

www.tao-rochester.org

1-888-664-1463

May, June, July, August 2007

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MEMBERSHIP MEETINGS

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

Wednesday, May 16, 7 pm

Speaker: John Masucci, Vice President of TAG of Syracuse, speaking on support of the caregiver in the transplant world. John is a kidney recipient who became interested in caregiver support when he saw the challenges his wife faced when no such resource was available.

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.

Wednesday, June 13, 6 pm PICNIC! Any time after 3, eat 6:30

One week earlier, different location!

Mike and Sally Stelljas have invited us to have our June picnic at their home in Geneseo. Bring a dish to pass, we will have subs and drinks. Bring picnic games. And folding chairs. Please call Karen Gledhill, 586-9252, kgledhill@rochester.rr.com if you plan to come.

Directions to home of Sally and Mike Stelljes, 5341 Booher Hill Road, Geneseo NY 14454 Home phone 585 245 9579 Cell phone 585 519 2753.

Allow 50 minutes from Rochester. Take route 390 south (Corning) and get off 390 at Exit 9 (Lakeville/Conesus Lake). Turn left off the exit ramp onto Rt. 15. Check your odometer at this point. We are approx. 7 miles from the exit. When you see Fratellis restaurant on the left the road will split with Rt. 15 going to the left. GO STRAIGHT onto Rt. 256 which is West Lake Road. Cross Rt. 20A where you will see Minnehans on the left hand corner. Watch for the green signs which indicate the areas of the lake. When you see LONG POINT we are one mile south from that point. You will make a right hand turn onto BOOHER HILL ROAD. After the corner house we are the first house on the right after a woodsy area. It is a grey house and the number is 5341.

Deadline for September - October, 2007 *Transplant Times* - Wednesday, August 8

In Memoriam - Ron Barnard

Ron died peacefully Friday, April 13, 2007. In the fall of 1992, he was a founding member of TRIO Rochester, our predecessor organization, and will be remembered as a gentle, witty presence at our meetings through the years.

His widow, Linda, also an active member of TAO, asked that memorial gifts be sent to TAO. She sent this message: "Thank you to everyone who gave Ron and me your prayers and support this past year. It meant so much to both of us. Thank you now for all the cards and support for our family now that Ron is resting comfortably with our Lord. Thank you, Linda B."

TRANSPLANT ANNIVERSARIES OF TAO MEMBERS - May, June, July, August

Roger Duryea -- 05-01-95 Kidney
Phil Sinaguglia -- 05-04-04 Kidney
Shelley Whitney -- 05-09-03 Lung
Patricia Bianchi -- 05-16-02 Liver
Nancy Thompson -- 05-18-93 Liver
Barbara Robida -- 05-18-02 Liver
Patricia Terra -- 05-20-02 Liver
Bonnie Patten -- 05-21-95 Liver
Richard Orczyk -- 05-23-91 Heart
Mike Yendrzski -- 05-25-02 06-09-02 Liver
Ralph Toscano -- 03-01-89 06-01-90 Cornea
Shelley Stone -- 06-05-95 Lung
Joseph Logalbo -- 06-07-03 Kidney
Kevin McCorry -- 06-11-04 Bone marrow
James Fyfe -- 06-12-06 Heart
Ethel Jean Schrader -- 06-15-02 Liver
Otto Schuster -- 06-23-01 Liver
Bernice Eblövi -- 06-27-02 Liver
Karen Lee Sommer -- 06-27-06 Liver
Joanne Tucker -- 07-01-06 Liver
Phillip Ronzo -- 07-19-96 Liver
James Blake -- 07-24-04 Liver
Giulio Verde -- 07-30-98 Heart
David Spiro -- 08-01-97 Liver
Donna Christy -- 08-05-00 Liver
Roger(Bud) Robinson -- 08-12-92 Heart
Moirä Miller -- 08-17-05 Liver
Joseph Yahn -- 08-27-94 Heart
David Watts -- 08-30-90 Kidney

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

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

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 \$25, \$50 and \$100.

River Run August 25

Volunteers needed for RUN Committee
Strong Memorial has asked if anyone from our group would be interested in being on a committee that is forming for the 2007 River Run. The money collected from the Run will go to support transplant patients who have financial hardship. The event will be held August 25 and more information will follow.

If you are interested in being part of the steering committee for the River Run, please let Karen Gledhill know at 586-9252 (or kgledhill@rochester.rr.com). She will forward your name to the correct individuals.

Thanks

Karen Gledhill

New Greeting Card

Hallmark's new line of "Journeys" cards features a card appropriate for a living donor or a deceased donor's family. The card reads "What you did was amazing, beyond generous and kind. You started a miracle. You gave the gift of life. How can anyone ever thank you enough for that?"

It sells for \$2.29 and is a beautiful card. The "Journeys" line offers "encouraging words along life's way" and includes all sorts of neat cards. Just wanted to share the find!

Karen L. Guarino

Elections Coming

Members - Once again it is time to vote for new board members of TAO. We have 4 positions that are open and available for you to be an integral part of TAO.

Would you like to become more involved with TAO? Do you have some ideas that you feel would be a benefit to all the members of TAO? Have you always wanted to join a Board of Directors, but never asked?

These might be the questions going through your mind, and now is the best time to ask and learn. You can contact Joanne Schum, board member who is working on the election nominee committee about what involvement entails, the good that you can offer and receive, what it is like to be a board member, and she can also hook you up with other board members so that you can learn what their experience has been like.

We are also in need of a Treasurer. This is not as difficult as it may sound. You do not have to use a computer, but can if you like, and anyone can tackle this position, no prior experience is necessary, and no accounting background is required. Mike Stelljes is the present Treasurer and he will be happy to assist you in turning this position to you and showing you the ropes.

Suzanne McNamara has been a leading force for TAO for years and she would like to give up her board member status and also producing the newsletter. So we are looking for a board member who might like to do the newsletter - Suzanne has a program to do this and will turn over her knowledge to you.

May 16th are the election at the TAO membership meeting. Please let Joanne know of your interest by May 10th if you are interested.

Board meetings are once a month and presently on the 2nd Wednesday of the month. There is interest in changing this to the 3rd Wednesday, just before the member meetings to reduce time dedication.

Being a board members is rewarding, not much work involved and a great group to be working with to help promote organ donation and the needs of pre and post transplant patients and families.

Joanne Schum luckylungsforjo@aol.com 585-671-7635
Joanne Schum twoluckylungs@juno.com

2008 Transplant Games It is time to begin thinking about the 2008 Transplant Games and setting up the appropriate committees to ensure we do our best to recruit athletes for the Games in Pittsburgh (July, 2008) and hopefully raise enough funds to send the athletes representing Upstate New York.

If you are interested in participating as a Steering Committee Member or a member of a committee (travel, fund-raising/sponsorship, recruitment, advertising, uniforms, etc.) please e-mail me (MarciaJ@Rochester.rr.com) with your level of interest. Please let me know as soon as possible so we can set up the committees and plan for 2008.

Thanks, Marcia Johnson

Clinic Volunteers

SUPPORT, ADVOCACY, EDUCATION and AWARENESS are the four words used in our TAO brochure as reasons for joining our organization. If you have been looking for a way to support the mission of TAO, please consider the following idea:

TAO sponsors a volunteer program where transplant recipients meet with potential transplant candidates on his/her "eval" day. The program began last July and each clinic day since then two volunteers have been on duty to 'MEET and GREET' potential transplant candidates. Well over two hundred candidates have been greeted by transplant recipients and given a folder of info to use as a guide on eval day. The program has been well received by both staff and patients.

Up 'til now we have only been able to meet with potential candidates for a liver transplant. We are hoping to expand our program so that potential candidates for a kidney transplant can also be included.

On Wednesday, March 21 Transplant Coordinator Pat Milot conducted a very informative session for the transplant clinic volunteers. The bulk of the time was spent learning about the liver transplant program but in addition Pat provided a very comprehensive overview of Strong's transplant program and also some information regarding kidney transplantation. Linda Hicks, renal Social Worker, joined us for part of the time.

During the power point presentation, participants had the opportunity to ask questions and make comments. We all agreed that we learned a lot and it was time well spent.

If you are a transplant recipient and would like to learn more about our program please contact: Sally and Mike Stelljes, (585) 245 9579, salstell@rochester.rr.com.

Transplant clinic volunteers at Education Session

Front: Ray Lyman

Rear: Bernice Eblovi, Pat Milot (coordinator), Richard Perez, Frank Imburgia and Jerry Bluff



The Beat Goes On

"And the Beat Goes On" will be going again this year. This is a fund raiser for the transplant program to raise enough money to establish a house for transplant families from out of the area to stay while their family members are hospitalized awaiting transplants. The date is FRIDAY, MAY 18 starting at 6:00 P.M. It will be held at the Burgundy Basin Inn on Marsh Road in Pittsford. The evening includes a chicken barbeque and dancing to "Me-n-the Boyz" and "Second Chance" There will be raffle items and items for a silent auction as well as a 50-50 raffle. All this for only \$25.00 per person. Christine Arcara, 349-0686.

TAO-Hornell Chapter

On Sunday, March 25, three of our TAO members traveled to Hornell to meet with member Kim Wood about starting a Chapter of TAO in her area. Kim is a donor family member and this has been a goal of hers for a long time now.

Board member Sandy McNitt had prepared a very comprehensive agenda which was reviewed and discussed.



The items included will help Kim plan and facilitate her first meeting in May. Sally and Mike Stelljas shared with Kim what TAO has offered them and gave ideas for future meetings.

The picture shows (left to right) Sandy McNitt, Kim Wood, and TAO Treasurer Mike Stelljas in front of DeSales Hall where the meetings will be held.

The Board of Directors of TAO is excited to announce the start of a new Chapter of TAO in Hornell. We are fortunate to have existing TAO member Kim Wood offer her time and experience to lead this new group. She is a donor family member and is a committed advocate for organ, eye and tissue donation.

Understanding that many TAO members cannot make TAO's general membership meetings each month in Rochester area, the Hornell Chapter will offer some of you the opportunity to attend meetings closer to home. TAO – Hornell Chapter will provide the same support for transplant recipients, candidates, and their families, donor families; provide education and information on transplantation and related issues; and promote organ and tissue donation awareness.

TAO – Hornell Chapter meetings will be held on the second Tuesday of the month at 6pm. Frequency of meetings will be determined by members.

Directions: 390S, Exit 4 (second Dansville exit), right to rte. 36 through Hornell(rte. 36 is Maple City Dr.), left at E. Van Scooter Street (across from St. James Mercy Hospital) take first right on Monroe Drive. Straight ahead is Desales Hall across from Hornell Gardens Apartments.

First meeting is planned for Tuesday, May 8th and all TAO members are invited to attend. Come and share your ideas for future meeting topics and your personal experiences. Members in the Rochester area will come to support the start of this new Chapter.

If you have any questions, please call Kim Wood at (607) 324-0913.

Lilac Festival Parade Saturday, May 12

The Lilac Festival Parade is just around the corner – Saturday, May 12. If you are interested in riding on the float this year, I will need to know by Monday, May 7. We will be preparing signs for all those that will be riding on the float. If you are a transplant recipient, please tell us again what kind of transplant and the year you received the transplant. Members of donor families, we will have a sign for you that reads Donor Family and the name of your loved one on the other side of the sign.

I haven't yet received the packet of information from the parade organizers regarding parking, etc. This should come next week. Plan on the usual, arriving at the designated parking place (last year it was the Psych. Center on Elmwood) by 9:30 a.m. The parade begins (usually) at 10:30 and we are done (usually) by 12 noon.

Once I receive the packet of information, I will either mail information to you or email all to arrange for you to come by the office to pick it up.

This year, we will have one of the member organizations of C-DOT (MTF) hosting a tailgate coffee/juice/and eats prior to the parade. I'll find out exactly what time they will be set up, but I assure you, earlier than all will get there.

As always, we go rain, shine, clouds, or whatever - unless its canceled. Dress in layers! Bring anything you'll need during the duration (food, meds, water, umbrella, suntan lotion, etc.).

If you have a blue C-DOT t-shirt old or new one!- YOU MUST WEAR it. Unfortunately we will not be getting our new supply by the time of the parade. If you don't have one, there are a few of us who have more than one.

If you are one of those individuals, please email me back what size the extra is and maybe we can match it up with someone for that day who does need one.

THE MOST IMPORTANT THING TO DO RIGHT NOW IS TO LET US KNOW IF YOU WILL BE RIDING WITH US. WE HAVE A CAPACITY OF SEATING 32 PEOPLE. LET'S FILL THE FLOAT THIS YEAR AND SHOW THE COMMUNITY HOW MUCH WE APPRECIATE THEIR SUPPORT.

AND – THE BIGGEST NEWS – WE HAVE A DEDICATED FLATBED FLOAT – DESIGNED BY TAO MEMBERS, BUILT BY JOE ODENBACH !

Thanks, as always.

Karen Guarino, 272-7890, kguarino@rehpb.org

Dialysis at Sea

While surfing around for information on a cruise we're taking in May, I ran across some information on a company called Dialysis At Sea Cruises. They specialize in scheduling cruises with dialysis machines for patients that require that service. Each cruise is accompanied by a board eligible/certified nephrologist and one or more dialysis nurses, depending on the number of dialysis cruise patients. The medical staff is English speaking and recruited mostly from the U.S. and Canada. They use the new generation Fresenius 2008K for dialysis treatment.

More information and a schedule of their cruises for 2007 can be found at <http://www.dialysisatsea.com>. I thought this might be useful to TAO members that need dialysis but would also like to be able to take a cruise vacation.

Dave Johnson

TAO-Rochester Board of Directors 2006/2007

Name	Phone	Email	Office	Term Exp.
Ron Barnard	227-2887	barnardr1@peoplepc.com	Board Member	2007
(Deceased, April 2007)				
Karen Gledhill	586-9252	kgledhill@rochester.rr.com	Vice President	2008
Karen Guarino	272-7890	kguarino@rehpb.org	Rep. Rochester Eye and Tissue Bank	
Linda Hicks	275-8306	linda_hicks@urmc.rochester.edu	Rep. Dept. of Transplantation, SMH	
David Johnson	889-1346	davejohn@rochester.rr.com	Board member	2008
Suzanne McNamara	385-3144	shawmcn@aol.com	Board member (<i>Times</i> editor)	2007
Sandy McNitt	359-8015	sdmcnittot@aol.com	Board member	2007
Janice Odenbach	216-9856	janiceodenbach@aol.com	Board member	2007
Richard Padula	272-4936	Richard_Padula@urmc.rochester.edu	Rep. Finger Lakes Donor Recovery Network	
Jerry Runion	865-7461	jgrunion@rochester.rr.com	Board member	2008
Joanne Schum	671-7635	twoluckylungs@juno.com	Board member	2008
Mike Stelljes	245-9579	mstellje@rochester.rr.com	Treasurer	2007
Dennis Stenshorn	323-1392	dstensh1@rochester.rr.com	President	2008
Shelley Whitney	334-8267	whitney618@aol.com	Secretary	2008
<u>OTHERS NOT ON THE BOARD:</u>				
Laurie Packard	425-8034	kidtr0311@aol.com	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/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 _____



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Transplant Times

TAO/Rochester
5 Sandpiper Lane
Pittsford NY 14534

