

www.tao-rochester.org

1-888-664-1463

March, April, 2005

Dave Johnson, President, 585.899.1346

Suzanne McNamara, Editor 585.385

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, March 16, 7 pm. Pat Milot, Nurse Manager at Strong, will discuss "Liver Transplantation: Past Accomplishments, Future Challenges."

Friends of Strong Presents "To Your Heart's Content"

Saturday, March 19th, 2005 the Friends of Strong will host the event of the year. "To Your Heart's Content", a fashion show and auction to benefit Cardiac Rehabilitation at Strong Memorial Hospital. The event will feature some of "Strong's finest" nurses, administrators, doctors and surgeons from Cardiac Rehab modeling in the show.

Fashions will be by Lavant Garbe and Mentality, Lori Scott's new men's shop. Immediately following the show will be a live auction and live music by Bob Henry and the Goners for your dancing pleasure. For more information and tickets call 275-2420

Deadline for May-June 2005 *Transplant Times* -
Wednesday, April 20

Wednesday, April 20, 7 pm Dr. Richard Demme, will discuss: "An Overview of Ethical Issues in Transplantation." Dr. Demme is Associate Professor of Medicine and Humanities at the University of Rochester Medical Center. He is chair of the Strong Health Ethics Committee, sits on the Transplant Quality Council and is a member of the Independent Donor Advocate Team for the Living Donor Liver Transplant Program. Dr. Demme is a nephrologist who works with dialysis as well as kidney transplant patients. Besides his interest in medicine and ethics, Dr. Demme enjoys music and is a member of a trio that will be singing at the Kidney Foundation Touchathon..

Hornell VFW to Hold Dinner for Transplant Team (and anyone else)

Kim Wood, a very very active donor family member (she was a team member and donor family liaison at the 2002 and 2004 Games) will be hosting a dinner honoring the 2004 transplant team, donor families, family members and interested people at the Hornell VFW 6 pm, Saturday, April 9th. Members of the team will speak of their experiences at the Games. We will car pool to the dinner and back the same night. April is Organ Donor Awareness Month and what better way to celebrate than to have the community of Hornell see the miracle of transplantation. If you are interested, or have any questions, please RSVP to Joanne Schum at twoluckylungs@juno.com or call Karen Gledhill at 585-586-9252.

TRANSPLANT ANNIVERSARIES OF TAO MEMBERS - March, April.

Michael Gerchman -- 03-01-98 Liver
Ralph Toscano -- 03-01-89 06-01-90 Cornea
Laurie Packard -- 03-11-91 Kidney
Paula McKay -- 03-14-95 Kidney
Cynthia Boyer-Green -- 03-14-96 Kidney
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 -- 04-06-92 Liver
Penny Sayles -- 04-09-98 Kidney
David Berndt -- 04-12-02 Liver
Linda Marie Serenka -- 04-14-01 Kidney

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

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.

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

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

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. A committee has been formed to explore transplant related research projects in our area. Contact Linda Hicks or Penny Sayles with your ideas.

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.

In addition, we would like to thank LINDA BARNARD for being the Tops Tapes Lady for so long. She did an excellent job and we thank her for all her effort!

check our website www.tao-rochester.org

New York Alliance for Donation Legislative Education Day

Five people from the Rochester area and four from the Syracuse area traveled to Albany on Tuesday, February 16 to participate in lobbying efforts on behalf of the New York Alliance for Donation. Annette Curtis (Donor Recovery Network), Karen Guarino, Karen Gledhill and Sally and Mike Stelljes were joined by TAG members Paul Meigs, Ken Alt, and Liz and Katie Koagel. Katie is a ten year old who received a heart transplant at the age of nine months so it was a very heart-warming experience to spend the day with her.

We left Rochester at 5:15 am and had our first legislative appt. at ten o'clock. In some situations we met with legislative staff but we were successful in talking with Assemblyman Dan Burling and Assemblyman Jeff Brown. Staff members from the offices of Senators Dale Volker, James Wright, John DeFrancisco, Jim Alesi and Assemblyman David Townsend spent time with us discussing our agenda issues.

Topics for the day included requests for the following:

- Reinstitution of the \$250,000 into the state budget to be used for enhancement of professional education for physicians and public education about organ and tissue donation through state-wide radio spots.
- Support of legislation to revise the NYS Anatomical Gift Act to conform to changes in the National Uniform Anatomical Gift Act which allow individuals to make a direct donation of an anatomical gift without requiring two witnesses. This will allow NYS residents to establish their consent to donation with their signature alone like 39 other states currently allow.
- Support legislation to establish the dollar donation option for the NYS Life Pass It On Trust Fund to provide a source of ongoing funding for organ and tissue donation awareness and education efforts. This legislation will allow New Yorkers the option to donate a dollar at the time of renewal or receipt of a driver's license or non-driver ID card. A review of other states' experiences reveals a significant generation of funds from this program and NY must establish this plan.
- Support legislation to allow taxpayers in NY to check a box on the NYS Income tax form and donate one dollar to the Life Pass It On Trust Fund.
- Encourage the Dept. of Education to implement a requirement whereby the background on organ and tissue donation, as well as transplantation info, be incorporated in the curriculum of all students in health education and/or biology classes.

People in the legislative offices were anxious to hear stories from recipients and much valuable information was conveyed. After stopping for dinner in Herkimer and dropping off Syracuse folks, the Rochester contingent arrived home safely around ten p.m. It was a day to be remembered as we spent time with so many people who value each day as a gift.

Sally Stelljes

TAO GOALS

- To act as a support group for transplant candidates, transplant recipients and their families.
- To provide education and information on transplantation and the issues that surround it.
- 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.

World Transplant Games Opening Ceremony—Anyone?

A once in a life time event is coming to our area! The World Transplant Games are going to be celebrated in our area this summer. In the past, the World Games have been presented in Australia, England and various locations in Europe. This summer the World Games will take place in London, Ontario, Canada.

The Opening Ceremony will be Sunday, July 17 at the John La Batt Center—a 9000 seat indoor entertainment complex in London. Transplant athletes from the countries of the world will take part in the Opening Ceremony, as well as donor families. The Opening Ceremony is always a great event, as any one who has attended the US Transplant Games can tell you.

I am trying to gauge interest in chartering a bus for a day trip to the WORLD Games Opening Ceremony. The event tickets are free but have to be requested by mid-May. The cost of the trip would depend on the cost of the bus. If you are interested in attending, please e-mail me at ksgledhill@aol.com with the number of people that would be interested in going.

It is really an event that you will long remember.

Karen Gledhill

US Transplant Games - Ready for 2006?

The Transplant Team needs YOU!

The Transplant Team is looking for YOU! We are looking for existing and new members. If you have had a transplant (any kind, except hair 8~)), you are eligible to become a team member. It is that easy! Athletic ability is a plus, although not necessary. There are all levels of competition, from the amateur to the hard-core competitor.

Some of the sporting events that are offered at the Games include: badminton, basketball, bowling, cycling, golf, racquetball, swimming, table tennis, tennis track and field, race walking and baseball toss. The Games are about more than just winning, they are about camaraderie of your fellow participants and to show the world that transplantation works. The games are the largest gathering of its kind, showcasing the success of lifesaving organ transplantation.

Team Upstate New York has, in the past, been one of over 50 teams that have participated at the Games from throughout the United States. The next Games are scheduled for the summer of 2006 but we are starting the search for team members now! Our goal has been to bring more team members this year. If you are interested, please call Karen Gledhill at 586-9252.

Come join us for Spring Fling!

I am pleased to announce the first FUNdraiser for the 2006 Transplant Team. It is an evening that will feature refreshments, FUN!, entertaining, FUN, offer raffles, FUN and chocolate! The cost is only \$10. a ticket* (*and you get soooo much for your money!)

TAO in conjunction with Kaufmanns at Eastview Mall is sponsoring a SPRING FLING! Tuesday, April 12, Kaufman's will close their Eastview store to the general public starting at 6 p.m. Only those with tickets will be allowed in.

Attached to your ticket is a 25% off shopping pass for that evening. Anything that you purchase is an additional 25% off. There will be prizes and raffles thru out the store. By showing up at the store, you are automatically registered to win a \$1000. shopping spree. The evening will be packed with fashion shows, cooking demonstrations by the top chefs in the area, gardening and decorating tips, floral hints and workshops on accessories, make-up and more!

Tuxedoed waiters will be serving appetizers, wine tasting will be available from the New York State wineries. There will be desserts, a chocolate fountain and entertainment! It is an evening not to be missed.

Karen Gledhill at 586-925.