



Transplant Times

Newsletter of Transplant Awareness Organization of Greater Rochester

March / April 2009

www.tao-rochester.org

1.888.664.1463

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TAO Meets

3rd Wednesday of the Month

at the

Al Sigl Center

1000 Elmwood Ave.

7:00 to 9:00 pm

For meeting room locations, refer to Membership Meeting column at right.

Note door numbers to enter building and then ...

FOLLOW TAO SIGNS

From the President's Desk

Greetings! I hope you all have begun to unwind and recover from the holidays. It is always a stressful time, and I, for one, am looking forward to spring. The winter has been especially harsh this year, and that, too, can be difficult to endure, especially for those of us battling chronic illnesses. I am often asked by people who know my story how it is that I always seem so "up beat". I think about that a lot, and the only thing that comes to mind is **ATTITUDE**.

First of all, if you are feeling down and sorry for yourself, look around. There are always others far worse off than you. Take stock daily of all of the blessings you do have, and embrace them. Reach out and help someone. That is always therapeutic for me. And most of all, tell those you care about the most how much you love, need, and appreciate them. I want to share a short story I read recently. It was on "Email Ministry", and the author is unknown. The title is, appropriately, **ATTITUDE**. The point is obvious, and I hope you enjoy it as I did.

ATTITUDE

There once was a woman who woke up one morning, looked in the mirror, and noticed she had only three strands of hair on her head.

Well' she said, 'I think I'll braid my hair today!' So she did and she had a wonderful day.

The next day she woke up, and noticed she had only two strands of hair. 'H-M-M', she said, 'I think I'll part my hair down the middle today!' She did, and had a wonderful day.



**Jerry Runion,
TAO President**

The next day she woke up and realized she had only one strand of hair on her head. 'Well', she said, 'today I'm going to wear my hair in a ponytail' So she did, and had a great, fun, day.

The next day, she woke up and noticed their wasn't a single strand of hair on her head. 'Yeah!' she exclaimed. 'I don't have to fix my hair today!'

Continued on page 7

Membership Meeting Guest Speakers / Topics

February 18

Dr. Steven Wittlin, Endocrinologist
"Diabetes and the Transplant Patient"
AMSA Board Room Enter Door #1

March 18

Susan Hartfield, PharmD
"Outpatient Pharmacology Program for Transplant Recipients"
CAFETERIA Enter Door #5

April 15

Kate Norway, RN
Nurse Leader 6-1600
"Post Transplant Care"
CAFETERIA Enter Door #5

NOTE: Location has been changed for March & April meeting

Holiday Party

The TAO Holiday Party was held on Saturday, January 17 at the West Brighton Fire Hall. The evening was spent eating and talking with fellow members and their guests. A good time was had by all that attended. Mr. Dominic's catered the meal and the TAO board provided the delicious appetizers, desserts and beverage. Hopefully Bonnie will share her recipe for the spinach & artichoke dip! The environment was conducive to getting to know each other and sharing experiences. I personally can't wait to do it again and hopefully the rest of you will be able to join us!

- Debbie Yendrzeski

Ben Smeenk, (Kidney Recipient),
Bernice Eblovi, (Liver Recipient)
& Mike Swete (Liver Recipient)



(From Left to Right)

Linda Orrvick, Richard Orrvick, & Jeff Orrvick (Kidney Recipient) Jana Currie, (Double Lung Recipient) (Standing)

Melanie Runion, Karen McCissock



(From Left to Right)

Richard McNamara, Suzanne McNamara, (Heart Recipient) Bill Pfutner, Carol Weinlander, (Kidney Recipient) Dave and Shirley Newman (Kidney Recipient)

United Network for Organ Sharing

Candidates listed as of 1/30/2009

83,153	Kidney
16,473	Liver
2,761	Heart
2,320	Kidney/Pancreas
2,014	Lung
1,579	Pancreas
225	Intestine
82	Heart/Lung

108,607 TOTAL

Total may be less than sums due to patients in multiple categories

www.unos.org

New Website Launched

United Network for Organ Sharing has launched its newly updated **National Donor Memorial** Web site.

Visit the site at www.donormemorial.org and read more about the new features on the UNOS Web site at www.unos.org/news/newsDetail.asp?id=1200

TAO Wish List

- Folders with the 2 pockets (any color)
- Pens
- Pads of paper that will fit in 2 pocket folder
- STAPLES gift cards to buy labels, etc.
- Fleece - 1 yd. quantities, plain & patterned to match
- Joann Fabric gift cards
- LCD Projector

Food Safety and Transplant

- Elizabeth Keirstead, RD, CNSD;
Transplant Nutritionist, University of Rochester

Foodborne illness simply means an illness caused from the food you eat, when a bacteria or pathogen has contaminated the food. The United States food supply is among the safest in the world. Food is contaminated, in more cases, from person to person or the way that it is handled.

Why is food safety so important in transplanted persons? It is more of a concern during times that a transplant patient is undergoing surgery, ill/weak and in the elderly or very young. These are times when the immune system is busy fighting off infection. Another concern is at the time of transplant when immunosuppressant medications are at higher doses to avoid organ rejection, leaving you more susceptible to catching infections. As you go further from your transplantation date the less risk you have of rejecting and less risk of illness. Foodborne illness can easily dehydrate, if infected, and can lead to more serious conditions. It may also take you longer to recover from the symptoms. You can do several things to be preventative. This is an exercise that is done for the general population within food industries, however is not covered in detail unless a person has an interest in learning more about food safety.

There are many places and stages where food can become infected. Certain foods are at risk more than others. Where the food is grown, shipped, transported or stored can make a difference. People involved in preparation of the food items can matter the most, since this may occur after the food has been cooked.

Briefly two places to pay close attention to are uncooked items and animal products and 4 key points are:

Clean Wash hands and surfaces often. Take care of your equipment to assure it is clean (cutting boards, utensils, containers, blenders, food processors, meat grinders)

Separate Use barriers if there are any juices or open areas to the food. Use plastic bags provided in the produce and meat sections. Notice if your storage areas are clean and keep them clean by placing food on platters/plate. Avoid cross-contamination: this occurs when you cut up animal products on the same cutting surface and place nonanimal foods on the same surface without cleaning. Never place a cooked food back onto a plate where raw food had been placed, for example while grilling outside.

Chill/store Care and store food promptly. Chill or freeze animal products to slow down bacterial growth. It is a good idea to use containers or bags that are no more than 3-4 inches high to allow proper air flow for faster cooling inside your refrigerator and freezer.

Cook Cook and reheat food to proper temperatures. Use a thermometer if necessary. Be aware of raw foods eaten by habit or in certain types of foods such as homemade eggnog or raw cookie dough.

Know your grocer and pay attention to how they keep their facility, equipment, workers and pest control. If you have a distance to drive keep an ice chest or cooler handy for highly perishable items, especially when the weather is hot. When shopping pay attention to expiration dates on perishable products. Avoid items that look/smell suspicious. Observe if ciders, milks and cheese are pasteurized, in most stores they are. However, import, ethnic, or farm stores they may have signs advertising as fresh or organic and may not pasteurize – ASK! Purchase cans and bags that are dent and puncture free. Avoid jars or plastic containers that are bulging or cracked. It is always best to shop for perishable items last. Refrigerate

them within 2 hours of cooking, within 1 hour if the temperature outside is above 90°F.

There are some high risk foods to avoid:

- Contaminated water, including recreational sources (lakes, swimming pools), untested wells and reservoirs
- Unpasteurized milk, soft cheeses made from unpasteurized milk, unpasteurized ciders.
- Raw eggs. Some recipes may be eaten raw or contain raw ingredients such as fresh Caesar salad dressing, cookie dough, homemade eggnog or ice creams.
- Foods grown in areas of contaminated water or fertilization practices (manure).
- Raw meats, fish or undercooked ground meats. For example tartar, sushi, oysters.

What to do if you suspect you have a food borne illness (general guidelines):

1. Consult your transplant coordinator or physician, or seek medical treatment as appropriate.
2. Preserve the food by wrapping it securely, label date & time consumed and freeze it.
3. Save any packaging materials such as wrapper, carton or can. Write down the date and time consumed and location where purchased.
4. If you are certain the food is contaminated or would like to alert someone of the possibility you can contact your local health dept. (to locate your local dept) http://healthguideusa.org/local_health_departments.htm. If the item is meat: USDA Meat and Poultry Hotline, 1-888-MPHotline (1-888-674-6854) for hearing impaired 1-800-256-7072

If there are any concerns or questions regarding this topic, please contact Elizabeth Keirstead, RD, CNSD; Transplant Nutritionist, University of Rochester.

Other helpful websites:

For food storage chart

www.foodsafety.gov/~fsg/f01chart.html

Food and Drug Admin. www.cfsan.fda.gov

Centers for Disease Control & Prevention

www.cdc.gov/foodsafety (1-888-232-3228)

Gateway to Government Food Safety Information

www.foodsafety.gov

National Center for Infectious

Diseases/Water-Related Diseases

www.cdc.gov/ncidod/diseases/water/index.htm

US Environmental Protection Agency Office of Water

www.epa.gov/OW

Website for assistance with traveling abroad;

Centers for Disease and Prevention Website National Center for Infectious Diseases/Traveler's Health

www.cdc.gov/travel/index.htm

Mark S. Orloff, M.D., a longtime Rochester transplant surgeon, researcher and educator, has been named chief of the Division of Solid Organ Transplantation at the University of Rochester Medical Center.

A professor in the Department of Surgery, Orloff has been a kidney and liver transplant surgeon at URMC for 17 years, since joining the faculty in 1991.

"I am pleased to appoint Dr. Orloff to lead an extraordinary team of health care professionals who have earned a reputation for hard work and a dedication to their transplant patients and their families," said Jeffrey H. Peters, M.D., Seymour I. Schwartz Professor and chair of the URMC Department of Surgery. "His strong leadership of the clinical and research initiatives will help further support the missions of the Department of Surgery and the Medical Center's priorities of its Strategic Plan."

Orloff hails from the West Coast, where he earned his undergraduate degree at the University of California - San Diego, and his medical degree at the University of California School of Medicine - Los Angeles. He did his training in general surgery at UCLA, where he

stayed on for his fellowship in transplantation. He did an additional fellowship in hepatobiliary surgery at the Hammersmith Hospital in London and the University of Bern in Switzerland. He was an assistant professor of Surgery at UCLA prior to joining the faculty in Rochester in 1991.

Orloff has presented more than 130 research abstracts, published more than 65 journal articles in publications such as the *American Journal of Transplantation*, *Liver Transplantation*, and the *Journal of Experimental Medicine*, and contributed to numerous transplant-related books. He also is an ad hoc reviewer for the *American Journal of Transplantation*, *Transplantation*, *Liver Transplantation*, *Gastroenterology*, *Hepatology*, *Annals of Surgery* and the *Journal of the American College of Surgeons*.

He is a member of the Society of University Surgeons, American Society of Transplant Surgeons, Transplantation Society, Society for Surgery of the Alimentary Tract, Association for Academic Surgery and the Rochester Academy of Medicine, as well as a fellow of the American College of Surgeons.



New Pharmacy Program for Organ Transplant Patients

University of Rochester Medical Center would like to introduce to the members of the Transplant Awareness Organization to a new pharmacy program which targets in the needs and prescriptions of solid organ transplant patients. Unlike other pharmacies that may not be familiar with the issues around transplant patients or stock needed medications, the Transplant Pharmacy Drug Maintenance Program, offered through the outpatient pharmacy at Strong Memorial Hospital, is dedicated to the needs of solid organ transplant patients.

Our transplant pharmacy team understands that having a transplant is a life changing event with the need for lifelong medication. Our pharmacists specialize in monitoring your medication regimen for proper medication use, drug dosing and drug interactions. Our goal is to provide you with comprehensive pharmaceutical care through open communication with our customers and the transplant team to ensure access to life saving medications.

In addition to our specially trained pharmacists, our transplant team also consists of billing specialists and support staff who can assist you with your medication needs. The services we provide include:

1. Comprehensive review of the medication regimen for drug interactions and appropriate dosing based on kidney and liver func-

tion and indication for each medication

2. Education as to purpose, dose and side effects of each medication
3. Access to discuss any medication issue with a specially trained pharmacist via a toll-free telephone number or e-mail
4. Face to face access to the pharmacist during clinic visits
5. Access to a billing specialist to assist with specific prescription coverage questions
6. Direct telephone contact to assist with obtaining prescription refills
7. An automated refill line to refill prescriptions during off hours
8. Convenient pick up in our outpatient pharmacy or **free** overnight delivery via Fed-Ex
9. Competitive medication pricing with the ability to set up payment plans if deemed appropriate
10. Over the counter items available at discounted prices.

If you are interested in learning more about our Transplant Pharmacy Drug Maintenance Program, you may call toll free at 1-888-424-8141 between the hours of 8-4:00pm Monday through Friday. You may also e-mail us at:

transplantpharmacyprogram@urmc.rochester.edu
We look forward to hearing from you soon!

Help Wanted

Editor or Co-Editors for Transplant Times

No experience necessary. Responsibilities include: gathering articles for newsletter; editing; proofing; sending materials to publisher; meeting deadline schedule; folding; labeling and mailing newsletter. Full support of Newsletter Committee available. Must have computer, some knowledge of Publisher a plus.

If interested, contact Debbie Yendrzkeski at auggieday@aol.com

Secretary

Duties: taking minutes at Board and General Meetings, typing minutes, emailing and/or mailing minutes to Board. Send get well, sympathy and thinking of you cards as needed. The Secretary is a member of the Board and expected to participate on a committee. Some work outside of once a month meeting times may be required. Mini recorder available to record meeting discussions. If interested, please contact Sandy McNitt, sdmcnittot@aol.com or call (585)359-8015.

Sandy's Story

- by Sandy McNitt

My name is Sandy McNitt and I am your neighbor. In 1987 at the age of 21 I was diagnosed with a rare and fatal, lung disease called Lymphangioleiomyomatosis (LAM). LAM results in a progressive destruction of healthy lung tissue caused by cysts and abnormal growth of smooth muscle cells, not usually found in the lungs. Symptoms may include shortness of breath, cough, collapsed lung, chest pain, or fatigue. I had been active and healthy until my diagnosis, so this took my family and me by surprise.

After developing this disease, I did my best to stay as healthy as I could but I still progressed and eventually required oxygen to perform my everyday tasks. I worked as an Occupational Therapist for 13 years at a rehabilitation hospital in Schenectady, NY. I moved back to my hometown in 2004 to be near my family and have lived in Henrietta, NY since. I guess you never know when your life will be changed by the diagnosis of a life threatening illness. I have lived half my life with LAM and currently there is no treatment or cure. Research is being done, thanks to The LAM Foundation. For more information, visit their website, www.thelamfoundation.org.

The reason for sharing my story is to give a personal perspective to a serious problem. I will need to pursue lung transplantation in the near future. I am a volunteer for the Rochester Eye and Tissue Bank and Finger Lakes Donor Recovery Network. I help to raise awareness for eye, tissue, and organ donation.

Currently, I represent 1 of nearly 100,000 people waiting for a life saving organ transplant in the United States, 10% of those individuals are in NY State. About every 13 minutes someone is added to this list. What most people don't realize is this wait could be eliminated if more people considered becoming a donor. I don't say this lightly because it is a very personal choice. I am not writing this just to benefit myself. I will pursue transplant in Ohio and will rely on donors there. I am also the Vice-President of the Transplant Awareness Organization of Greater Rochester. This group gives support to those waiting for transplant; transplant recipients and their families. I am encouraged as I wait, that transplantation works since I have seen so many individuals living productive and full lives after their transplant. For more information visit www.tao-rochester.org

Give the Gift of Life by enrolling in the NY State DONATE LIFE Organ and Tissue Donor Registry. Signing your license may not be enough. As of July 23, 2008 anyone who enrolls will be in the consent registry, permission from your next of kin is not required. Those who enrolled prior to this date are "intent" only; therefore you are encouraged to re-enroll.

For more information about donation or to receive an enrollment donor form, contact Rochester/Finger Lakes Eye & Tissue Bank (585) 272-7890 or Finger Lakes Donor Recovery Network (585) 272-4930 or visit www.retb.org or www.donorrecovery.org

Your decision to become an organ or tissue donor may someday "donate life" to someone waiting for a second chance.

Calling All Living Kidney Donors

Are you a living kidney donor? Do you know someone who is? The NKF invites you to join us for *The Tree of Life: A Celebration Honoring Our Community's Living Kidney Donors*. Saturday, March 28th, 9-11 a.m. at Locust Hill Country Club. Contact Mary Jones at 585-697-0874 ext. 27, mary_jones@kidney.org for more details or to request an invitation.

Are You Taking Cellcept?

- by Dave Johnson

Are you taking Cellcept as part of your immunosuppressive regimen? If so, you may be interested in some great products from Roche Laboratories, Inc.

Roche has a program for Cellcept users called Cellcept for Living. You can sign up at www.cellceptforliving.com. Periodically they will send you free gifts, coupons and information by mail. In the past I've received trinkets like pens, mugs, a pedometer and a nice portable CD player. Yesterday I received a coupon card worth \$100 toward a Cellcept prescription or refills.

Financial Contributions

*We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO. If we forgot you, please let us know so that we may post in next issue. **THANK YOU.***

Norm & Phyllis Breen
 Rob Kochik
 Guy & Fran Valone
 Odenbach Family Trust (Janice Odenbach)
 Ann Finger
 Louis Mascaro
 Joanne Rourke
 Paula McKay
 Mike Swete

Editors Note:

We wanted to share this article that Sandy submitted for publication in another organization's newsletter. If you belong to a church group, organization, association or club, you may wish to submit an article to help raise awareness of TAO.

Transplant Anniversaries

Guy Valone	Kidney	Jan
Pat Stewart	Kidney	Jan
Ann Marie Scroger	Liver	Jan
Elizabeth Brian	Liver	Jan
Dan DiIulio	Liver	Jan
Frank Imburgia	Heart	Jan
Helen Cox	Kidney/Pancreas	Jan
Chuck Liberi	Kidney	Jan
Louis Mascaro	Kidney	Feb
Patricia Legge	Kidney	Feb
Aisha O'Mally	Heart	Feb
Jerry Bluff	Lung	Feb
Joseph Nolan	Kidney	Feb
Chester Palozzi	Liver	Feb
Matthew Felo	Lung	Feb
Greg Post	Kidney	Feb
Shirley Newman	Kidney	Feb
Dennis Wittman	Liver	Mar
Jan Sharp	Kidney	Mar
Thomas Louer	Liver	Mar
Rita Callaghan	Liver	Mar
Robert Hadsell	Liver	Mar
Paula McKay	Kidney	Mar
Karen Gledhill	Kidney	Mar
Penny Sayles	Kidney	Apr
Ginger Zimmerman	Heart	Apr
Linda Marie Serenka	Kidney	Apr
James Graczyk	Liver	Apr
Asya Zarkhi	Kidney	Apr
Bob Ray	Heart	Apr

Please accept our apology for the errors in the anniversary list in the last issue. This issue contains the anniversaries for January, February, March and April. We strive to be accurate and include everyone. If we've omitted your name please let us know so we may correct this. Thank you for your understanding.

Another Day Closer

Everyday is another day closer, closer to what you may ask?
 It's Another Day Closer to happiness and fulfillment,
 Another Day Closer to independence and freedom,
 Another Day Closer to your family and loved ones,
 For you see I have these, but yet I don't, they are just out of reach,
 But yet so close I can see them and taste them,
 Another day closer to resuming my life and moving forward,
 For you see I am stuck here in this room,
 Like a deer in headlights just waiting and wondering,
 What's next?
 For you see Another Day Closer means all of this and more,
 But for me Another Day Closer means;
 Another Day Closer to transplant,
 Another Day Closer to receive a gift from above,
 Another Day Closer for a chance at LIFE!!!
 That is what Another Day Closer means to me.

- written by John Stapleton

WELCOME new members

Welcome to our newest members Norman & Phyllis Breen! Originally from Michigan, Norm met Phyllis in West Virginia 38 years ago on a blind date set up by his army buddy, her brother. They have one daughter, Clairissa, and share their home in Fairport with a dog and a cat. Norm retired from Xerox after 33 years due to his health and received his heart transplant in May of 2007 at Strong Memorial Hospital. Phyllis continues to work and was just promoted to Vice President of First Choice Educational Tours, Group Sales Department. Congratulations Phyllis!

Norm keeps busy with his one-man printing business, woodworking, photography and computers. The Breens joined TAO for educational aspects and the social network of people in similar situations. They have jumped in with both feet, already making blankets for the *Blanket Project* and joining the Newsletter Committee. Phyllis always asks, "What kind of help do you need?" They look forward to volunteering at Strong and health fairs and possibly coordinating a fundraiser for TAO. We are glad to have them on board and welcome their help.

Wishes of Wellness

"Our healing thoughts go out to Sally Stelljes. We hope you're on your feet again soon!"

Let us all keep those listed in our thoughts as each continues to recuperate and offer support as needed. If you are aware of members that we should list in *Wishes of Wellness*, please call TAO and leave a message at 1-888-664-1463.

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National
DONATE
LIFE
Month

From the President's Desk ...continued

Attitude is everything. Be kinder than necessary, for every person you meet is battling something. Life isn't about waiting for the storm to pass.....It's about learning to dance in the rain !!!!!

Simple, but so powerful! I hope you can make our meeting this month. We have a great guest speaker, and, as always, time to sit together, share our thoughts and experiences, and support each other.

We are looking for anyone who would like to help as the Secretary of TAO. This position is an Officer on the Board. In addition, we also need some help on the Newsletter committee. If you are at all interested, or if there is something else you would be interested in, let us know.

I'll see you on the 18th, same bat time, same bat channel! Be there or be square! Sorry, I got a little carried away. See Ya !

Jerry

Gift IDEAS

A contribution to TAO in honor of or in memory of a loved one, special person or relative is always a thoughtful gift. It is a gift of caring that you can give on any occasion - a birthday, an anniversary or a special holiday.

Please make your check payable to:
Transplant Awareness Organization
Mail to: TAO, PO Box 23552
Rochester, NY, 14692-3552

Tops Never Stops . . .

Tops cards help TAO raise money. The Tops Gift Card Program allows our nonprofit organization to earn a 5 % return by selling Tops Cards. The more we sell, the more we earn. The cards are available in \$25s, \$50s and \$100s.

Join a Committee

Sunshine , Newsletter, Membership, Awareness
Interested? Call
1.888.664.1463

Transplant Times

Deadline

For:
May / June issue:

Monday, March 30

Submit

Articles /ideas email to:
aggieday@aol.com
kguarino@rehpb.org
or send by mail to:

TAO
PO Box
Rochester, NY
14692-3552

TAO www.tao-rochester.org

**G
O
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To act as a support group for transplant candidates, transplant recipients and their families.

To provide education and information on transplantation issues that surround it.

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.

Board of Directors & Officers

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Jerry Runion
jgruion@rochester.rr.com
(585) 733-3422

Vice President

Sandy McNitt
sdmcnittot@aol.com
(585) 359-8015

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Return service requested

PO Box 23552
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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- checkbox New Member checkbox Renewal checkbox \$10 Family checkbox \$10 Institutional
checkbox unable to make dues payment at this time Date _____

Extra contributions to help our organization are always welcome, and are tax-deductible. Make checks payable to::
TAO of Greater Rochester, PO Box 23552, Rochester, NY, 14692-3552.

Name (please print) _____ Spouse/companion _____

Address _____ City _____ State _____ Zip _____

Phone () _____ E-mail _____

- checkbox Candidate checkbox Recipient checkbox Family Member checkbox Donor Family checkbox Friend checkbox Professional

Candidate/Recipient information: # of Transplants _____ Hospital _____

Date(s) _____ Organ(s)/Tissue(s) _____