

Transplant Times

NEWSLETTER OF THE TRANSPLANT AWARENESS ORGANIZATION OF GREATER ROCHESTER



www.tao-rochester.org

1-888-664-1463

March, April, 2006

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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 Sigi Winton Rd. Annex

3399 S. Winton Rd., south of Jefferson Rd.

Enter from the back parking lot - go to the cafeteria

Wednesday, March 15 - 7 pm

Transplant Games

Marcia Johnson, Team Manager, Team Upstate NY, will speak about the current status of the transplant team and the US Transplant Games. The U.S. Transplant Games is a four-day athletic competition among recipients of organ transplants. The Games will be held Louisville KY in June. Competition in the U.S. Transplant Games is open to anyone who has received a lifesaving solid organ transplant-- heart, liver, kidney, lung, and pancreas. Bone marrow recipients are also eligible to participate. As much as the Games is an athletic event that calls attention to the success of organ and tissue transplantation, it is also a celebration of life among recipients, their families and friends. At present we have at least 23 people going to represent the Rochester area.

Wednesday, April 19 - 7 PM

Skin Cancer and Immune-suppressed Patients

Marc D. Brown, MD is a Professor of Dermatology and Otolaryngology and the Director, Division of Dermatology Surgery, Oncology, and Mohs Surgery at Strong Memorial Hospital. Dr. Brown's main interest is in the diagnosis, treatment and prevention of skin cancers and his practice is restricted to patients with skin cancer. Dr. Brown will speak about dermatology issues facing immunosuppressed transplant patients.

Deadline for May - June 2006 *Transplant Times* - Wednesday, April 12

Elections to Be Held

As stated in the TAO by-laws, TAO needs to hold elections again this spring. This allows TAO to start a new year with a new slate of officers to better serve our group. We have a committee looking for candidates to serve on the TAO Board of Directors. We are also looking for candidates for president, vice president and secretary. If you are interested please let Karen Gledhill or Sandy McNitt know.

The Board has monthly meetings, the Wednesday before the membership meeting, to plan the agenda, the speakers and address any issues that may come up. *Karen Gledhill, 586-9252, and Sandy McNitt, 359-8015.*

TRANSPLANT ANNIVERSARIES OF TAO MEMBERS - March, April

Jan Sharp -- 03-01-05 Kidney
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 -- 04-06-02 Liver
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)*

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

Karen Guarino Presents Report at National Communication Summit

Karen Guarino of Rochester Eye and Tissue Bank recently presented at the first national communication summit, on the successful partnership between RETB and Finger Lakes Donor Recovery Network to increase the number of people who sign pledged donor cards. The "Regional Donor Registry" partnership began in April 2004 and last year rose from 859 donor cards to almost 1200.

The summit, titled "Finding Common Ground," is a program of the Association of Organ Procurement Organizations, the national Coalition on Donation and HRSA (Health Resources Services Administration) - all of whom are committed to working together to increase organ and tissue donation.

Robyn Miller

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

Telephone Committee Needs Help

We are continuing to add members, and that means we need more people to make reminder calls. Sandy McNitt and Paula McKay coordinate this responsibility. They say that callers spend about ten minutes each month on their reminder calls. Contact Paula pmckay73@rochester.rr.com or 436-9032 or Sandy at sdmcnittot@aol.com or 359-8015.

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.

check our website www.tao-rochester.org

Patient Survey: Cancer Risk After Transplantation

From the National Kidney Foundation

Dear Transplant Recipient,

The National Kidney Foundation (NKF) seeks your help to improve education for transplant recipients. We invite your participation in a short survey that you can complete at home.

Background:

NKF has launched a study that will help us plan and develop effective educational information for future transplant patients. In particular, the study focuses on the education about cancer as a possible long-term risk of organ transplantation. The NKF is also interested in how well informed patients are of this risk when they are considering joining the transplant waiting list.

How It Works:

We will send you a brief survey in early April that asks you to share your opinions and experiences with us. You can complete it by mail or over the Internet. Either way it should only take you about 10 minutes to complete. Your answers will be anonymous and reported only after grouping them with answers from others.

Why You:

You have unique opinions and experiences that need to be included in this study. Your responses can help us better understand what has happened in the past regarding pre-transplant education about cancer risk, so we can make things better in the future. You do not have to have had cancer to participate in this study you only need to have had a transplant.

What You Need To Do:

In order to send you a survey we need either your mailing address or e-mail address by MARCH 17. Please send an email to transplantsurvey@kidney.org indicating whether you would like to receive the survey by email or regular mail. If you prefer regular mail, please provide your name and mailing address. This information will only be used to send you the survey. It will then be destroyed.

Thank you in advance for your participation in this important study . The results will be widely publicized and we will include a summary report on the NKF Web site in summer 2006.

Catherine Paykin, MSSW
Transplant Services Program Director

Gen Coorey, RN, BSN, MA(Ed)
Global Activities Director, Kidney Learning System (KLS™)

Finger Lakes Donor Recovery Network Data 2001-2005

Sample data tables and charts.

FLDRN Donors Over Five Years

2001	2002	2003	2004	2005
48	29	41	53	53

FLDRN Total Organs Recovered

2001	2002	2003	2004	2005
123	90	172	179	194

Regional Donor Registry Signed Pledge Cards

2004	1029
2005	1193

The "Regional Donor Registry" is a partnership between Finger Lakes Donor Recovery Network and Rochester Eye and Tissue Bank. It started in April 2004.

**The National Kidney Foundation of Upstate NY
Presents A
Euchre
Tournament
For the benefit of sending Team Upstate New York to
the 2006 US Transplant Games**

Sunday, February 26, 2006

Tournament 2 pm – 6 pm

Registration 1:30 pm

The Village Pub (formerly the Mug)

3240 Chili Ave. (Chili-Paul Plaza)

Price \$20

-- Advance ticket sale only --

Snacks, soda, pizza included in price of the ticket.

Prizes awarded to top 3 scorers. Raffle during the afternoon.

If you don't play euchre, you can support the team, come for snacks and participate in the raffles, by purchasing a ticket for \$10

Contact Teri Morganti 349-0442 or Marcia Johnson 889-7565

Rules for tournament play:

1. No partners, individual play
2. There will be 8 games played at 15 minutes each game. After game 4, we will take a 30 minute break for pizza and raffle activity, then continue the next 4 games also 15 minutes each
3. If there is a tie, we will have those people choose a partner (if necessary) for a 15 minute tie breaker game.
4. Prizes will be awarded to the top 3 scorers.
5. Each player will keep their own score card. After each game, the opposing team will initial the other players score card.
6. If you are still playing when the 15 minute time period is up, your hand can be played out as long as the cards have been dealt. If they haven't been dealt, your game is over. The losing team will move to the table to their left and the winners will remain at the same table. Don't play with the last person you played with.

7. Most important: HAVE FUN! This is a fund raiser. Enjoy your afternoon and thank you for supporting your Upstate New York Team!

The Man Who Lost His Face

How a severely burned World War II pilot with a will to live helped launch the age of organ transplants

From December 12, 2005 Newsweek by Joseph E. Murray, M.D. with Anthony L. Komaroff, M.D.

As doctors start performing face transplants, it's ironic that the story of human organ transplantation began with a man who lost his face. On December 22, 1944, a 22-year-old pilot named Charles Woods taxied down a runway in Kurmitola, India, carrying 28,000 pounds of aviation fuel. The plane exploded on take-off. Woods survived, but suffered severe burns over 70 percent of his body. The fire erased his face, destroying his nose, eyelids and ears.

No one had ever lived with such severe burns, but Woods had an indomitable will. Six weeks after his accident, he arrived at Valley Forge General hospital, an Army hospital in Pennsylvania where I was stationed. He was still clinging to life. Woods needed new skin, and in desperation, we took the skin from a recently deceased soldier, with his family's permission, and draped it onto Woods. This "foreign" skin normally would have been rejected by Woods's immune system within 10 to 14 days – too soon for his skin to grow back. However, possibly because of his debilitated condition, his immune response had been tamed. The new skin survived for more than a month –buying Woods just enough time to save his life.

Over the next two years, we operated 24 times to build Woods a new face - a new nose, eyelids and ears - but he still looked like no one you have ever seen. When we were through, Woods looked in the mirror, walked out into the world, raised a family and built successful businesses. He died in 2004.

I returned from the war and resumed my surgical training in the repair of faces misshapen by injury and disease. I also joined a team at Peter Bent Brigham Hospital dedicated to attempting kidney transplantation as a treatment for kidney failure. Many thought organ transplantation could never work because the patient's immune system was likely to reject a transplanted organ. But I knew something had tamed Woods's immune system. So transplantation did not seem like a futile quest to me.

After several years developing the necessary techniques, I learned about a 22-year-old man, Richard Herrick, who was dying of kidney failure, and who had an identical twin brother, Ronald, with two healthy kidneys. A kidney from an identical twin would not be rejected as "foreign." So, on Dec. 22, 1954 - 10 years to the day after Charles Woods was burned - we performed the first human organ transplantation from a living donor. Later advances made transplantation successful among people who were not identical twins.

Last year I helped light the torch at the 2004 Transplant Games in the Minneapolis Metrodome. More than 2,000 competitors were on the field, all of them with a transplanted organ. And all of them with a debt to a man who lost his face, but not his will to live.

Submitted by Ernst Baier

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, donors, family and friends are welcome. Meetings are held monthly and include programs of interest to the transplant community.

DONOR DAY AGAIN HOSTED BY SATURN

Saturday, February 11 was Nation Donor Day brought to you by the Saturn dealerships national wide. TAO, as a member of C-DOT was again represented at the Penfield Saturn dealer. Karen Gledhill and Bonnie Haefner manned a booth at the Saturn dealership to pass out information that concerned organ and tissue donation. Along with several organizations, the Red Cross was also represented at the dealership. They had a blood drive that was active throughout the day.

Linda and Ron Barnard stuffed approximately 200 packets of information that were distributed through-out the week to customers who had any type of service done at the Saturn dealership. We wish to thank the Saturn dealership with their support for this event.

Karen Gledhill

Spring Fling Coming Again

April 11 is a date to save and write in your calendar!

A new and improved Spring Fling has been announced by Kaufmann's. The event this year will be held April 11th at the Kaufmann's at Eastview Mall. The money raised will again be used to fund the NKF's Transplant Team as they are preparing to attend the National Games in June.

Kaufmann's will again be offering 20% discount shopping passes; chances to win great prizes and a \$1000 Shopping Spree; have a fashion show and tips from the experts through out the evening; hor doeuvres, desserts, beverages and musical entertainment. Tickets will be available after February 23rd. Call the Kidney Foundation, 697-0874, for details and help the Transplant Team in their efforts!

Karen Gledhill

New Column for the Transplant Times

Many times over the past two or three years Mike and I have thought about someone in the transplant community and wondered how he/she was doing. We realize that many members of TAO are not able to attend meetings for various reasons. HOWEVER, we would like to know how you are doing.

Thus, the birth of a new column for the TRANSPLANT TIMES, aptly entitled HOW ARE THINGS GOING????

If you are reading this and feel like sending us a note please do so. Let us know how things are going and with your permission we will publish comments in the next issue of TRANSPLANT TIMES. I have told Suzanne, the editor, that I would put comments into a format for the newsletter so please send notes to me, either by e-mail, phone or snail mail. Thanks and we hope to hear from you soon!!

Sally Stelljes, 5341 Boohar Hill Road, Geneseo NY 14454, (585) 245-9579 salstell@rochester.rr.com

TAO-Rochester Board of Directors 2005/2006

Name	Phone	Email	Office	Term Exp.
Ron Barnard	227-2887	barnardr1@peoplepc.com	Board Member	2007
Lisa Faucz	671-3914	lfaucz@rochester.rr.com	Secretary	2007
Karen Gledhill	586-9252	ksgledhill@rochester.rr.com	Vice President	2006
Karen Guarino	272-7890	kguarino@rehpb.org	Rep. Rochester Eye and Tissue Bank	N/A
Linda Hicks	275-8306	linda_hicks@urmc.rochester.edu	Rep. Dept. of Transplantation, SMH	N/A
David Johnson	889-1346	davejohn@rochester.rr.com	President	2006
Suzanne McNamara	385-3144	shawmcn@aol.com	Board member (<i>Times</i> editor)	2006
Sandy McNitt	359-8015	sdmcnittot@aol.com	Board member	2007
Dan Newhouse	663-4508	tatmandan@aol.com	Board member	2006
Janice Odenbach	216-9856	janiceodenbach@aol.com	Board member	2007
Robyn Miller	272-4936	robyn_miller@urmc.rochester.edu	Rep. Finger Lakes Donor Recovery Network	N/A
Penny Sayles	624-4126	psayles@brockport.edu	Board member	2006
Joanne Schum	671-7635	twoluckylungs@juno.com	Board member	2006
Mike Stelljes	245-9579	mstellje@rochester.rr.com	Treasurer	2007
Dennis Stenshorn	323-1392	dstensh1@rochester.rr.com	Board member	2006

OTHERS NOT ON THE BOARD:

Laurie Packard	425-8034	kidtr0311@aol.com	Membership chair
James Grossman	325-2112		TAO attorney

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
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