



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

# Transplant Times

August - September, 2014

www.tao-rochester.org

1.888.664.1463

## A Message from the President

### Inside this issue:

TAO June Picnic .....	2
Save the Date .....	4
Life Can Change in an Instant .....	5
High Season for Food Poisoning .....	6
Kidney Connection Comes to Rochester .....	7

It was great to see everybody at the TAO picnic. The food was really good and Debbie, Bonnie and Bev did a great job putting it all together.

Many people help keep our organization running smoothly. Our Vice President Debbie, not only works hard at putting together the picnic, Holiday Recognition Party, but she also helps Norm put together the newsletter, and spends a lot of time keeping our finances in check. Geoff Foley does a great job with the website and is always there to send out notices to the membership. Beverly our secretary keeps our minutes and helps with hospitality. Bonnie Haefner can be counted on to set up the food or snacks for the meetings, the picnic or the holiday party. Norm does all our printing and maintains the membership list and anniversary list. The board and officers spend a lot of time working to keep things happening throughout the year and making everything run smoothly. Thank you to all.

There is still a lot of summer left and we should all try to protect ourselves from the sun by using sun screen as some of the medications that we take make us more susceptible to skin cancer.

Also be aware of other summer hazards, like mosquitos for West Nile disease. Transplant recipients are at increased risk as medicines they take can make it hard to fight infections. When outdoors you should also beware of deer ticks which can cause Lyme disease; after you return from outdoor activity



check yourself for these critters that burrow under your skin.

Our September meeting will feature Mary Ann Lester, DDS who will give a presentation to our members about Oral health issues, pre- and post-transplant.

We hope to get Karen Miltner for a food demo at one of our fall meetings. I am sure that this will be a very enjoyable evening for everyone that attends.

Bob Munn passed away on July 2, 2014; our condolences go out to his wife Judy and his entire family. Bob and Judy have been a part of the transplant visitation team.

Remember that we are always looking for volunteers to help expand our group. In order to grow we need new ideas and people to help implement these ideas.

*Matt Felbo*

**Membership Meeting**  
**Guest Speakers / Topic**  
**September 15**  
**MaryAnn Lester**  
***The Importance of Oral Health Pre- and Post-Transplant***

## TAO Meets

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

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

## Thirteenth Annual Rochester River Run/Walk

The Thirteenth Annual Rochester River Run/ Walk was held on Sunday April 6, at Genesee Valley Park. The event was the most successful run/walk to date with 549 participants! Prizes were awarded to the top pledge collectors and runners in various age categories. \$18,000 was raised to benefit transplant recipients and their families.

Next year the run/walk will be held April 12, 2015. Hope to see you there!

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## May TAO Meeting



## TAO June Picnic

The TAO picnic was held on a sunny, tropical afternoon/evening at Buckland Park. Delicious food was devoured by over 30 TAO members and their families. The play area was enjoyed by the younger folks while some of the older folks played the washer toss. Transplant stories were exchanged as well as personal stories. Everyone enjoyed Geoff's shortbread cookies, maybe we can get him to share the recipe with us!



## Transplant Anniversaries

Tom Fuoco	Heart	August	2008
Lisa Faucz	Kidney	August	2008
Moiria Miller	Liver	August	2005
David Spiro	Liver	August	1997
Lisa Abbey	Heart	September	2008
Tom Arcara	Heart	September	2005
Ernst Baier	Kidney	September	2000
Philip Travis	Kidney	September	2011
Ivan Tzoontchev	Kidney	September	2000
Debbie Vernam	Kidney	September	2004
Marianne Benvenuti	Liver	September	2006
Marcia Marcheson	Liver	September	2008
Joanne Schum	Lungs (2)	September	1997

## 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

## Transplant Times

### Submission Deadline

**For October - November 2014 issue:  
September 5, 2014**

**Articles /ideas email to:**

**auggieday@aol.com or send by mail to:**

**TAO, PO Box 23552, Rochester, NY 14692-3552**

## Contributions

**Lori Laine**

**Geoff Foley**

**Joyce & David Davis** in memory of their daughter Stacia Faye Davies-Vogt's 42nd Birthday. (Donor Family).

## Our Sympathies

**We extend our sincere condolences to:**

**Judy Munn & Family on the passing of Bob Munn**

**The family of Patricia Bianchi**

## Wishes of Wellness

**Kathy Wesline**

**Phyllis Breen**

## Board of Directors & Officers

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### Membership

Norman Breen

Karen Porterfield

## Save the Date . . .

**Sunday, August 17 Donate Life Night** with the Rochester Red Wings. Contact Amy at 585-272-4930

**Sunday, August 24** the Transplant Games Team will be serving up garbage plates at the Red Wings game.

Come and support the Red Wings and the Transplant Games Team.

**Saturday, September 13 Sip, Savor, and Support**

A wine and beer tasting with food accompaniments. A fun evening to help support the work of the Harbor House of Rochester. 6 pm - 8 pm at the Doubletree Inn 1111 Jefferson Road, Henrietta, NY

**Monday, September 15 RETB Golf Tournament**

Rochester Eye and Tissue Bank will be holding their second annual Golf Tournament at Shadow Lake Golf Club. Please contact Karen at 585-272-7890 for more information. Golfers, donations and sponsors are welcomed!

### Join a Committee

Sunshine, Newsletter,  
Membership, Awareness  
Interested?

Call **1.888.664.1463**

### 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, August 21 @ 12 noon**

Zebb's Bar & Grill - 1890 Clinton Ave. S. Rochester  
- and -

**Thursday, September 18 @ 12 noon**

Hicks and McCarthy - 23 S. Main St. Pittsford

### Heart Transplant/VAD Support Group

**Thursday, August 14 at 6:30 p.m.**

Hosted by Melissa Guerin, LMSW Heart Failure /  
Transplant / Artificial Heart Program Social Worker  
- and -

**Thursday, September 11 at 6:30 p.m.**

Hosted by Melissa Guerin, LMSW Heart Failure /  
Transplant / Artificial Heart Program Social Worker

### All Heart Transplant/VAD

Meetings held at 7th floor conference room  
near 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

### United Network for Organ Sharing

*Candidates listed as of 7/25/2014*

<b>101,008</b>	<b>Kidney</b>
<b>15,770</b>	<b>Liver</b>
<b>4,010</b>	<b>Heart</b>
<b>2,054</b>	<b>Kidney/Pancreas</b>
<b>1,615</b>	<b>Lung</b>
<b>1,188</b>	<b>Pancreas</b>
<b>263</b>	<b>Intestine</b>
<b>53</b>	<b>Heart/Lung</b>

**123,198** **TOTAL**

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

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

## Life can change in an instant

October 2013 I would first see a cute couple's photograph on Facebook pass it by and see it again. The photograph would be linked to a family's search for a kidney. Next to the cute couple's photograph I read "Let's find a Kidney" I thought I would read a story about people far away that I would have no connection to. It turned out this family lived ten minutes away from me and a man was in need of a kidney that was blood type O. I instantly thought I am reading this for a reason. The written message touched my heart and I thought what if this was me or my loved one? I am blood type O and I live so close to them. From that moment I decided to follow my inspiration. The Facebook link provided the website and phone number to Strong Memorial Hospital Solid Organ Transplant for Interested readers.

I have always been a compassionate person. I have been a registered organ donor on my driver's license since I was nineteen. I never had a family member or friend face the challenges of organ related illness.

I took the health survey online the next day after reading the article. I received a phone call from a living donor

advocate a few days later. The transplant program requested I meet and designate my wishes to the specific person before going any further. I called my potential recipient and his wife the very next day and met them the next Saturday. All parties were in shock that a complete stranger would offer to donate a kidney. My only answer was that I was inspired and motivated to help that man and his family. They decided to let me try.

After passing the health assessment and meeting my potential recipient, simple blood and urine samples were taken to start the initial process of matching my kidney to the recipient.

Months of blood and urine samples and extensive medical, social, and emotional testing took place for me as well as my recipient. Messages and a few more meetings took place between the recipient, family, and I.

I remember having feelings of hope and eagerness as the months passed. The process of becoming a living organ donor was long. No stone was left unturned by the donation process and team. I felt confident in the transplant program, team, and surgeons every step of the way.

Everything ended up being a match. Blood is matched even days before the surgery. I think both families were on edge for phone calls giving the green light for a surgery date. April 15<sup>th</sup> 2014. Once that phone call came everything happened very fast. I let my employer know my intentions months before I would be taking leave so they could prepare for my absence. I set up 4-6 weeks (less than the suggested 6-8 weeks) recovery time off from work.

Once the surgery date was set my administrator contacted the proper insurance company. The absence

counted as short term disability. The transplant team has social workers who are assigned to each case. I highly recommend taking advantage of handing your disability paper work to them.

The social workers are very fast and take care of doctors signatures. Through the transplant team they offered a voucher for a hotel close to the hospital the night before surgery for the donor and recipient. I have worked less than a year at my job. Through short term disability I was paid about \$120.00 a week. Luckily my family helped with small financial bills and groceries until I went back to work. All pre and post appointments, lab work, and surgery were covered by the recipients insurance and the kidney acquisition fund. Parking and travel cost are not covered although sometimes vouchers and organizations help with those costs.

Pre operation and post operation in the hospital was considered "text book" for my laparoscopic kidney donation. I had little to no complications. I stayed three days in the hospital working on pain control. Being on the same floor as my recipient, gave both families a chance to support one another. Recovery at home was tough for the first two weeks with sleep disturbances and incision pain. The transplant team makes every step of the way manageable and they are available to the donor 24 hours a day.

The donor is followed by the transplant team every few weeks, months then one year after donation. The programs services are available to the donor for life if needed in the future.

I went back to work full time as a dental hygienist five weeks after surgery. Everyone heals differently and may need more time off from work depending on their job and personal recovery.

My kidney recipient and his family stay in touch through Facebook, text messages, walks at our local lake, and dinner occasionally. I enjoy having become part of a wonderful family. My family was concerned and skeptical at first, but with education about living donation and being a part of my journey, having learned so much they are advocates now.

I was a healthy stable person whose life would not be adversely affected by kidney donation. The recipient's family allowed a stranger to come into their lives to help. I became fully informed and helped someone in an important way. I am thankful for the opportunity to have become a living donor and would do it all over again.

-Jaime DiPronio

## High Season for Food Poisoning

*One out of six Americans gets sick every year from some sort of foodborne illness*

By Deborah Jeanne Sergeant

"Summer complaint" is an antiquated term for severe bouts of diarrhea common during the warmer months of the year. In the very young, elderly and sick, the illness could be fatal. Though our grandparents and great-grandparents didn't fully understand what caused the illness, linking it to warm weather was apropos.

"People need to be aware summer's a time for fun and being outdoors, but one out of six Americans gets sick every year from some sort of foodborne illness, usually from poor food handling" said Beth Smythe, registered dietitian with the New York State Dietetic Association.

Food should remain within the window of 40 degrees to 140 degrees for only two hours and, in 90-degree temperatures, one hour. The number of bacteria in food that temperature doubles every 20 minutes. Nesting bowls of cold foods in bowls of ice may help improve its safety a little as can keeping food out of direct sunlight\*

Hot foods that are covered and in insulated containers such as slow cooker crocks may also be warmer than those transferred to non-heated containers.

If in doubt, "stick with things that are non-perishable like rolls, chips, and peanuts" Smythe said. "Fruit salad would take longer to spoil than a potato salad."

Sarah Guilbert, clinical dietitian with University of Rochester Medical Center, said that the 40 to 140 degree range is important to note because "bacteria love to grow at that temperature range" and that's how food becomes contaminated to the point where it can cause illness.

If you're the host, "keep the hot food in the oven above 140 degrees until it's ready to be served" she said. "Keep cold salads below 40 and only take it out [of the refrigerator] once you're ready to eat"

Smythe added, "Hopefully, most of what you cook right away you eat right away. They do have hot packs you can microwave before you leave and you can help keep food a warmer temperature, B if you can't keep it warm enough err on the side of caution and get rid of it."

You can also help guests to curtail illness by using smart food handling strategies. Bring raw and cooked foods in separate coolers. Don't serve cooked foods in the same containers that held them while they were raw.

Don't reuse ice in the cooler to cool drinks since it could be contaminated with bacteria. Thoroughly clean the picnic table and benches with hot, soapy water ahead of time or use a tablecloth. Offer hand sanitizer if soap and water aren't readily available.

Use different cooking utensils and plates for handling raw and cooked meat at the grill. Use a meat thermometer to check for doneness. Relying upon color or cooking time isn't as accurate.

It may seem like a lot of fuss for a picnic, but "small children, elderly or people with a compromised immune system or allergies can be more susceptible to foodborne illness/" Smythe said, "And healthy people get sick, too."

## TAO benefits from Fundraiser at HoJack Bar & Grill

HoJack Bar & Grill (R. 98 in Carlton, NY) held a fundraiser which included the band "Fuse" who donated their time, as well as raffles, games and a great time while raising transplant awareness.

Funds raised for Donate Life benefited UNYTS, FLDRN and TAO.



(L) Lori Laine with owners Dan and Brenda Conrad

**Don't forget to visit and like our Facebook Page**

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



**SHARE IT WITH OTHERS**

## Kidney Paired Exchange Update

Last year we performed three chains which means that three of our patients received kidney transplants through the NKR and KPD Programs. We have already performed one chain so far for 2014 and the year is still young so we are anticipating surpassing last year's total.

If you had a living donor who was evaluated in the past and deemed not a candidate because he/she was incompatible, please have the donor call our office at (585) 275-7753, press 1 if interested in paired exchange.

For more information on the Paired Exchange Networks, please visit these websites: National Kidney Registry (NKR) [www.kidneyregistry.org](http://www.kidneyregistry.org)

UNOS Paired Donation (KPD)  
[www.transplantliving.org](http://www.transplantliving.org)

## URMC Kidney Transplant Program Celebrates 2000th Kidney Transplant!

Our 2,000th kidney transplant was performed in February 2014. Patient Nathan Coons, 30, of Brockport is home and doing well.

This comes 47 years after our very first kidney transplant on April 12, 1966. This milestone would not be possible without the efforts of our dedicated staff (past and present) and the concerted efforts of the many departments and disciplines involved with the coordination and care of transplant recipients and living donors from pre-transplant to post-transplant.

We continue to explore and implement innovative ways to increase transplant numbers (such as our living donor referral system -BREEZE, Paired Donor Exchange, ABO Incompatible Program, Immune Desensitization). We continually strive to improve quality in terms of patient care and safety.

***Congratulations Kidney Transplant Team!***

## Changes in Kidney Transplant Allocation

The Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS) are in charge of reviewing the current kidney allocation policies and have selected committees to make recommendations for improvements. Many of the policies have been in place for the last 20 years when there were fewer people waiting for a transplant.

Nationwide there are more than 96,000 people listed for a kidney. Locally, the wait time has increased and many are waiting 5 years for a transplant. Because

there are not enough kidney donations to meet the current demand, policy changes have been redesigned to better match recipients to the potential function of a donor kidney.

In June 2013, the OPTN/UNOS Board of Directors approved the policies for deceased donor kidney allocation that will take effect by the end of 2014.

What does this mean for you?

**No one will lose time on the wait list.**

**If you started on dialysis prior to being listed you may gain time.**

For more information about the kidney allocation changes go to: <http://optn.transplant.hrsa.gov>

*From URMC Kidney Transplant Program News - April 2014*

## Kidney Connection comes to Rochester!!

The Kidney Connection Inc. is pleased to announce that we have added the Rochester area to our website.

People living in the Rochester area who are in need of a kidney can post their profile free of charge on our site and we promise to do everything we can to promote the site so your living donor can find you!

We have had several success stories. Complete strangers have come forward and have saved the lives of people in need in our area. We support neighbor helping neighbor so any non-medical expenses associated with living donation, e.g. travel, food and lodging, are minimal.

If you are on the waiting list for a kidney transplant and live in the Rochester area, we encourage you to send in your profile. Go to [www.kidneyconnection.org](http://www.kidneyconnection.org). Under Kidney Connections, click on the "Rochester Connection" and "Add to our Rochester List".

Write a story about yourself or if you are not comfortable doing that, then ask a family member or friend to write one for you. Please remember to submit a photo. We want you to stand out as a person and not just a number on a waiting list. This is a FREE site started by local women who either needed a transplant or who had a loved one in need. We do not profit in any way. Our reward is the satisfaction we feel when 2 people connect and a transplant takes place.

An article was recently published where Jason Swinehart and Jaime DiPronio were doing well after kidney transplant surgery that was performed at Strong Memorial Hospital in Rochester. Swinehart's family turned to Facebook. DiPronio, 28, who did not know the family, saw their post and agreed to donate one of her kidneys. There are amazing people in this country who are willing to be living donors. They just need to know how to find you

If anyone is interested in helping us as a local contact person we would appreciate it very much.

Please call Jeanette Ostrom at 716-450-8958 or email [rostrom@stny.rr.com](mailto:rostrom@stny.rr.com) if you have any questions.  
[www.wnykidneyconnection.org](http://www.wnykidneyconnection.org)



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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.