

[www.tao-rochester.org](http://www.tao-rochester.org)

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September, October 2007

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Transplant Times Co-Editors

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## MEMBERSHIP MEETINGS

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

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.

### Deadline for November - December, 2007 *Transplant Times* - Wednesday, October

September 19, 7pm: Rob Kochik - Director of the Finger Lakes Donor Recovery Network

October 17, 7pm - Board will present Strategic Plan

## WELCOME BACK FROM TAO PRESIDENT

I would like to welcome everyone back from a nice summer to 2007/2008 TAO meetings. I would like to welcome our newest members of board of directors, Please welcome Bonnie Haefner, Sally Stelljes and Debbie Yendrzeski to their new positions on the board. Also welcome back Sandy McNitt and Janice Odenbach returning board members. The TAO Board would like to thank Suzanne McNamara for her time on board and as Transplant Times editor. One of Tao's goals is to provide support, information to members, recipients, candidates and their families. We hope to bring useful and a variety of information to our monthly meetings

This will be our "WELCOME BACK" meeting a time to see friends you have not seen all summer and share ideas for upcoming meetings. The speaker for this meeting is Rob Kochik Director of Finger Lakes Donor Recovery Network. Looking forward to seeing everyone.

Dennis Stenshorn, President TAO

### In Memory:

Roger Donald (Bud) Robinson Fairport: Suddenly, at the age of 65, on August 9, 2007, in the arms of his loving wife. Our strength and our rock, he is home, free of pain. No man on earth loved stronger or gave more to his family and friends.

**TRANSPLANT ANNIVERSARIES OF TAO MEMBERS -  
September, October**

Ivan Tzontchev - 09-05-00 Kidney  
Ernst Baier - 09-05-00 Kidney  
Joanne Schum - 09-12-97 Lung  
Suzanne McNamara - 10-01-93 Heart  
Carrie Rodriguez - 10-02-05 Kidney Pancreas  
Michelle Halloran - 10-09-97 Kidney  
Claudia Ciresi - 10-18-94 Liver  
Susan Bennett - 10-19-98 Kidney  
Keith Oliver - 10-28-02 Liver  
Daniel Newhouse - 10-30-90 11-17-95 Kidney  
Dennis Kovey - 10-30-01 Kidney  
David Johnson - 10-31-00 Liver

***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  
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**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](mailto:kgledhill@rochester.rr.com)). She will forward your name to the correct individuals.  
Thanks

*Karen Gledhill*

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**In Memory of:**

**Joyce McKay**- June 23, 2007 - Paula McKay said that this was quite unexpected and she was not ill for very long.

**Susan Moody** - July 1, 2007 -Susan was an active member of TRIO/TAO for years, until she became more ill. She was an interesting and involved person. I will miss her. Suzanne McNamara

**Marge Guarino** - July 8, 2007 - Karen's mother passed away. She was a resident at the Friendly Home for many years. Our thoughts and prayers are extended to Karen and her family.

**Katherine Schum** - July 18, 2007 - Joanne's mother passed away unexpectedly. She had her 87<sup>th</sup> birthday on July 14<sup>th</sup> and truly enjoyed the last week in her life. She was not sick, nor did she suffer. She died in her sleep. She is now with her daughter Mary Lou.

## TAO BOARD RETREAT

The Marriott Courtyard in Corporate Woods was the site chosen for the TAO BOARD RETREAT held on Saturday, June 23, 2007. For three very intense hours, ten board members met and worked with Karen McKissock. As facilitator of the session, Karen began the process of developing STRATEGIC PLAN for TAO for the years 2007-2010. The ideas for the plan were part of the brainstorming session that ensued. Accomplishments, strengths, threats and opportunities were presented and discussed. The three hour session ended with a draft of a vision statement for TAO. The remaining work is to continue at the August 8<sup>th</sup> board meeting. Submitted by Sally Stelljes



Karen McKissock, Karen Guarino and Dennis Stenshorn at retreat

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## TAO DONATIONS

Following is a list of people who have made monetary donations to TAO:

Joseph and Joanne Rourke  
Peter and Luba Davis  
Kevin and Julie McCorry  
Robert and Linda Serenka  
Karen Guarino  
David and Marcia Johnson  
Ann Finger Family  
Gerald Bluff  
Leo and Patricia Bianchi  
Chester Palozzi  
Tom Arcara

Following is a list of memorials:

Richard F. Odenbach Family Trust  
Stephanie Stewart in memory of Roger Fisher  
Faucz Family and Rita Lesnick in memory of Katherine Shirley

The following individuals and groups made monetary donations in memory of Ron Barnard:

Janice Odenbach, Rochelle Whitney, Clayton and Audrey Barnard, Dennis and Cindy Helzer, Rita Lesnick and Lisa Faucz, Charles and Marie DeMarco, Wendall and Priscilla Brown, Rebecca Brown, The American Legion Greece Post #468, Helen and David Cox, Dr. Norman and Heather Silverman, Anne Dubin and David Rosenthal, Marlene Rabinovitch, Daniel and Bonnie Bernstein, Stanford University, Kathleen and Earl Gurslin, Fred and Janice Brule, Sally and Mike Stelljes, William and Penny Sayles, Frank and Priscilla Imburgia, David O'Keefe, James B. Isaac, Michael and Judy Milazzo, John and Mary Ann McCabe, Cecil and Nancy Thompson, Bernadette M. Connell, Marlene Begy, Fremont and Carole Clow, Sue and Bob Gordon, Jane and Stuart Jones, Charlene Rischenole, Bonnie Haefner, Adanell N. Owens, Kristine A. Hamilton, Robert and Margaret Engel, Lee and Beverly Weeks, Andrea Fish and Stephen Roth, Eugene Post, Shirley Tuites, Ronald and Ann Duell, Marjorie and Charles Gebo, James and Joanne O'Reilly

Gratitude Is Good Medicine For Organ Recipients After immunosuppressants, the best medicine for organ transplant patients might be gratitude.

In a study of organ recipients, researchers from UC Davis and the Mississippi University for Women found that patients who keep "gratitude journals" score better on measures of mental health, general health and vitality than those who keep only routine notes about their days. "We found that increased feelings of gratitude can cause people's well-being and quality of life to improve," said Robert Emmons, a UC Davis professor who specializes in the study of gratitude. Emmons conducted the study with Stefanie Greiner and Stephanie Ivie of the Mississippi University for Women. The study included four male and 12 female transplant recipients recruited via transplant e-mail groups and Web sites for transplant recipients. After completing initial questionnaires about their health and wellbeing, the subjects were randomly assigned to one of two groups. One group kept routine daily notes about medication side-effects, how they felt about life overall, how connected they were to others and how they felt about the upcoming day. Patients in the other group answered the same questions but were also asked to list five things or people they were grateful for each day and why they were grateful for them. They were asked to reflect on what they wrote as well. After 21 days, mental health and general wellbeing scores had risen for patients in the gratitude group but declined for those in the control group. Patients in the control group also reported a loss of vitality, while the grateful patients experienced no change. "It's likely that health and vitality scores declined in the control group because, unlike the experimental group, they did not benefit from the protective effect of gratitude," Emmons said. "Having a chronic medical condition puts one at risk for deteriorating mental health, and a reduction in one's sense of general health and vitality is an indicator of this. Gratitude may serve as a buffer against these risks." Emmons is a leading contributor to the positive psychology movement and the author of the recently released book "Thanks! How the New Science of Gratitude Can Make You Happier."

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### Mending Broken Hearts

There is a lot of mending in the annual one million angioplasty procedures, 400,000 coronary artery by pass grafts, and 2,000 heart transplants. And, soon to come will be the artificial hearts.

Since receiving the miracle of a heart transplant in 2003, I have devoted my time to advocating organ and tissue donor awareness. The shortage of donors for transplantation has not improved since 2003. There are over 100,000 people waiting for some form of a transplant and unfortunately 1/3 of them will die.

Incredibly, medical advancements have given me a second chance to watch my sons in business, spoil 4 grandchildren, hit a golf ball, and enjoy all the pleasures of life. The future is going to be exciting and my legacy hopefully will include being a small part of the cure for heart disease.

What is more amazing is the dedication of staff at Strong Memorial Hospital program in Heart Failure and Transplantation. Director Dr. Lewey Chen, MD., and director H. Todd Masney, MD and the rest of their group are steadfast in helping a never ending line of arriving strangers to live. Their commitment makes even the most loyal employees elsewhere pale in comparison.

I not only thank them for my personal gift of life, I salute the tremendous giving of their daily lives to heal others. They are the heroes who mend the broken hearts.

Frank Imburgia, Pittsford, NY

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## West Nile Virus and Transplant Recipients

Transplant recipients are at increased risk of severe West Nile virus disease. Medicines taken by transplant recipients can make it hard to fight infections. Transplant recipients may develop the severe forms of WNV disease, including encephalitis, meningitis, and even death, more often than persons with normal immune systems.

Symptoms of severe WNV disease include high fever, headache, neck stiffness, stupor, disorientation, coma, tremors, muscle weakness, vision loss, numbness, and paralysis. Symptoms can last several weeks, and neurological effects can be permanent.

In the general population, usually there are no symptoms with WNV, but it may cause less severe illness with fever, headaches, body aches, nausea, or vomiting. Sometimes this includes a skin rash on the chest, stomach, and back. These symptoms typically last a few days - but may last several weeks.

There is no specific treatment for WNV disease. Human vaccines for WNV are still in the early stages of development.

Hints to help prevent WNV:

1. Use protective clothing and effective repellants whenever you go outdoors.
2. Mosquito proof your home. Install or repair screens on windows and doors to keep mosquitoes outside.
3. Empty water from buckets, cans, pool covers, flowerpots, pet water dishes, birdbaths, and other items daily because mosquitoes lay eggs in standing water.

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## Research Spotlights TV Portrayal Of Organ Donations, Spurs Advocates

***Purdue University research about how organ donation is portrayed on television has inspired a Hollywood advocacy group.***

***Susan Morgan, associate professor of health communication, has found that inaccurate storylines about organ and tissue donation stop people from registering as organ donors. As a result, Donate Life Hollywood was created to discourage the "stolen-kidney" storyline from television and film, said Tenaya Wallace, director of the national campaign.***

***"Professor Morgan's research has inspired us to put Hollywood on alert," Wallace said. "We have been passive about this problem, but we now have evidence that what viewers think about organ donation is directly related to what they see in television storylines. This is not just about creative license. We want Hollywood writers, producers and executives to know there is a public health impact."***

***The most commonly portrayed inaccuracies involve black markets for organs, doctors not saving a potential donor's life, organs being stolen from people and people with money receiving higher priority on waiting lists, Morgan said.***

***"During 2004 and 2005, organ donation appeared as a primary storyline on entertainment television in more than 80 episodes in medical dramas, police shows, comedy and daytime soap operas," Morgan said. "It is difficult to believe that none of these appearances presented organ donation in an accurate or positive light, but that is what we found."***

Morgan's follow-up study shows that viewers, especially those who had not decided if they would register as donors, were influenced by what they saw on TV.

***Donate Life Hollywood is producing DramAlerts for media and organizations about donation/transplant storylines before they air. The goal is for these alerts to inspire news stories about donation that use the storylines as a timely news peg. The campaign also will organize an effort called After the Show, in which talking points will be provided for advocacy groups and individuals who want to write letters to scriptwriters, producers and network executives about inaccuracies and offer praise for accuracy.***

Similar efforts made a difference in how HIV and AIDS was treated in film and television in the 1980s, and breast cancer before that. Today, it also can make a difference in how organ donation is depicted, Morgan said.

"Perpetuating myths keeps people from signing up," Wallace said. "We need to be vigilant. The real stories are so full of drama and inspiration and things writers are looking for. They are drama enough."

***One of Morgan's studies about how organ donation storylines are perceived will appear in the journal Health Communication this summer and another was published in Clinical Transplantation in 2005. The results of her most recent media study were presented at the annual meeting of the American Public Health Association as well as at the International Communication Association conference. Morgan also serves as a board member of Transplants Recipient International Organization.***

***The Organ Procurement and Transplantation Network and the Division of Transplantation Services estimate that more than 96,000 people are waiting for transplants and many will not receive a transplant in time. Fewer than 40 percent of Americans have signed organ donor cards, and only about half of their families consent to the donation of a loved one's organs. Hearts, intestines, kidneys, livers and lungs are just some of the organs that can be transplanted.***

Morgan also is leading the New Jersey Workplace Partnership for Life, which provides tailored health campaigns about organ donation in workplace settings. She is working with 45 New Jersey organizations, including Johnson & Johnson, Fuji Film, L'Oreal Paris, Ethicon, Pathmark, Robert Wood Johnson Hospital and the New Jersey Department of Labor, to encourage more people to sign up as potential organ donors. The project is supported by a \$1.67 million grant from the U.S. Department of Health and Human Services' Division of Transplantation.

The workplace program is seeing positive results by using each company's intranet site, newspapers, newsletters and posters to feature stories from co-workers about how organ donation has touched their lives, Morgan said.

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## New device offers alternative to heart transplant

More than 300,000 people die every year from an enlarged heart. For Gary Reed, 53, fueling up, revving up and mowing his own lawn are normal activities he never takes for granted. Just six months ago, Gary was too sick to walk more than a few feet on his own. "The only thing that was stuck in my mind at that time was death. I'm looking at death, eyeball-to-eyeball. There's no getting around it," said Reed. Gary suffered from advanced Cardiomyopathy. His heart was enlarged and couldn't efficiently pump blood through his body. Gary was often weak and out of breath. Even a pacemaker couldn't correct the problem. A heart transplant looked like Gary's only hope, until doctors suggested this, a new device called the HeartNet. The HeartNet is made out of a metallic material called nitinol, which conforms to the shape of the patient's heart. Researchers say putting on the sleeve reduces the stress on the heart and prevents it from getting bigger. "The weaker the heart gets, the bigger it gets. And the bigger the heart gets, the higher the risk of death," says cardiac surgeon Dr. Srinivas Murali. Surgeons insert the device through a tiny incision in the side of the chest onto the tip of the beating heart. Then, they slide it into place. The surgery takes just one hour. "It's like a second chance at life," says Reed, who was back on his feet within weeks thanks to a permanent "hug" around his heart. Doctors plan to study the effectiveness of the HeartNet Support System in 270 patients over the next two years. It could be a viable alternative for those who are not good candidates for heart transplants.

Source: <http://www.whcc.com/article/stories/S168182.shtml?cat=566>

## TAO-Rochester Board of Directors 2006/2007

| 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                      |          |  |                                    |           |
| Jerry Runion                    | 865-7461 | <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      |
| Mike Stelljes                   | 245-9579 | <a href="mailto:mstellje@rochester.rr.com">mstellje@rochester.rr.com</a>           | Treasurer                          | 2007      |
| Sally Stelljes                  | 245-9579 | <a href="mailto:salstell@rochester.rr.com">salstell@rochester.rr.com</a>           | Board Member                       | 2009      |
| Dennis Stenshorn                | 323-1392 | <a href="mailto:dstens1@rochester.rr.com">dstens1@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 Yendrzski                | 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/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



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Transplant Times  
TAO/Rochester  
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