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**Transplant Times Co-Editors:**

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**Deadline for March, April, 2008 Transplant Times - Wednesday, February 13**

**- MEMBERSHIP MEETINGS -**

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

**Meetings are on the 3<sup>rd</sup> Wednesday of the month from 7:00 - 9:00 p.m.**

**Pinnacle Lutheran Church, located at 250 Pinnacle Road corner of Stone Rd.**

Go south on Winton Rd. from Jefferson. Winton becomes Pinnacle. Take Pinnacle to the light at Stone Road, turn left, the parking lot is behind the church. Use the Office entrance.

**DUE TO A CONFLICT WITH PINNACLE LUTHERAN CHURCH,  
THE FEBRUARY 20, 2008 and MARCH 19, 2008 TAO MEETING  
WILL NOT START UNTIL 7:30PM.**

**Bad weather:** if the Rush Henrietta School district is closed due to weather then there would be no TAO meeting at the Church. Meetings would be canceled.

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## Upcoming Meeting Topics

### January 16

Mary Anne Lester, periodontist – Dr. Lester will discuss the benefits of maintaining a healthy mouth and gums specifically geared to patients that have transplants and are on numerous medications that can also exacerbate gum problems. Question and answer time will be included, some come with your questions.

### February 20 & March 19

During the summer TAO board members spent time “brainstorming” on how to increase TAO’S mission to the local transplant community. We ended the sessions with a Strategic Action Plan for 2007 – 2010. The board broke this down into three committees they are: Increase Media Support, Increase power & distribution of newsletter to outside members, Identify Events that will raise TAO awareness.

Because of shortened meeting times in February & March (times are 7:30 – 9pm) the board felt it may be helpful to have “Working Meetings” during that time and ask Members of TAO to help plan for the future.

All TAO members are encouraged to come and join one of the committees to help make TAO a better organization. You can also help by informing pre and post transplant recipients about TAO and what it has to offer.

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## Dues Notices

The dues notices that were sent out have 2007 on them. **The dues you are paying are for 2008.** Sorry for any confusion.

Thanks, Laurie Packard

## TRANSPLANT ANNIVERSARIES OF TAO MEMBERS – January, February 2008

Charles Liberi -- 01-05-95 Kidney  
Dawn Meschi -- 01-10-01 Kidney  
Jane Clewell -- 01-11-05 Liver  
Helen Cox -- 01-11-96 Kidney Pancreas  
Patricia Stewart -- 01-23-94 Kidney  
Frank Imburgia -- 01-30-02 Heart  
Patricia Alexander -- 01-31-05 02-09-05 Liver  
Patricia R. Legge -- 02-01-96 Kidney  
Wayne A. Dickinson -- 02-02-97 Liver  
David Beatson -- 02-07-01 Heart  
Aisha O'Mally -- 02-09-04 Heart  
Louis Mascaro -- 02-20-79 Kidney  
Gerald Bluff -- 02-22-05 Lung  
Kevin Kain -- 02-22-02 Liver  
Peter Unbras -- 02-24-02 Liver

***Congratulations! Did we miss yours? Get your date wrong? Please call the editor!***

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### 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, Transplant Awareness Organization of Greater Rochester, PO Box 23552, Rochester, NY 14692-3552

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### Keeping in Touch

New Members: Marianne Bennett, Rich and Laurie Forbes

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Donations received since 10/1/07: Joanne Rourke, Ralph Toscano

Memorials since 10/01/07: Shirley Tuites in memory of Dick Tuites. Lisa Faucz and Family in memory of Hartter

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**TOPS never stops.....**Helping TAO Raise Money -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.

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### TRANSPLANT LEGISLATION – submitted by Sally Stelljes

Currently in two committees of the House of Representatives, bill H.R. 1035 would provide credit for donation of certain life-saving organs (as in living organ donation). Credits would include unreimbursed costs paid by the taxpayer in connection with the transplant and any lost wages of the individual in connection with the transplant. Randy Kuhl, who represents the 29<sup>th</sup> Congressional District is a co-sponsor of this bill. Anyone who has questions is welcome to contact PAUL in Congressman Kuhl's Washington DC office. The phone number is (202) 225-3161. Congressman Kuhl also has offices in Fairport (585) 223-4760 and Bath (607) 776-9142. As members of the transplant community, I encourage you to write a letter to your own representative in Congress asking for support of this important legislation. When you write your letter, try to include a personal anecdote that involves transplantation. Perhaps you were tested to be a living donor or know someone who has been through this type of transplant. My husband Mike received his liver transplant from our son Michael in 2001. Both husband and son are thriving and we are grateful each day for this gift. A sample letter of support has been posted on the TAO website. The website can be accessed at [www.TAO-Rochester.org](http://www.TAO-Rochester.org)

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### **MAJOR TRIUMPH FOR TRANSPLANTATION – CONGRESS PASSES THE LIVING KIDNEY ORGAN DONATION CLARIFICATION ACT (H.R. 710)**

WASHINGTON, D.C., - After months of debate, both the House and Senate voted this week to pass the final paired donation legislation. This legislation amends the National Organ Transplant Act (NOTA) to clarify that criminal penalties do not apply to paired donations of human organs and to further amend Section 310 of NOTA to include a clear, concise definition of paired donation. The bill is called the "Charlie Norwood Living Organ Donation Act," named after transplantation champion, the late Congressman Charlie W. Norwood (R-GA) and is expected to become law soon.

Passage of the bill opens the door for implementation of a national registry that would facilitate matching incompatible living kidney donation pairs. "The bill will undoubtedly increase the chances for patients with end stage renal disease to receive living donor transplants, thus increasing their quality of life, and also reducing health care costs," said Richard B. Freeman, ASTS Legislative Chair.

The paired donation bills were re-introduced in the House in January by Congressman Norwood (R-GA) and Representative Jay Inslee (D-WA), the following month by Senator Carl Levin (D-MI) and 11 others in the Senate. "Senator Levin was the driving force behind this legislation and deserves great credit for pushing this bill across the finish line. Hundreds of transplant recipients in the years to come will owe their lives to his fine work, as well as the diligent efforts of Congressman Jay Inslee, the House sponsor, Chairman John Dingell and Chairman Ted Kennedy," said Dr. Freeman. The ASTS is grateful to these champions without whom this legislation would not have become law.

In his floor statement in support of this bill, chief Senate sponsor Carl Levin said, "there are those who energetically led the effort in educating Congress on the need for paired donation and they have long been a progressive force in organ donation and transplantation. I thank Dr. Robert M. Merion, Professor of Surgery at the University of Michigan Transplant Center and Secretary of the American Society of Transplant Surgeons (ASTS), as well as Dr. Goran B. Klintmalm from Baylor University Medical Center and President of the ASTS, for their tireless advocacy for this lifesaving legislation... Senate passage and enactment of this legislation is a fitting tribute that honors the memory of six members of the University of Michigan Transplant Team, who died in a tragic plane crash while on an emergency mission to deliver life-saving organs to the University of Michigan Hospital to save the lives of transplant patients."

In October, several ASTS transplant surgeons participated in the second ASTS Congressional Fly-in of the year meeting with more than 25 congressional offices. Recalling several delays throughout 2006 and 2007 to pass the paired donation legislation, ASTS members met directly with key Senate and House leaders in an effort to find common ground. The ASTS further acknowledges the efforts of its members who earlier in the year answered the Call to Action, writing letters and making phone calls, petitioning their respective congressional representatives to support the Act.

Moreover, ASTS is hard at work educating Congress on other needed legislative changes such as extended immunosuppressive coverage for Medicare beneficiaries and removal of financial disincentives for donation; keeping with the ASTS mission to foster and advance the practice and science of transplantation for the benefit of patients and society.

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### **Bringing Home to the Hospital: Blankets for Patients -by Maria A. Fiorille**

In mid-October 2006, Sharon D. Fiorille became a patient of Strong Memorial Hospital, awaiting a liver transplant. This would be her second liver transplant resulting from the disease Primary Sclerosing Cholangitis. Thanks to the great gift of organ donation, she received another chance at life in early November. Unfortunately, after a difficult recovery, Sharon passed away in late January 2007 at the age of 50. Sharon was my mother. Throughout her many hospital stays, she always longed for that "little piece of home." When cards and flowers didn't make the grade, I made her a homemade fleece blanket. She fell in love with this little treasure; in order to bring it home for washing, I had to make her a replacement so she wouldn't be without it a day. After my mother passed away, it was brought to my attention that some patients are awaiting organs or recovering from transplants with no family or loved ones by their side. In my mother's memory, I have started a project to bring homemade blankets to patients in the hospital. These simple fleece, quilted, or knitted blankets may be able to bring a smile to the faces of those who are recovering. Please help me bring a bit of home to the hospital. Anyone wishing to donate blanket materials or make a monetary donation can send items to the Sharon Fiorille "Sign an Organ Donor Card" Fund, PO Box 444, Moravia, NY 13118. For more information on the project or to volunteer to help make blankets, please contact Maria at mafiorille@gmail.com or 315-224-6538.



Photo of Pittsburgh, Pennsylvania. This will be the location of the 2008 transplant games. July 11<sup>th</sup> to 16<sup>th</sup> we will have a group from Rochester headed to the games to “strut our stuff”. Please consider going along with us. The next team meeting will be January 7<sup>th</sup>, 5:30pm at National Kidney Foundation Offices. Thanks to Mike Swete for the photo.

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### Future meeting topics:

Do you have an idea for a speaker for a future meeting? Submit your ideas to Dennis [dstensh1@rochester.rr.com](mailto:dstensh1@rochester.rr.com)

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### Depression: Could it Happen to You?

If you have a chronic illness or a transplant, depression could happen to you. Although you are grateful for receiving your transplant, you are now more at risk for depression than people without a chronic medical illness. The daily stress of following strict medical routines, adjusting to physical changes, explaining to others about your illness and fighting to fit into a world where you are not quite sick and not quite well can take its toll on your mood. Combined with stress, the inability to solve life's everyday problems can lead to depression. Your risk of depression can increase if you are socially isolated and have lost contact with loved ones, or your health care providers. When people are forced to live with a chronic illness, it can lead to changes in self-esteem that can be another factor contributing to depression. The way you view yourself, and how much you perceive your illness to limit you can contribute to depression. This is called self-illness schema and has been shown to be a key contributor to depression in patients with a chronic illness. Metabolic changes and medication side effects are two ways your illness can contribute to depression. Additionally, depression is more likely if one or both of your parents suffered from depression. There are many ways to manage depression these days. For some, emotional and social rehabilitation alone can help. Increasing your contact with others and planning enjoyable activities on a regular basis can help improve your mood. Returning to an active life can be an important step to help relieve your depression. Physical activity has been shown to help alleviate depression in some people. For many patients suffering from depression especially if that depression is greatly interfering with their day to day functioning, anti-depressant medication is recommended. Because depression is often affected by the neurotransmission of certain brain chemicals, medication that helps our brain chemicals, medication that helps our own brain chemistry work better, can often lift depression. Just because you have received a long awaited transplant doesn't mean that your adjustment to living with chronic illness is over. Feelings of fear and inadequacy are common, especially during the first few years following transplant.

(Source: Transplant Chronicles)

## TAO-Rochester Board of Directors 2007/2008

Name	Phone	Email	Office	Term Exp.
Karen Gledhill	586-9252	<a href="mailto:kgledhill@rochester.rr.com">kgledhill@rochester.rr.com</a>	Vice President	2008
Karen Guarino	272-7890	<a href="mailto:kguarino@rehpb.org">kguarino@rehpb.org</a>	Rep. Rochester Eye and Tissue Bank	
Bonnie Haefner	334-7034		Board Member	2009
Linda Hicks	275-8306	<a href="mailto:linda_hicks@urmc.rochester.edu">linda_hicks@urmc.rochester.edu</a>	Rep. Dept. of Transplantation, SMH	
David Johnson	889-1346	<a href="mailto:davejohn@rochester.rr.com">davejohn@rochester.rr.com</a>	Treasurer	2008
Sandy McNitt	359-8015	<a href="mailto:sdmcnittot@aol.com">sdmcnittot@aol.com</a>	Board Member	2009
Janice Odenbach	216-9856	<a href="mailto:janiceodenbach@aol.com">janiceodenbach@aol.com</a>	Board Member	2009
Rob Kochik	272-4930	<a href="mailto:rob_kochik@urmc.rochester.edu">rob_kochik@urmc.rochester.edu</a>	Board Member	2009
Jerry Runion	733-3422	<a href="mailto:jgrunion@rochester.rr.com">jgrunion@rochester.rr.com</a>	Board Member	2008
Joanne Schum	671-7635	<a href="mailto:twoluckylungs@juno.com">twoluckylungs@juno.com</a>	Board Member (Times Editor)	2008
Sally Stillness	245-9579	<a href="mailto:salstell@rochester.rr.com">salstell@rochester.rr.com</a>	Board Member	2009
Dennis Stenshorn	323-1392	<a href="mailto:dstensh1@rochester.rr.com">dstensh1@rochester.rr.com</a>	President	2008
Shelley Whitney	334-8267	<a href="mailto:whitney618@aol.com">whitney618@aol.com</a>	Secretary (Times Editor)	2008
Debbie Yendrzkeski	377-6028	<a href="mailto:auggieday@aol.com">auggieday@aol.com</a>	Board Member	2009
<b>OTHERS NOT ON THE BOARD:</b>				
Laurie Packard	425-8034	<a href="mailto:kidtr0311@aol.com">kidtr0311@aol.com</a>	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 of Greater Rochester, PO Box 23552, Rochester, NY 14692-3552

- \$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



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Transplant Times  
TAO/Rochester  
1104 Bay Road  
Webster, NY 14580

