

www.tao-rochester.org

1-888-664-1463

September October 2004

Dave Johnson, President, 585.899.1346

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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

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, September 22, 7 pm. TAO's new season, new president and new adventure about to begin.

Now that you have gotten the kids safely back to school, and you have time on your hands (ha), it is time again to think about attending the monthly TAO meetings.

The first meeting of the new season will take place **Wednesday, September 22**. This meeting is our annual "Welcome Back" meeting. See old friends, meet new ones, greet your new president **Dave Johnson** and find out details about the programs for the 2004-2005 season.

The meeting will include **members of the Transplant Team** and their families who will talk about their experiences at the **Games** this summer in Minneapolis. We will have **Karen Guarino** speak on her perspective as a professional attending the games. We will also have one of the **Donor Families** talk about the games from their perspective.

Please join us. It should be entertaining and informative. Don't miss it!

TAO will be sponsoring a booth @Strong Pediatric Family Support Resource Fair to be held on Tuesday, **September 28**, from 4:00 pm until 7:00 pm. The Resource Fair is being sponsored by Golisano Children's Hospital and will be held in the Six Nations Cafeteria, at Strong Memorial Hospital. The fair is being planned to reach out to the community and raise awareness of available resources.

Wednesday, October 20, 7pm "Living donor kidney program." Dr. Martin Zand, MD, PhD, Associate Professor of Medicine, Medical Director of the Kidney Pancreas Program at Strong Memorial Hospital.

National Donor Sabbath Weekend, November 12-14, 2004. See page 5.

Deadline for November - December *Transplant Times* - Wednesday, October 13.

check our website www.tao-rochester.org

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

Smita Jayakar -- 09-16-99 Liver

Esther Dieter -- 09-21-96 Kidney

Kathleen McClelland -- 10-01-02 Liver

Suzanne McNamara -- 10-01-93 Heart

Michelle Halloran -- 10-09-97 Kidney

Armett Shepherd -- 10-16-00 Kidney

Susan Bennett -- 10-19-98 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!

(Note: this list is members only)

In Memoriam

We have lost two active members over the summer.

Walt Bossert, our former Treasurer, died July 19. TAO sent a gift to the American Diabetes Association.

Jean McDade died in early June. Jean was an active member who participated enthusiastically in our discussions.

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

The following people have recently made donations to TAO:

Mary Ellen and David Baxter

Dick and Suzanne McNamara, in memory of Walt Bossert

Welcome to New Members

Jake Robinson, Kidney, Strong

David Berndt, Liver, Strong

Donna Christy, Liver, Strong

Donna & Thomas Crosby, Donna donated part of her liver to son Patrick, Strong

Bernice Eblovi, Liver, Strong

James Blake, Liver, Strong

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.

Saving Tops Tapes and Pop Tabs

Please remember to save the cash register tapes when you go shopping at Tops Friendly Markets. Linda Barnard collects and counts them and turns them in periodically. A nice portion of our budget comes from this source. Linda is collecting pop tabs from aluminum cans. Bring tapes and tabs to the meeting, or mail them to Linda Barnard at 281 Guinevere Dr. Rochester NY 14626.

Girl Scout Troop Continues to Help TAO

Amanda Packard, daughter of Laurie Packard (our Membership Chair), and her Girl Scout Troop 201, continue to help TAO by savings Tops tapes and pop can tops. This past year they have saved over \$7000 worth of tapes and 68 pounds of pop can tops. There are approximately 1700 pop can tops per pound, so you can see that is a lot of pop can tops. Thanks you so much for your support!

Donate your car to TAO

Like an old friend, your "slightly used" car can be considered part of the family. As such, you want to ensure that when its days are near the end, it is taken care of. Your old car, boat or trailer can help TAO and our fund raising efforts. May we suggest you contact Insurance Auto Action, They will arrange pick up, vehicle and send auction the TAO their portion. It sounds simple. It is. Keep it in mind!



Local Athletes Participate in 2004 US Transplant Games

The 2004 US Transplant games were held on July 27th through August 1st at the University of Minnesota in Minneapolis. 14 transplant recipients from the Upstate NY area participated in the games, as well as 2 donor families.

Team Upstate NY began preparing for the games last summer by raising funds to pay the expenses of the games participants. We held 2 golf tournaments, a Fast Ferry raffle, a SuperBowl Party, a Euchre Tournament, a Bowling Party, and a topless car wash (it was not a pretty sight!). Funds were also obtained through donations by many team sponsors.

The trip to Minneapolis was fairly smooth and enjoyable. The one minor glitch was that I found out I somehow made the TSA's "Do Not Board" list. After a few phone calls, and verification of my passport, I was allowed to board. After arrival at Minneapolis and hotel check-in (half stayed at the Holiday Inn, half at the Day's Inn) we proceeded to registration, where we got to stand in line for 2 ½ hours. After registration we proceeded to the vendor's area to pick up our freebies from the drug companies. Neat stuff, but no drugs.

Wednesday was mostly a free time and those who registered the day before got to explore Minneapolis. Some went to the Mall of America, some the Minnesota Zoo, and some took the city trolley for a tour of downtown Minneapolis. That evening was the opening ceremonies at the Hubert H. Humphrey Metrodome. This is the home of the Minnesota Twins and Minnesota Vikings. The theme of this year's games was the celebration of the 50th anniversary of the first kidney transplant. The first successful kidney transplant was performed at Peter Bent Brigham Hospital in Boston in 1954. The medical team of doctors Joseph E. Murray, John Hartwell Harrison and John P. Merrill performed the transplant on identical twins.

After some opening remarks, the athletes paraded onto the field by team, beneath arches stating "DONATE LIFE", displaying to the world that "Transplantation Works". The parade of athletes

included moose heads and cows, hard hats, straw hats and Native American headdresses, showgirls and playing cards, Liberty Bell hand puppets and pennants. After the walking across the field the teams proceeded to their seats in the stands. This was followed by the most moving part of the night, the parade onto the field of the donor families. The friends, family and athletes in the stands were on their feet, and it was a very lengthy standing ovation as the donor families took their seats. The speeches were important too. MC Ken Howard spoke and introduced the other speakers. These included co-host Jim Cunningham, President Bruiniks from the host University of Minnesota, Governor Tim Pawlenty, Fred Brown and Dr. Brian Pereira of the National Kidney Foundation, Dr. Joseph Murray, Sean Elliott, Larry Hagman, Brian O'Callaghan of Novartis Pharmaceuticals Corporation, the title and founding sponsor of the U.S. Transplant Games, and Father Patrick Sullivan. Perhaps the most moving speeches were given by donor mom Jean Janohsky and Jimmy Lynch, recipient of Allen Janohsky's kidney and pancreas. As Lynch simply put it, "You are our heroes."

During Thursday, Friday and Saturday Team Upstate NY participated in various athletic events, including swimming, bowling, badminton, basketball, golf, cycling, track and field events, and volleyball. (My apologies if I omitted any events). Everyone did well in their events, and luckily there were no serious (ahem) injuries. Team Upstate NY took 3 medals, one Gold, one Silver, and one Bronze. Some highlights:

Karen Gledhill – gold medal – Women's 50m Breaststroke

Tom Jansen – silver medal – Men's 1500m run

Tom Jansen – bronze medal – Men's 800m run

It should also be noted that Karen finished 4th in Women's 20K cycling, despite a sore back (butt). And Bonnie Haefner made a jump shot from the top of the key in basketball that had the crowd electrified!

Friday night the team took a trip to Dinkeytown, a several block area near the U of M campus. There was supposed to be a street festival in honor of the games, but apparently Dinkeytown didn't get the

word. It was an educational experience though. Linda Barnard finally learned the difference between a roach clip and a bong. We left Dinkeytown just as the police arrived.

Saturday night was the closing ceremony at the Minneapolis Convention Center. Jim Cunningham was the MC and congratulated all the participants. Leslie Morrison, Transplantation Specialist for Novartis who is also a kidney transplant recipient, presented the Mickey Mantle Award – which recognizes the transplant athlete who has overcome great challenges to participate in the Transplant Games – to Kathy Miller. Among other things, Miller recently developed adult respiratory distress syndrome, which required her to undergo rehab to relearn basic life skills such as talking, eating, and walking. Former Olympic Track star Carl Lewis also spoke, noting the excellent organization and logistics of the game. He apparently didn't ride the shuttle buses. The ceremony was closed with a benediction from Father Naughton of Team Alabama and the extinguishing of the flame.

Following the closing ceremony was the final games party. The theme of the party was “dancing through the decades”. Participants were encouraged to dress up in period clothes, and there were many tie-dyed shirts and poodle skirts in sight. And a roach clip. Several bands played period music and cars from each decade were on display. Dinner commemorated the invention of the TV dinner. It was served on an aluminum compartment platter, with your choice of Turkey and dressing or Salisbury steak. It wasn't too bad either.

Sunday we attended a Minnesota Twins game at the HHH Metrodome and had a great time. It was an exciting game, with the Twins beating the Boston Red Sox 4-3. Afterwards some of the team went to the Minneapolis Rib Festival. You could tell who went by the BBQ sauce on their shirts.

A special mention goes to the individuals and organizations that sponsored Team Upstate NY, allowing us to attend these games. They include TAO of Rochester, the Finger Lakes Donor Recovery Network and Rochester Eye and Tissue Bank who provided the uniforms, Strong Health

Solid Organ Transplantation Dept., Preferred Care, the National Kidney Foundation of Upstate NY, TLF Graphics, KB Graphics, Inc., Pizza Hut, Proietti's Italian Restaurant, Jet Black Sealers, The Mug, Dave & Marcia Johnson and Janice Odenbach.

A special thanks goes to those individuals that worked hard to organize and coordinate the team. Jerry Runion worked long and hard organizing 2 golf tournaments as well as acting as our first team manager, and subsequently was unable to attend. Dan Newhouse assumed the thankless job of team manager and spent considerable time and effort coordinating lodging, transportation, registration, and generally absorbing abuse. Also to Joanne Schum, who acted as team secretary taking numerous minutes and sending out reminders. And to Sean Costello, our team captain. I'm not sure what he did, but he was an inspiration to us all.

The next US Transplant Games will be in the summer of 2006. Several rumors were floating around about location, the most often mentioned was Pittsburgh. But who knows. Mark your calendar now, and plan to attend. We need more athletes!!

Dave Johnson

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
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.”

Ninth Annual National Donor Sabbath: November 12 – 14, 2004

The Council for Donation of Organs and Tissues (C-DOT) will be sending out Donor Sabbath packets to places of worship in the Rochester and Syracuse regions encouraging participation in recognizing this interfaith event. Included in the packets will be sample bulletin/newsletter inserts, donor pledge cards, reading samples for sermons, and examples of how to participate.

How Can You Help?

- Ask your place of worship to participate during National Donor Sabbath.
- Deliver a packet of information personally (call Karen Guarino, 1-800-568-4321, to receive one)
- Ask to speak during worship, or at coffee hour about your personal transplant experience
- arrange and staff a display at your place of worship (materials and donor cards available by calling Karen Guarino)

There will be a listing of places of worship to receive Donor Sabbath packets at the next TAO meeting. You are asked to review this to make sure your place of worship is represented. Or, call Karen Guarino to make sure.

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 at (585) 272-7890 or 1-800-568-4321

Health Fairs

- Wed., Sept. 15 SUNY Brockport
- Thurs., Sept. 23 Kodak Global Logistics
- Fri., Sept. 24 Ortho-Clinical Diagnostics
- Sun., Oct. 3 West Webster Fire Dept. Open House
- Wed., Oct. 6 Bausch & Lomb, Rochester, NY
- Thurs., Oct. 7 2004 Family Health and Fitness Fair at the Dome Center
- Tues., Oct. 19 Seneca County Self-Insurance, Waterloo, NY
- Sat., Oct. 30 Soldiers & Sailors Memorial Hospital Community Health Fall Fest, Penn Yan, NY

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.

New License Plate for New York

The Department of Motor Vehicles Commissioner has announced a new custom license plate “Life - Pass It On” to benefit organ and tissue donation and research.



The initial cost for the new license plate with a number assigned by the DMV is \$43, with an annual rental renewal fee of \$25. A personalized version with the motorists choice of two to six characters, including spaces., is available for \$68, with an annual renewal fee of \$50. The annual renewal fee is in addition to the regular registration fee is billed every two years in every case, \$20 of the annual renewal fee will be deposited to the credit of the Life Pass It On Trust Fund, overseen by the Department of Health.

This plate is available to anyone who has a passenger or commercial vehicle registered in New York State. To order your “Life - Pass It On” license plate, visit any DMV issuing office, DMV’s website at www.nvsdmv.com or call the DMV Custom Plates office at 518-402-4838, Monday thru Friday, 8-4:30 pm.

Rochester Eye & Tissue Bank, Finger Lakes Donor Recovery Network - New Collaboration

The Rochester Eye & Tissue Bank and the Finger Lakes Donor Recovery Network are collaborating in an effort to raise awareness about organ, eye and tissue donation and to increase participation in local donor registries.

The nonprofit organizations have for many years worked together to educate the public about organ and tissue donation, says Linda Fraser, executive director of the Rochester Eye & Tissue Bank. "This is a collaborative arrangement that combines our resources to advance our missions."

"This partnership further strengthens our existing alliance and allows us to operate more efficiently to educate about donation and register potential donors," says Robyn Kaufman, executive director of the Finger Lakes Donor Recovery Network, a part of the University of Rochester.

In addition to hosting cooperative educational programs for community, church and school groups, as well as attending health fairs and community events, a joint brochure and donor card was developed to reduce confusion with the public regarding agencies working in organ and tissue recovery. Additionally, the agencies have combined their volunteer training programs and are exploring other ways to reduce duplicate efforts.

The Rochester Eye & Tissue Bank also will assist the Finger Lakes Donor Recovery Network by including FLDRN's database of pledged donors a resource that is considered when an individual dies and is eligible to donate organs and tissue. Finger Lake's database contains 8,000 names of western and central New York residents, while the Eye and Tissue Bank's database contains 86,000 names.

The Rochester Eye & Tissue Bank, a nonprofit agency established in 1952, recovers and distributes eyes, musculoskeletal, skin and cardiovascular tissues for transplant, medical education and research. The agency serves the NY counties of Monroe, Livingston, Wayne, Ontario, Seneca, Yates, Steuben and Schuyler, as well as North Central, PA.

The Finger Lakes Donor Recovery Network covers 19 counties with a population of 2.4 million, and serves 44 hospitals and the University of Rochester Medical Center and SUNY Upstate Medical University transplant centers. Last year the program bested its five-year average in terms of number of organ donors recovered.

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.