



A newsletter of the Transplant Awareness Organization of Greater Rochester  
Providing support, understanding, education & resources for transplant recipients, candidates & their families

# Transplant Times

October - November, 2014

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

1.888.664.1463

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### Membership Meeting Guest Speakers / Topic October 20

Curtis Haas, Pharm. D., FCCP, BCPS

### November 17

Cooking Demonstration with Karen Miltner

### TAO Meets

**3rd Monday of the Month  
6:30 P.M.**

**Christ Episcopal Church  
Fellowship Room  
36 South Main Street  
Pittsford, NY**

## A Message from the President



I am back from the Transplant Games of 2014. We had a lot of fun and we met a lot of donor families, recipients, and family support people. Even though it was very hot in Houston it was also a lot of fun.

We have an exciting year ahead with speakers and of course our holiday party and summer picnic. We will continue to have a light snack at each meeting.

In October, we will have Curtis Haas from Strong pharmacy to discuss transplant drugs. In November, Karen Miltner will do a cooking demonstration with a Thanksgiving theme. In December, we have our Christmas gift wrapping day at Barnes and Noble. Our Holiday Party will be held on a Saturday in January. We have a lot of events coming up so look on line at our website or in the *Transplant Times*.

National Donor Sabbath is on November 14-16, please look for opportunities to try encouraging others to sign up to be an organ and tissue donor. In 2013 there were 10,500 people on the waiting list for an organ. 1,500 were on the list for more than a year, 539 died while waiting and 381 were too sick to receive an organ. New York State is third from the bottom of the list of all the states.

We are still looking for volunteers to work on some of the projects mentioned in this letter; there are other areas where we can always use help, like the newsletter, hospitality, and membership.

Winter will soon be here so get your flu shot and stay warm. Remember to support our group and others to promote organ and tissue donation.

*Matt Felio*

## 2014 Transplant Games of America

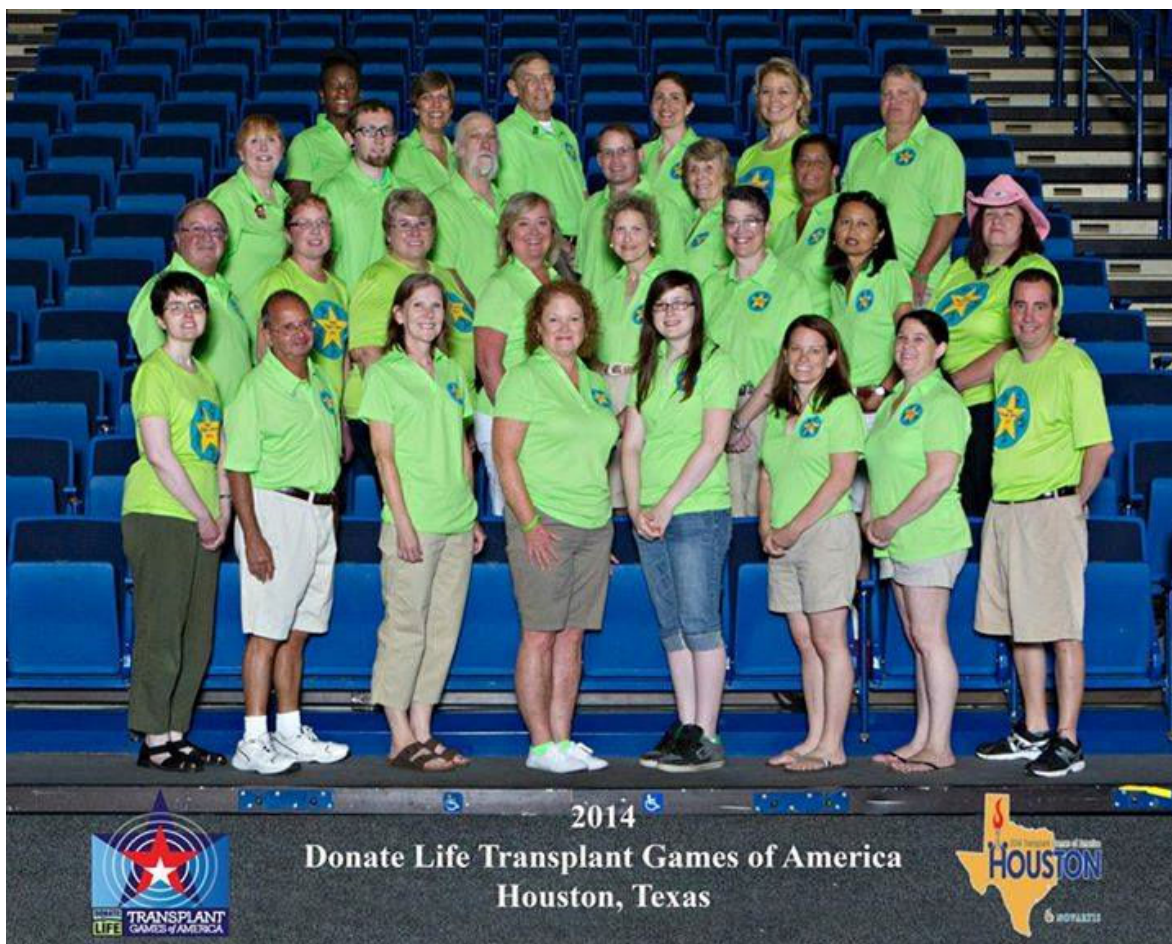
Several TAO members attended the Transplant Games of America in Houston, Texas, July 11-15. The competition is a multi-sport festival event for individuals who have undergone life-saving transplant surgeries. Competition events are open to living donors, bone marrow recipients and organ, eye and tissue recipients. There also were events for donor families that honored both them and their loved ones for their selfless Gifts of Life.

Our President Matt Felo, Bonnie Haefner, Benjamin Smeenk, Mike Swete, Joanne Shum along with nine others made up team Finger Lakes. Matt was a first time attendee, stating "I returned from the Transplant Games with a renewed energy to sign people up to become organ donors. Seeing 3,500 donors' families, recipients, and family support and the enthusiasm of the different organizations has given me a different outlook. Talking with the participants and hearing their stories was both uplifting and sad."

Despite the hot weather the team returned home with 8 medals. Bonnie took the gold medal in badminton and

came in fourth in table tennis in her age division! Congratulations Bonnie!

These were Bonnie's sixth games and it's just as emotional as the first year! Bonnie got to reconnect with a fellow competitor from the previous games that was awaiting a second heart transplant and could barely compete. This year the woman came running toward Bonnie, calling her name, healthy after surviving another heart and kidney transplant! "You feel so connected to everyone because you've all experienced the same things" said Bonnie. Bonnie is also representing donor families having been able to donate her Mom's corneas. "It's wonderful meeting people, thanking the donor families, you feel everyone is so happy to be alive, it's a very uplifting experience" said Bonnie. "The temperatures were in the high 90's yet it felt like a hundred and ten degrees," said Matt. Matt and Bonnie agreed and said, "It is an amazing experience and we are hoping to make the games in Cleveland in 2016."



# Transplant Anniversaries

Susan Bennett	Kidney	October	1998
Bernard Blocchi	Liver	October	1996
Claudia Ciresi	Liver	October	1994
Michelle Halloran	Kidney	October	1997
Dave Johnson	Liver	October	2000
Dennis Kovel	Kidney	October	2001
Louis Latorre	Liver	October	2007
Bob Legge	Kidney	October	2009
Thomas Murphy	Liver	October	2009
Keith Oliver	Liver	October	2002
Carol Pfuntner	Kidney	October	2001
Carrie Rodriguez	Kidney/Pancreas	October	2005
Marsi Rohde	Kidney	October	2013
Mary Stein	Liver	October	2005
Donna Crosby	Liver	November	2003
Peter Davis	Liver	November	1996
Bob Munn	Liver	November	2010
Daniel Phillips	Liver	November	2009
Jerry Runion	Kidney	November	1994
Alice Sceusa	Liver	November	2002
Michael Stelljes	Liver	November	2001
Mike Swete	Liver	November	1995
Eric Wright	Lung (2)	November	2006



## Transplant Times

### Submission Deadline

For December 2014 - January 2015 issue:  
November 3, 2014

Articles /ideas email to:  
auggieday@aol.com or send by mail to:  
TAO, PO Box 23552, Rochester, NY 14692-3552

## Welcome New Members

Larry Rosner  
Marcia Marcheson

## Wishes of Wellness

Our healing thoughts and prayers go out to **Kathy Wesline, Dave Spiro and Phil Travis**



## 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

### Board of Directors & Officers

- |                       |                   |                   |
|-----------------------|-------------------|-------------------|
| <b>President</b>      | Matt Felo         | Linda Barnard     |
| <b>Vice President</b> | Debbie Yendrziski | Geoff Foley       |
| <b>Treasurer</b>      | Karen Gledhill    | Karen Guarino     |
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| <b>Membership</b>     | Norman Breen      | Amy James         |
|                       |                   | Janice Odenbach   |
|                       |                   | Karen Porterfield |



## September's Featured Speaker . . MaryAnn Lester



(L) TAO Board member Geoff Foley with MaryAnn Lester whose topic was "The Importance of Oral Health Pre- and Post-Transplant"



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[www.facebook.com/TaoOfRochester](http://www.facebook.com/TaoOfRochester)



**SHARE IT WITH OTHERS**

**WE NOW HAVE 290 LIKES!**

### Join a Committee

Sunshine, Newsletter,  
Membership, Awareness  
Interested?

Call **1.888.664.1463**

### Give Delta Sonic Car Washes for the Holidays and help TAO at the same time!!

TAO will be offering Delta Sonic car wash gift cards in time for the holidays. These make the perfect stocking stuffer or buy a few for yourself! **We are offering \$5 Gift Cards at a discount of 2 for \$5 (yes, half price!!).**

The gift cards will be available after December 10. You can pre-order by sending a check for the number of gift cards you'd like to **TAO, PO Box 23552, Rochester, NY, 14692-3552. Please include your name and address so we can send you the cards when they come in!** Orders may also be placed online by going to [www.tao-rochester.org](http://www.tao-rochester.org) and click on the link.

The cards retain their full \$5 value through February 10, 2015, and are valued for \$2 for 60 days after February 10, 2015. All proceeds go to support TAO programs. Thank you for your support!



## Save the Date . . .

### Sunday, October 5 2014 Upstate and Western NY Kidney Walk

#### @ Frontier Field

Check-in time: 9:00 AM  
Start time: 10:30 AM  
Contact: Jessica Cipolla @  
jessica.cipolla@kidney.org  
(585) 598-3963 ext. 30

### November 14 – 16 National Donor Sabbath

During National Donor Sabbath, faith leaders from many religions, donor families, transplant recipients, and donation and transplantation professionals participate in services and programs to increase awareness of the need for the lifesaving and enhancing gifts passed to others through transplantation and encourage people to sign up in their state registry as organ, eye, tissue, donors.

Start now. Ask your faith leader to support organ, eye and tissue donation during National Donor Sabbath by; mentioning it in a sermon, including information in a bulletin, providing donor cards to congregants, or letting a transplant recipient share their personal story.

If you are planning to recognize National Donor Sabbath at your place of worship and would like donor cards and other materials to hand out, contact Kathy Miller @ kmiller@rehpb.org or Amy James @ amy\_james@urmc.rochester.edu

### Saturday, December 20 Gift Wrapping at Barnes and Noble Pittsford Plaza

Details to follow in the next newsletter.

## 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.

## Support Group Meetings

### "Open Airways" - Lung Gathering Group

Thursday, October 16 @ 12 noon

Winfield Grill 647 Winton Road N, Rochester

Thursday, November 20 @ 12 noon

Hicks and McCarthy - 23 S. Main St. Pittsford

### Heart Transplant/VAD Support Group

\* Thursday, October 9 @ 6:30 p.m.

Speaker from the Finger Lakes Donor Recovery Network

\* Thursday, November 13 @ 6:30 p.m.

Speakers Nina and Denise, Nurses for the Heart Failure / Transplant / Artificial Heart Program

**\* All Heart Transplant/VAD Meetings are held at the 7th floor conference room near the 7-3400 Corridor unless otherwise indicated.**

## Shopping at Amazon?

Don't forget, TAO can benefit from your purchases. Simply go to [www.tao-rochester.org](http://www.tao-rochester.org) and click on the Amazon widget and do your shopping!

## United Network for Organ Sharing

*Candidates listed as of 9/14/2014*

<b>101,307</b>	<b>Kidney</b>
<b>15,659</b>	<b>Liver</b>
<b>4,046</b>	<b>Heart</b>
<b>2,056</b>	<b>Kidney/Pancreas</b>
<b>1,617</b>	<b>Lung</b>
<b>1,185</b>	<b>Pancreas</b>
<b>259</b>	<b>Intestine</b>
<b>53</b>	<b>Heart/Lung</b>

**123,433** TOTAL

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

[www.unos.org](http://www.unos.org)

## NY Falls Short of National Average in Organ Donation

*Michael Virtanen  
Associated Press*

Albany — Far fewer New Yorkers have signed up as organ donors than Americans as a whole, prompting the state to seek help boosting enrollment and shortening its list of patients who die waiting.

A study from Excellus Blue Cross Blue Shield showed 22 percent of New York adults in the donor registry, compared with 48 percent nationally. The study also said 539 New Yorkers died awaiting a transplant last year while others became too sick and ineligible.

"There are too many New Yorkers losing their lives when they could and should be saved," said Aisha Taylor, executive director of the nonprofit New York Alliance for Donation.

Currently, 8,667 people are on New York's list for a kidney and 1,352 for a liver. Almost 1,500 of them have been waiting more than five years. Others need a pancreas, heart, lung or intestine.

One reason cited for New York's relatively low rate is leaving registration in the hands of the state. Eight of 10 states with the highest sign-up rates, ranging up to 84 percent, have nonprofits running their registries, according to donation advocates.

New Yorkers can sign up when they renew their driver's licenses or register to vote, or at other times through the Department of Motor Vehicles online. The state Health Department is drafting a bid request for outside help to increase registration.

So far, 2.5 million adults statewide have given legal consent to donate their organs when they die, which was authorized under state law in 2008. Another 950,000 indicated their intent to do so after the database was first established a decade earlier, though still needed for those would-be donors would be the consent of their health care proxies, legal guardians or heirs.

Advocates want that group to re-register to give their legal consent, as well as people who may have simply signed their driver's licenses without entering the information by computer into the actual registry. They say that would both clarify a would-be donor's intent and take pressure off the family in what can be an emotionally wrought situation.

"It is a legal consent, just as if you signed a paper in front of two witnesses," said Dr. Frank Dubeck, vice president and medical director at Excellus, the nonprofit health insurer based in Rochester. He believes many more organs are transplanted as a result of registrations than if medical personnel simply approach families in the hospital after someone has died. Unless a registered donor has placed particular restrictions, any of their viable organs or tissue can be recovered for transplants, he said.

Donation is limited to those who are medically eligible, and who don't die of diseases like metastatic cancer that would make their organs unusable for someone else.

The New York State Organ Procurement Organizations last year reported recoveries from 352 organ donors in New York, including 76 who were on the state registry. Several organs can be taken from one donor

New York has 17 hospitals that have collectively done 38,361 transplant surgeries from 1988 through April of this year in New York City, Long Island, Buffalo, Albany, Syracuse, Rochester and Westchester County. They did 1,670 last year, fewer than in the previous eight years, and 572 in the first four months of 2014, according to the federal Organ Procurement and Transplantation Network. Virtually any hospital can recover organs from deceased donors, with transplantation organizations sending in teams to do it.

They are distributed to patients on the transplant list based on scores that include medical urgency and geography, meaning the time it takes to deliver them. "We do try to match organs locally first if we can," said Joel Newman, spokesman for the United Network for Organ Sharing. The nonprofit manages the nation's organ transplant system under a federal contract.

### United Way Reminder:

You can donate a portion or all of your United Way contribution to the Transplant Awareness Organization. As a donor designation agency, our agency number is 2493.



**Flu Season is approaching.  
Get Vaccinated!**

# Your Medications Are Essential to Your Transplant Health

## Understanding the importance of taking medication

Taking your medications exactly as prescribed by your doctor is critical to your transplant health. A survey showed that organ loss was 7 times higher in people who were not following their doctors' instructions. Examples of not following your doctor's instructions include: not taking your full dose of medication, not taking your medication at the same time every day, and not keeping scheduled medical appointments.

## Preventing organ rejection

After surgery, your immune system often thinks that your new organ is a foreign infection and tries to clear it from your body. This natural response is known as organ rejection. Your doctor gives you medications (called immunosuppressants) to help prevent organ rejection

and allow your transplant to function in your body. Taking your immunosuppressants and other medications exactly as prescribed is one of the essentials to transplant success.

## Staying dedicated to your health

To help protect your health and that of your transplanted organ, it is very important to take your medications, even if you're feeling great. Your medications are what are helping you feel better. Remember, rejection can happen at any time—even many years after your transplant.

Missing doses of your medications can change the amount of drug in your blood. Irregular drug levels can lead to rejection and the loss of your transplanted organ. Be sure to follow your doctor's instructions, exactly. If you miss a dose of medication, call your doctor right away.

***Additional resources about transplant health are available at [TransplantExperience.com](http://TransplantExperience.com).***

## Helpful Tips for Staying on Track With Your Medications

Following your medication regimen and your transplant team's instructions can sometimes be difficult, but there are a lot of ways to help make it easier. The following table offers ideas that you may find helpful.

Common Issues	Helpful Tips
<b>Forget to take medication</b>	<ul style="list-style-type: none"> <li>• Use a pocket organizer to indicate times and medications to take</li> <li>• Organize your medications in a pill box with a timer</li> <li>• Write down all important information about each medication (for example, when to take, what dose, with or without food, etc.)</li> <li>• Make taking your medications a part of your daily routine (for example, take them after you shower)</li> <li>• Use an alarm that will remind you to take your medications at the same time each day</li> <li>• Ask your doctor if there is a simpler regimen you can follow</li> </ul>
<b>Difficulty refilling medication</b>	<ul style="list-style-type: none"> <li>• Use pharmacy services such as automatic refills and medication delivery</li> <li>• Mark the date on your calendar for when you need to refill your prescription</li> </ul>
<b>Medication cost</b>	<ul style="list-style-type: none"> <li>• Talk to your transplant team about insurance assistance programs and medication financial support programs</li> </ul>
<b>Side effects</b>	<ul style="list-style-type: none"> <li>• If you are experiencing bothersome side effects, talk to your doctor about ways to help manage them—don't stop your treatment</li> <li>• Keep phone numbers of your transplant team with you—store the numbers in your mobile phone or keep them on a card in your wallet</li> <li>• Work with your transplant team to develop a nutrition and exercise program that may help you feel healthier and stronger</li> <li>• Ask your doctor if there are different approaches and options to help reduce your side effects</li> </ul>
<b>Getting to your appointments</b>	<ul style="list-style-type: none"> <li>• Keep your appointment card in your wallet as a reminder</li> <li>• Write your appointments on your calendar so you see them often</li> <li>• If your cell phone has a reminder feature, set a reminder for your appointment day and time</li> <li>• If you cannot drive, talk to friends and family when appointments are made to see if someone can provide a ride</li> <li>• Check public transportation schedules for convenient times to make appointments</li> </ul>



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Subscriptions@tao-rochester.org

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TAO PO Box 23552 Rochester, NY 14692-3552



TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- DUES: \$20 Family \$100 Institution New Member Renewal Date unable to make dues payment at this time

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

- Candidate Recipient Family Member Donor Family Friend Professional

Candidate/Recipient information: # of Transplants Hospital

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

If you do not wish the date of your transplant to be published in the Transplant Times each year on your anniversary date, please check.