and time again teachers tell us that students appreciate and learn much from your personal stories.

**Your New Kidney: An Owner's Manual**  
**(A Guide for Kidney Transplant Recipients)**

Have you or someone in your family had a kidney transplant? Join Upstate New York's Kidney Foundation for this informative program with speaker, Dr. Martin Zand, M.D., Ph.D., the Director of the Kidney/Pancreas Transplant Program at the University of Rochester Medical Center. Learn what tools you need to keep your new kidney operating at peak performance; blood pressure and cholesterol controls, immunosuppressive medication compliance, good preventative medicine practices, routine care of common illnesses—coughs cold and the flu, talking to your primary care physician about your special needs, and the key role your emotional health plays.

Sunday, November 7, 2004 from 1:30-3:00 PM  
Academy of Medicine Auditorium, 1441 East Avenue,  
\$5 Suggested donation per transplant family.

To reserve your spot please call the NKF at 697-0874 X30 or email [kidneyinfo@kidneynyup.org](mailto:kidneyinfo@kidneynyup.org)

*Shelby Page, Communications Director, National Kidney Foundation of Upstate New York*

As all of us are out and about, sharing personal transplant stories, staffing a display at a health fair, or presenting to a group, here are some terms that explain, in a sensitive, appropriate way, donation practices. More and more we hear these terms used in both public and professional arenas. *Karen Guarino, Rochester/Finger Lakes Eye & Tissue Bank*

**Appropriate Terms**

"Recover" organs & tissues  
"Deceased" donation "  
"Mechanical/Ventilator" support

**Inappropriate Terms**

"Harvest" organs & tissues  
Cadaver/Cadaveric" Donation  
"Life" support

**BARNES AND NOBLE WANTS US BACK!**

Because of our excellent wrapping abilities (??), we have again been extended an invitation to use our gift wrapping talent at the Barnes and Noble stores in the area. Besides raising extra funds, these gift wrapping sessions provide TAO an excellent way to get exposure for our organization and promote the need for organ donation.

As in the past we will have many slots to fill, so if you have any time at all, please lend us a hand. In Greece, the dates are Fri., Sat., Dec. 10, 11, 10 am to 10 pm. In Pittsford Plaza, Sun. Dec. 12, 10 am - 8 pm, and Tue., Dec. 14, 12 - 10 pm  
*Call Dave Johnson, 889-1346.*

**E-Mail Addresses Needed**

In an attempt to update our database and send out important information electronically, we are asking that any member of TAO that has an e-mail address, please send it to me. We will keep them for TAO

use only. We are hoping to use this information to send you meeting notices and organ and tissue news. We will investigate using a group mail list. Thank you in advance for your help. Please send your e-mail address to: [vp@tao-rochester.org](mailto:vp@tao-rochester.org).

**“The Gift of a Lifetime” Website**

*From Paul Meigs of TAG, the Transplant Recipient Organization in Syracuse:*

<http://www.organtransplants.org> is a comprehensive web resource about organ and tissue donation. The site chronicles the stories of patients awaiting transplants and donors of life-saving organs and tissues. It also contains resources for teachers and students including the Flash animated "Interactive Body," a "History of Transplantation," and information about brain death, myths and common questions, information about becoming a donor and more. The Gift of a Lifetime is sponsored by the national Coalition on Donation.