



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, 2013

www.tao-rochester.org

1.888.664.1463

## A Message from the President

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### Membership Meeting Guest Speakers / Topics

**September 16 @ 6:30 p.m.**  
"Pizza Party - Social Event!!"

**October 21 @ 6:30 p.m.**  
Doug Doehring - Genentech  
"Immunosuppressants -  
Cellcept and Valcyte"

### TAO Meets

**3rd Monday of the Month at  
6:30 P.M. (NEW TIME)**  
Christ Episcopal Church  
Fellowship Room  
36 South Main Street  
Pittsford, NY

It's summertime in Rochester and as usual, if you don't like the weather just wait a few minutes and it will change. As I was sitting here, it was raining and now the sun is coming out. When I went for my walk this morning it was 64 and now it is 75. The reason for my starting my letter this way is to remind everybody, especially transplant patients that they should use sun screen every day.

Whether it is sunny or not, when you leave the house put it on. Someone told me that his dermatologist suggested putting on sun screen (a broad spectrum SPF 50 minimum) as soon as you get out of the shower in the morning. You should also try to see your dermatologist for any sore spot or new bump that does not look right. The sooner you see them and have it taken care of, the better off you will be. These cancerous growths can grow very fast and it is best to have them removed early.

Coming in the fall the Transplant Games will host a Casino Night on October 19 8:00pm till 11:00pm at the Moose Lodge in Henrietta (the details will be on our website soon), we are looking for volunteers, and the money raised from events will go to the transplant games fund. The games are planned for July 11-15, 2014 in Houston, Texas. Hope to see you there.

Don't forget the Rochester Eye and Tissue Bank's Golf Tournament at Shadow Lake Golf & Racquet Club on September 16<sup>th</sup>. Check our website for



information about the tournament. This should be a fun event for both golfers and non-golfers.

Try whenever you can to support the local transplant groups at their events this year, it helps them help others.

It was great to see everybody at the picnic. Thank you for all that responded to our survey, there's still time if you haven't.

Hope you are having a nice summer and that we will see you at the next members meeting on September 16.

*Matt Felo*

## New Start Time for Meetings is now 6:30 PM

## Families and Caregivers

When you discover that your loved-one needs a transplant, you probably have many questions. As a family member or caregiver, you will need to support your loved-one throughout the transplant process. And if you are the primary caregiver, you'll need to understand the patient's health and medications.

### Understanding the Disease

As the caregiver, you'll need to understand the disease. Research it with the patient, and help the patient stay healthy before surgery. Know the danger signs of the disease, and have contact information for the patient's transplant team. Come with your patient to medical appointments and play an active role in the discussion. The more you know and understand the situation, the better care you can provide.

### Know the Medications

It is essential that you know what medications your loved-one is taking. Help your patient stay on schedule for taking the medications and learn about the side effects of each medication.

### Advocate for the Patient

You are a key advocate for the patient. You should find out the patient's wishes in the event he or she becomes incapacitated. You may also help by scheduling appointments, locating medical records, watching out for the patient's safety, and making sure the patient is receiving the care he or she needs.

### Physical Care

After surgery, the patient will need help with their physical care. You may need to help him or her get to appointments, organize medicines, make meals, and perform household chores. You may also need to help transport the patient.

### Emotional Support

Perhaps the most important part of being a patient's caregiver is to provide emotional support. Transplant surgery is an extremely stressful and emotional time. You can help ease the anxiety by listening and being supportive. Simply spending time with a transplant patient lets them know you care.

*Source: Johns Hopkins Medicine Web site*

## 10 Ways to Cope With Caregiving

1. **Get regular physical activity.** It's a good energizer, reduces stress, helps control blood pressure and cholesterol and helps maintain a healthy weight. Start by walking 15 minutes a day, even if it's just around the yard.
2. **Eat heart-healthy foods.** They give you more energy, combat depression and help prevent health problems.
3. **Take time every day to do something that you enjoy.** Read, listen to music, do crafts, cook - whatever makes you happy and relaxes you.
4. **Keep humor in your life.** Laughter is good medicine. It quickens the pulse rate, stimulates blood circulation, activates muscles, increases oxygen intake and fosters relaxation. And remember, laughter is contagious!
5. **Get out once a week.** Go to a coffee shop, attend events in your community or at your house of worship, take a class or visit a friend. Ask for help if your loved one needs constant attention.
6. **Treat depression and stress.** Recognize signs and symptoms. When they start to occur, do something about them. Get help. Talk it out. Admit your feelings.
7. **Take care of your business.** Keep your checkbook balanced, work when you need to, spend time with friends and family and keep planning for the future.
8. **Keep all medical and dental appointments.** If you're sick, you won't be able to do what you need to do for your loved one. Ask for help when you need to get away and take care of your health.
9. **Think positive.** Refresh your mind every day. Admit your limitations. Pat yourself on the back for the job you're doing. If you're feeling guilty or angry, it's time to take a break.
10. **Stay connected with the outside world.** Don't isolate yourself. Stay in touch, even if it's just by phone or online. Talk about something other than your situation and maintain an interest in the world outside your caregiving role.

*Source: American Heart Association and American Stroke Association*

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



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

**SHARE IT WITH OTHERS**

## 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.

# Annual TAO Picnic June, 2013

About 40 TAO members, their families and friends enjoyed this annual gathering held on Monday, June 18, at the Carmen Lodge in Brighton, NY. The weather was seasonal, the food tasty and desserts – as always – plentiful. Tableside conversations while munching appetizers were abundant. Those of you who couldn't attend this year, we hope to see you next year!



## Twelfth Annual Rochester River Run/Walk 5k

The Twelfth Annual Rochester River Run/Walk 5k was held on Sunday April 21, at Genesee Valley Park. The event was the most successful to date, raising \$16,000 to benefit transplant patients and their families. A cool spring morning was enjoyed by all. Prizes were awarded to the top pledge collectors and runners in various age categories.

A Middleport man traveled 60 miles to Rochester to celebrate his fifth anniversary of his new heart. "Today is my re-birthday" said Douglas Hemingway, 66, as he prepared to run with about 400 others. Participants, including 52 organ recipients, gathered for a ceremony prior to the race to recognize organ donors for their gift. The transplant team of surgeons, coordinators, hepatologists, cardiologists, nephrologists were there to honor the recipients, donors, as well as run. Candles were lit to honor all donors, living and deceased.

The Thirteenth Annual Rochester River Run/Walk 5k will be held April 2014.

## RIT's Imagine

Saturday May 4 RIT's Imagine was a huge success for Rochester Eye and Tissue Bank (RETB) and blifeny@RIT. Seventy-nine individuals enrolled in the NY State Donate Life Registry and many others stated they were already registered. RETB's bean bag toss was a hit with all ages. Those who tried to toss the bean bag through a hole, which represented the eye's pupil, was made even more difficult wearing glasses that simulated corneal blindness.



RETB's bean bag toss was fun and informative!



Volunteers at the blifeny@RIT table got Seventy-nine individuals enrolled in the NY State Donate Life Registry.



National Donate Life Blue and Green Day is one of Donate Life America's initiatives to register new organ, eye and tissue donors by drawing attention to this life-saving decision on both a local and a national stage.



MCC's Health, Physical Education and Wellness Club, under the guidance of TAO member Penny Sayles, kidney recipient, pose for their picture for the second annual Wear Blue & Green Day at MCC Friday, April 19.

## Skin Cancer Prevention

*From the International Transplant Skin Cancer Collaborative*

**Solid organ transplant recipients are up to 65 times more likely to develop skin cancer than people without transplants.**

*Three simple steps to follow*

### Step #1: Daily Sun Protection

Use broad spectrum sunscreen daily with SPF of 30 or greater.

1. Use protective clothing. This is defined as long sleeve shirts with conservative neckline and long pants with a tight fabric weave. Clothing such as this is usually considered by many as very hot, and thus not worn. However, this doesn't have to be the case. Loose, light-weight fabrics can be worn that are protective and stylish. Most clothing provides adequate protection as long as it is worn. The one exception to this may be a white cotton T-shirt, worn by many during the warm seasons, which provides a UPF of only ~5.
2. Wear a broad-brimmed hat. Baseball style caps provide no protection for the ears, which is a common area for skin cancer to occur.
3. Avoid sun exposure as much as possible between the hours of 10AM and 4PM. Attempt to concentrate outdoor activities into early morning, late afternoon, and evening. If your shadow is shorter than you are, you're likely to sunburn.
4. Avoid tanning beds. A tan obtained in a tanning bed does NOT provide protection from harm sunrays.
5. Wear sunglasses.
6. Seek shade.
7. Don't stay in the sun for prolonged periods of time, even if you are wearing sunscreen.
8. For more detailed information on each of these sun protective behaviors please check the Sun Smart site ([http://www.sunsmart.com.au/sun\\_protection](http://www.sunsmart.com.au/sun_protection))

### Step #2: Monthly Self Skin Examination

In a brightly lit room, with two mirrors, look over your entire skin surface. Do this once a month. A family member may assist with examination of the back, but if they are not consistently available, you can use two mirrors for this exam.

([http://www.skincarephysicians.com/SkinCancerNet/skin\\_examinations.html](http://www.skincarephysicians.com/SkinCancerNet/skin_examinations.html))

### Step #3: Timely Skin Examination by a Dermatologist

You should receive at least one complete skin examination by a dermatologist closely after the time of your transplant (within 4 months if possible).

Your physician will then recommend how often you should receive subsequent skin examination. This depends on the number of risk factors for skin cancer, and the amount of skin disease and sun damage that you have. It may range from every month to only as needed (provided that your primary care or transplant physicians were examining your skin on routine yearly exams.)

## Support Group Meetings

### "OPEN AIRWAYS" - LUNG Gathering Group

**August 15 at noon.** George's Restaurant, 1601 Penfield Rd., Rochester, NY (In the Panorama Plaza)

### HEART Transplant/VAD Support Group

**Thursday, August 8 at 6:30 p.m.**

Bethany Barney RD-Dietician  
All things Heart Failure

**Thursday September 12 at 6:30 p.m.**

Dr. Mark Nickels - Psychiatrist for all transplant programs.

Meetings are held at the seventh floor conference room near the 7-3400 corridor.

## United Network for Organ Sharing

*Candidates listed as of 8/1/2013*

<b>97,078</b>	<b>Kidney</b>
<b>15,796</b>	<b>Liver</b>
<b>3,554</b>	<b>Heart</b>
<b>2,067</b>	<b>Kidney/Pancreas</b>
<b>1,671</b>	<b>Lung</b>
<b>1,188</b>	<b>Pancreas</b>
<b>257</b>	<b>Intestine</b>
<b>48</b>	<b>Heart/Lung</b>

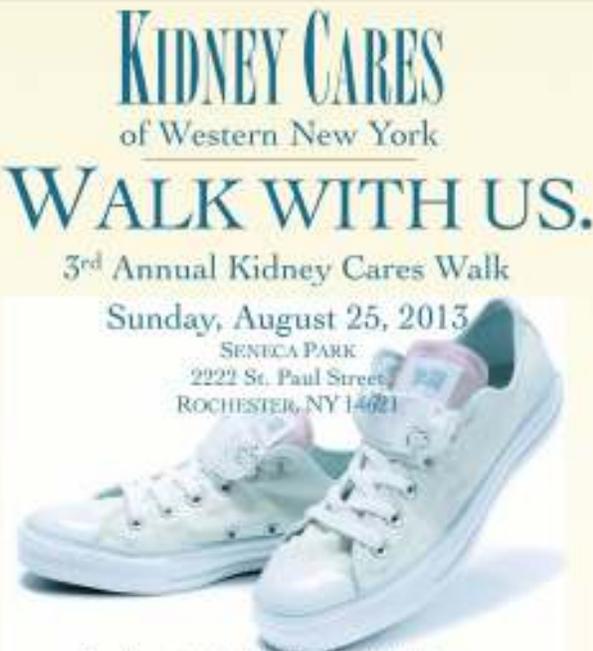
**119,103** **TOTAL**

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

**www.unos.org**

## Save the Date . . .

### Third Annual Kidney Cares Walk. Sunday, August 25



**KIDNEY CARES**  
of Western New York

**WALK WITH US.**

3<sup>rd</sup> Annual Kidney Cares Walk  
Sunday, August 25, 2013  
SENECA PARK  
2222 St. Paul Street,  
ROCHESTER, NY 14621

Register for the Walk or Build a Team.  
Go to - [www.kidneycares.org](http://www.kidneycares.org)

Sign-in: 8:30 AM  
Walk starts: 10 AM

Sponsorships available.

Our annual Kidney Cares Walk is one of our most important fund-raising events. With your help we can make our 2013 Kidney Cares Walk even more successful. This year promises to be a fun-filled event for the entire family. Register today or start a team with your friends, family or co-workers. To register and download a pledge form, go to our website [www.kidneycares.org](http://www.kidneycares.org). It's a great way to spend a day and help support the local kidney community. Be sure to subscribe to our E-newsletter to receive announcements and keep up-to-date on the latest developments from Kidney Cares.

If you can't attend the walk, you can always make a financial contribution at our website. Every dollar raised helps us achieve our mission. We can't do it alone. We need your help.

Thank you for your support.

Call Kidney Cares 585-467-4627 Email: [kidneycares@gmail.com](mailto:kidneycares@gmail.com)

### Join a Committee

Sunshine, Newsletter,  
Membership, Awareness  
Interested?

Call **1.888.664.1463**

### "Brighter Tomorrow" Golf Tournament

#### Monday, September 16 Fundraiser

Rochester Eye & Tissue Bank "Brighter Tomorrow"  
Golf Tournament at Shadow Lake, Penfield, NY  
Call Kathy Miller @ (585)272-7980 for details

### Casino Night fundraiser Saturday, October 19, 2013

The Donate Life Transplant Games of America is a festival style multi-sport event for athletes who have either undergone lifesaving transplant surgeries or are living donors, and competition is open to anyone who has received a solid organ transplant. The games began more than two decades ago with a simple goal – to highlight the importance of organ and tissue donation. Today, the goal remains the same. It has grown into an event bringing recipients and donor families together in a celebration of life. If you are interested in joining Team Finger Lakes to attend the Games in Houston, TX July 10 -15, 2014, please contact Amy James at (585) 683-3174. Team spots are being finalized soon!

Team Finger Lakes is having a Casino Night fundraiser with proceeds helping to send our athletes to Houston. If you are interested in attending the Halloween themed Casino Night, you can buy tickets by contacting Tanya Herrold at (585) 705-2515. Tickets are \$15 before September 15, 2013 or \$25 after that. You can also purchase tickets at the door for \$25. Each ticket will get you \$500 worth of chips (no cash value). The event is being held, Saturday, October 19, 2013 from 8 – 11 p.m. at the Moose Lodge, 5375 West Henrietta Rd. Food, entertainment, photo booth, and a costume contest are just some of the things to look forward to – hope to see you there!

## Transplant Times

### Submission Deadline

For October / November 2013 issue:  
September 3, 2013

Articles /ideas email to:

[auggieday@aol.com](mailto:auggieday@aol.com) or send by mail to:

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

## Wishes of Wellness To

Our healing thoughts and prayers go out to:  
Cindy DeShane, Laurie Packard, Kathy Wesline and Matt Felo

## Transplant Anniversaries

Rick Clark	Kidney	July	2004
James Connolly	Liver	July	1990
John Dedloff	Heart	July	2011
Cindy Deshane	Liver	July	2005
Bonnie Gottorff	Kidney	July	2005
Cheryl Helfer	Kidney	July	2002
Daniel Klimek	Cornea	July	2011
John Odell	Liver	July	2010
Shawn Pangburn	Liver	July	2011
Richard Perez	Liver	July	2003
Patricia Ridge	Kidney/Pancreas	July	2006
Philip Ronzo	Liver	July	1996
Joanne Tucker	Liver	July	2006
Giulio Verde	Heart	July	1998
Dean Kiefer	Kidney	July	2012
Lisa Faucz	Kidney	August	2008
Tom Fuoco	Heart	August	2008
Moirra Miller	Liver	August	2005
Rebecca Snyder	Heart	August	1998
David Spiro	Liver	August	1997
Lisa Abbey	Heart	September	2008
Tom Arcara	Heart	September	2005
Ernst Baier	Kidney	September	2000
Marianne Benvenuti	Liver	September	2006
Marcia Marcheson	Liver	September	2008
Joanne Schum	Lungs (2)	September	1997
Philip Travis	Kidney	September	2011
Ivan Tzoontchev	Kidney	September	2000
Debbie Vernam	Kidney	September	2004

## TAO Survey

Thank you for your survey responses! If you haven't sent it back, there's still time! You should have received a survey electronically or by mail. Please take the time to give us your feedback, we worked hard putting this together and appreciate your help.

If you did not receive a survey you can go to [tao-rochester.org](http://tao-rochester.org) and click on the surveymonkey link or contact TAO and we will send you one. Thank you!

**Congratulations to Rebecca Snyder** - winner of the \$50.00 Amazon Gift Card!

## Contributions

We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO.

### Donations:

Chuck Lundeen

### Memorials:

Ernst Baier in memory of Bea Baier  
Mary Frances LaRose in memory of Jack Wesline

If we omitted you, please let us know so that we may post in the next issue. **THANK YOU.**

## 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

## Welcome New Members

**Michael Erban - Liver recipient**  
**Peggy Olrich - Liver recipient**  
**Scott Stewart - Kidney recipient**  
**Jagdish Tandon - Candidate**

## Board of Directors & Officers

### President

Matt Felo

### Vice President

Debbie Yendrzeski

### Treasurer

Kathy Wesline

### Secretary

Bev Shank

### Membership

Norman Breen

Linda Barnard

Chris Barry MD,  
Ph.D.

Geoff Foley

Karen Gledhill

Karen Guarino

Bonnie Haefner

Amy James

Janice Odenbach

Karen Porterfield

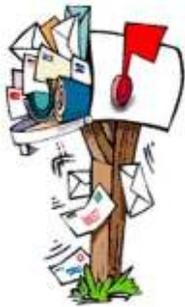


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TAO / Rochester Membership Application

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)