



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

# Transplant Times

March / April 2013

www.tao-rochester.org

1.888.664.1463

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## Membership Meeting Guest Speakers / Topics

**March 18 @ 6 p.m.**

Pizza Party

**April 15 @ 6 p.m.**

Dinner and Speaker

Doug Doehring:

*Immunosuppressant Medications*

## TAO Meets

**3rd Monday of the Month at 6:00 P.M. (NEW TIME)**

**Christ Episcopal Church**

**Fellowship Room**

**36 South Main Street**

**Pittsford, NY**

## A Message from the President



Well, the ground hog didn't see his Shadow so spring must be on its way. Don't get your lawn chairs out just yet; I believe that Phil has been wrong before.

Starting in March, TAO meetings will alternate its venue alternating between a social and a guest speaker and starting at a new time!

### **We are kicking off the March meeting with a Pizza Party at 6 PM.**

Come and share your transplant stories, meet new people and enjoy some food and drink. In April, we will have a short dinner hour with speaker, again starting at 6 PM. The May meeting will be "movie night" with Dr. Richard Demme sharing his films dealing with transplantation. Popcorn will be provided! June will be our annual picnic and then we are off for the summer. So, mark your calendars with the new time, 6 PM, same place, new format! We look forward to seeing you!

Please visit the new TAO web site for updates, it is very user friendly. I would like to thank Geoff and Thanh, they did a terrific job getting the new site up and running.

March is Eye Donor Month and April is Donate Life Month. For the past three and a half years I have been involved with the Rochester Eye & Tissue Bank / Finger Lakes Donor Recovery Network, Friends of Strong, and TAO. The lack of organs in New York is quite high; some people have

waited for five years or longer. There are over 117,000 in the United States waiting for an organ. In New York there are over 12,000 awaiting organs. If you are not an organ and tissue donor, please consider signing up to be one. Call your family members, neighbors and friends and ask them to consider signing up to be a donor. We each know what the gift of life means to all of us. Whether you wanted to dance at your daughter's wedding, see your grandchild's first step, without the gift of the organ you received you would not have been able to do so. Please, do what you can to increase the number of organs and tissues available for transplant.

I often ask family members of those who are waiting for a transplant if they are enrolled the NYS Donate Life Registry. Amazingly many are not. In The Finger Lakes region only twenty-six percent of those eligible (18 years of age or older) have enrolled in the registry. Overall, New York State ranks third from the bottom of the list of those states with registries. I urge all members to try to promote Donate Life Month.

*Matt Felo*

# New Start Time for Meetings is now 6:00 PM

## The Transplant Process

*Transplant data shows that more and more people receive transplants every year and that many people with transplants are living longer after receiving their organ(s) than ever before. The Transplant Team:*

There are many people at the transplant center who work to make a transplant successful. Each person on the "transplant team" is an expert in a different area of transplantation. The transplant team includes all or some of the following professionals:

- **Clinical transplant coordinators** have responsibility for the patient's evaluation, treatment, and follow-up care.
- **Transplant physicians** are doctors who manage the patient's medical care, tests, and medications. He or she does not perform surgery. The transplant physician works closely with the transplant coordinator to coordinate the patient's care until transplanted, and in some centers, provides follow-up care to the recipient.
- **Transplant surgeons** perform the transplant surgery and may provide the follow-up care for the recipient. The transplant surgeon has special training to perform transplants.
- **Financial coordinators** have detailed knowledge of financial matters and hospital billing. The financial coordinator works with other members of the transplant team, insurers, and administrative personnel to coordinate and clarify the financial aspects of the patient's care before, during, and after the transplant.
- **Social workers** help the patient and their family, understand and cope with a variety of issues associated with a patient's illness and/or the various side-effects of the transplant itself. In some cases, the social worker may perform some of the financial coordinator duties as well.

### *Waiting Times:*

Waiting times vary widely for many reasons. The shortage of organs causes most patients to wait for a transplant. The amount of time a patient waits does not show how well a transplant center or OPO is doing its job. Each patient's situation is different. Some patients are more ill than others when they are put on the transplant waiting list. Some patients get sick more quickly than other patients, or respond differently to treatments. Patients may have medical conditions that make it harder to find a good match for them.

How long a patient waits depends on many factors. These can include:

- blood type (some are rarer than others)
- tissue type
- height and weight of transplant candidate
- size of donated organ
- medical urgency
- time on the waiting list
- the distance between the donor's hospital and the

- potential donor organ
- how many donors there are in the local area over a period of time and
- the transplant center's criteria for accepting organ offers

Depending on the kind of organ needed, some factors are more important than others.

### *Patient Notification:*

Potential recipients often contact the OPTN to ask if they are on the National Patient Waiting list. Unfortunately, the OPTN cannot provide this information. A patient's presence and status on the waiting list should be discussed with the patient's transplant team.

- The transplant program must notify patients in writing within ten business days of registration that the patient has been placed on the national transplant waiting list (including the date the patient was listed), or
- The transplant program must notify the patient in writing ten days after completion of the evaluation that the patient will not be placed on the patient waiting list.
- Once listed, if the patient is removed from the waiting list for any reason other than transplantation or death, the transplant program must notify the patient in writing within ten business days that the patient has been removed from the list.

This policy is intended to improve communication between transplant centers and their patients and to help patients better understand the listing and transplant process.

### *Options to Consider:*

As an informed participant, it is important that transplant candidates know their treatment options. Some patients choose to list at hospitals in different parts of the country, change hospitals, and transfer their waiting time to a different center or receive a transplant from a living donor.

- **Multiple Listing:** Sometimes patients choose to register for a transplant at more than one hospital. When a patient lists at a transplant hospital, they are generally considered for organs from a donor in that local area first. If a patient is put on the list at more than one transplant hospital, they will be considered for donor organs that become available in more than one local area. National transplant policy allows a patient to register for a transplant at more than one transplant hospital. However, each hospital may have its own rules for allowing its patients to be on the list at another hospital. Patients should ask each hospital whether it allows its patients to list at more than one transplant

*(continued on page 3)*

## The Transplant Process continued

hospital. Being listed in more than one area does not guarantee an organ will become available faster than for patients registered at only one transplant hospital. Generally, each transplant center will require the patient to go through a separate evaluation, even if the patient is already listed at another hospital.

- **Transferring Waiting Time:** Patients may switch to a different transplant hospital and transfer their waiting time to that hospital. Waiting time from the original center is added to the time collected at the new hospital.  
The transplant teams at the first hospital and the new hospital will be responsible for coordinating the exchange of information and notifying UNOS of the transfer of waiting time. Patients should ask each hospital if transferred waiting time will be accepted.
- **Variability among Transplant Centers:** Hospitals can vary widely in the number of transplants they perform and the characteristics of the donor and recipient pool. Organ procurement organizations can vary widely in the number and types of donors they receive each year.
- **Living Donation:** In addition to deceased organ donation, patients may also receive organs from living donors. In 2007, more than 6,300 living donor transplants were performed. With more than 100,000 people currently waiting for a transplant in the U.S., the need for donor organs is far greater than the supply. Living donation offers an alternative for individuals awaiting transplantation.  
The first successful living donor transplant was

performed between identical twins in 1954. Since that time, hundreds of patients have received successful transplants from living donors. Parents, children, brothers, sisters, and other relatives are eligible to donate organs to family members. Unrelated donors (for example, spouses, or close friends) may also donate their organs if they are a match for the candidate and the transplant hospital approves.

### *For More Information:*

As scientists learn more about transplantation, new ways are developed to help recipients and their new organs survive longer. Almost every year since 1988, the number of patients that survived at least one year after their transplant has increased. A large amount of data is available to help patients make informed healthcare choices about transplantation. The OPTN and the Scientific Registry of Transplant Recipients (SRTR) provide data to assist patients in choosing a transplant hospital. The federal government's Web site, [www.organdonor.gov](http://www.organdonor.gov), is an excellent source of donation information as well as the UNOS Patient Services' toll free number (888) 894-6361, which patients can call to request a general or organ-specific information packet.

This work was supported in part by Health Resources and Services Administration contract 234-2005-37011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

## 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**

## Coming Up

**Saturday, April 6, 2013**

### **Casino Night**

Fundraiser to support Team Finger Lakes  
Moose Lodge, Rochester, NY  
Details at [www.donorrecovery.org/news/](http://www.donorrecovery.org/news/)

**Saturday, June 15, 2013 @ 6 PM**

### **And the Beat Goes On. . . .**

Fundraiser for Harbor House of Rochester  
Doubletree Hotel, Rochester.  
Ticket sales begin March 15, 2013  
Call 585.473.1779 or visit  
[www.harborhouseofrochester.org](http://www.harborhouseofrochester.org)

## Support Group Meetings

### "OPEN AIRWAYS" - Lung Gathering Group

- **Thursday, March 14, at 12 Noon**  
Hicks and McCarthy, 23 S. Main St., Pittsford
- **Thursday, April 11, at 12 Noon**  
Winfield Grill, 647 Winton Rd North, Rochester  
Contact Geoff Foley at 585-383-1559 or geoff21@yahoo.com if interested in attending.

### HEART TRANSPLANT/VAD SUPPORT GROUP

- **Thursday, March 14, at 6:30 p.m.**  
Amy James, Finger Lakes Donor Recovery Network
- **Thursday, April 11, at 6:30 p.m.**  
Dr. Mark Nickels, Psychiatrist for Transplant,URMC

Location: Strong Memorial Hospital  
7th Floor Conference Room  
(Near the 7-3400 corridor)

## April is Donate Life Month Mark Your Calendar

**Friday, April 12** – Donate Life Awareness Night with the Rochester Amerks. For details, go to [www.donorrecovery.org](http://www.donorrecovery.org), click on Raising Awareness

**Friday, April 19** - Wear blue/green day and bring awareness to organ & tissue donation. Organize a group at work to wear shirts, scarves, ties, dresses in any combination of blue and green. Send your photo to us!

**Sunday April 21** - 11th Annual Rochester River 5K Run and Walk @ 10 a.m. hosted by Strong Memorial Hospital Transplant Programs and Friends of Strong. It will be held at the Roadhouse Shelter at Genesee Valley Park. There will be a ceremony honoring recipients at 9:30, all recipients are welcome. The event supports the patient care fund. Are you unable to attend but still want to support this event? Contributions can be made out to the Friends of Strong/River Run and sent to Nancy Metzler, Transplant Administrator, University of Rochester Medical Center, 601 Elmwood Avenue, Box Surg/Txp, Rochester, NY 14642.

**What you can do as a recipient**—Write a letter to the Democrat and Chronicle's op-ed page. Tell your transplant story and emphasize the need to enroll in the NYS Donate Life Registry and the need for organ & tissue donation.

## Local National Kidney Foundation

The National Kidney Foundation (NKF) in Upstate and Western NY has a new look and a new location. NKF has moved to an office at 310 Packett's Landing, Fairport, NY. They will continue to provide kidney disease education, patient support, health screenings and resources to communities throughout the Upstate and Western NY region.

Staff members include Megan Alchowiak, Community Outreach Manger; Jessica Leenhouts, Community Outreach Assistant; and Elissa Rowley, Program Assistant.

### NKF continues to award patient scholarship

NKF continues to award the Joseph DiMartino Patient Scholarship and is now accepting applications for the 2013-2014 academic year. The award provides two scholarships valued at \$500 as a one-time grant to one graduating high school senior and one adult kidney patient who exemplifies courage, strength, determination, generosity of spirit, and kindness.

This generous award is made possible by the family of Joseph DiMartino, a kidney patient who valued education and life long learning opportunities.

To be eligible, you must:

1. Be a kidney dialysis/transplant patient residing in Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne or Yates county
2. Graduate from high school the year you apply OR provide proof of graduation from high school or equivalent education
3. Maintain at least a "C" average
4. Be accepted at an accredited 2 year, 4 year, or trade school (Tech institution, community college, state or private college.

With the completed application form, you must include: a high school or college transcript, copies of college acceptance letters, two letters of recommendations, one letter from a medical doctor/facility validating diagnosis of kidney disease, and an essay 150-450 words in length.

For more information and to obtain an application form, call Elissa Rowley, Program Assistant, 585-598-3963.

## 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

## Improve Your Health with Small Diet Changes

by Suzanne Youngers

BIG health improvements can happen when using these simple changes. It takes little effort to make these changes in the way you eat to reap multiple benefits and better health. These changes can be incorporated into anyone's daily routine. When making these changes you will find they effortlessly become part of your daily routine. You will find yourself feeling the differences that these changes have made to your entire body and health.

Extra-virgin olive oil or coconut oil can be used in place of margarine and sprays. Exchange olive oil or coconut oil for others to coat baking pans, in recipes, and for cooking.

Eat vegetables, remembering to get at least 5-7 servings daily, in omelets, casseroles, soups, smoothies, or by juicing. Incorporate vegetables into every meal.

Whole fresh fruit should be your main snacks. Get at least 2-3 servings a day, by itself, with yogurt as a parfait, topping a salad, in a smoothie or by juicing.

Vegetable protein can replace animal protein (beans, legumes, soy foods, & nuts) once, twice, or more a week. Try a meatless day during the week. You can always do this more during the week if you prefer.

Eat salmon, tuna, sardines or anchovies, and any other sources of omega-3 fatty acids, once or twice a week. They can be used in a sandwich, on a salad, on a pizza, or as a main dish.

Also an Anti-Inflammatory Diet can help anyone with inflammatory ailments like arthritis and autoimmune disorders like Crohn's, and colitis. You can achieve your healthy goals for the year.

<http://www.facebook.com/2bHealthyWithSuzanne/>  
[www.2BHealthywithSuzanne.com](http://www.2BHealthywithSuzanne.com)

## Board of Directors & Officers

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## Transplant Anniversaries

Ralph M. Toscano Jr.	Cornea	March	1989
Dennis Wittman	Liver	March	2004
Karen Gledhill	Kidney	March	2008
Cynthia Boyer-Green	Kidney	March	1996
Rita Callaghan	Liver	March	2001
Jana Currie	Lungs (2)	March	2008
Robert Hadsell	Liver	March	1997
Thomas Louer	Liver	March	2004
Paula McKay	Kidney	March	1995
Jan Sharp	Kidney	March	2005
James Graczyk	Liver	April	2002
Donald J. Leone	Liver	April	2009
Chuck Lundeen	Liver	April	2008
Susan Maglisco	Liver	April	2010
Sharon Mooney	Kidney	April	2010
Gerald Muto	Kidney	April	2010
Bernie Pierce	Lungs (2)	April	2011
Penny Sayles	Kidney	April	1998
Linda Marie Serenka	Kidney	April	2001
Merrillan Thomas	Kidney	April	2010
G. Murray Thomas	Kidney	April	2010
Asya Zarkhi	Kidney	April	2003
Ginger Zimmerman	Heart	April	1998
Wayne Dickinson	Kidney	April	2008
Michelle Halloran	Kidney	April	2010

## United Network for Organ Sharing

Candidates listed as of 2/18/2013

<b>95,295</b>	<b>Kidney</b>
<b>15,742</b>	<b>Liver</b>
<b>3,416</b>	<b>Heart</b>
<b>2,121</b>	<b>Kidney/Pancreas</b>
<b>1,646</b>	<b>Lung</b>
<b>1,197</b>	<b>Pancreas</b>
<b>254</b>	<b>Intestine</b>
<b>54</b>	<b>Heart/Lung</b>

**117,145** TOTAL

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

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

## Recipe Ideas

### St. Patrick's Day Breakfast Whole Grain Breakfast Porridge



Total Time: 1 hour 15 min – Cook time: 50 min.

Preparation Time: 15 min

Yield: 4 servings

Taken from Food Network.com and altered for transplant by, Elizabeth Keirstead, RD.

Photograph by Kana Okada: Food Network.org – recipe altered.

#### Ingredients

- steel-cut Irish oats
- 1 -2-inch piece orange peel

- 1 cinnamon stick
- 1 to 2 tablespoons packed dark or light brown sugar
- 1/4 teaspoon salt (optional)
- 1/4 cup dried fruit (cranberries, cherries, raisins and/or chopped apricots/blueberries/peaches)
- Chopped nuts, maple syrup and/or milk, for serving (optional)

#### Directions

Follow directions on container to make 4 servings. Add orange peel & cinnamon stick. After made...

Stir in sugar. Add the dried fruit (if require lower potassium use lower potassium dried fruits such as Cranberries, Cherries, Blueberries, Peaches.)

Serve the warm porridge with nuts, syrup and/or milk, if desired.

May vary depending on brand of rolled oats purchased (ESTIMATED) Per Serving: Calories: 287; Total Fat: 1 gram; Saturated Fat: 0 grams; Protein: 8 grams; Total carbohydrates: 50 grams; Fiber: 5 grams; Cholesterol: 0 milligrams; Sodium: 151 milligrams

### Cottage Pie Made Healthy and Renal Friendly

*Cooking Light, November 2010*

Maureen Callahan with changes by Elizabeth Keirstead RD  
Transplant Nutritionist, UPMC

#### Ingredients

- 1 Tablespoon all-purpose flour
- 1 Tablespoon butter, softened
- Cooking Spray
- 1 1/2 cups Chopped Onion
- 1/2 cup Chopped Carrot
- 1 – 8 ounce package Cremini or button mushrooms, thinly sliced (can substitute other vegetable such as green beans)
- 1 pound extra-lean ground beef\*\*
- 2 Tablespoons no salt added tomato paste
- 1 cup fat-free, lower sodium beef broth – if using turkey or chicken use lower sodium chicken broth.
- 1/4 teaspoons freshly ground black pepper
- 1/4 cup chopped fresh parsley
- 1 Tablespoon fresh thyme leaves
- 1/2 teaspoons salt (can omit)
- 3 cups leftover mashed potatoes \*\*
- 3/4 cup or 3 ounces shredded reduced-fat sharp white cheddar cheese, divided\*\*
- Paprika – optional

\*\*Options to lower sodium, potassium, fat: Can use lean ground turkey or shredded chicken/turkey in place of ground beef. To lower potassium can substitute mashed

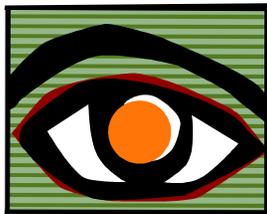
potatoes with mashed cauliflower (steam/cook in water or low sodium chicken broth until tender and mash.) To lower sodium in cheese by either fully substitute or dilute with Swiss cheese (1/2 cheddar and 1/2 Swiss cheese).

#### Preparation

1. 1. Preheat oven to 350°.
2. 2. Combine flour and butter; stir well. Heat a large nonstick skillet over medium-high heat. Coat pan with cooking spray. Add onion and carrot; sauté 5 minutes. Add mushrooms; sauté for 5 minutes or until lightly browned. Remove vegetables from skillet. Add meat to pan; cook 5 minutes or until browned, stirring to crumble. Stir in tomato paste, and cook 3 minutes. Stir in broth and pepper. Return vegetables to pan, and bring to a simmer. Stir in parsley, thyme, and salt. Add flour mixture, and cook for 1 minute or until thick, stirring constantly.
3. 3. Spoon meat mixture into an 8-inch square glass or ceramic baking dish coated with cooking spray, spreading evenly. Combine the potatoes (or mashed cauliflower) and half of cheese; spread this mixture evenly over meat mixture. Top with remaining cheese. Sprinkle with paprika if desired. Bake at 350° for 20 minutes or until bubbly. NOTE: can brown up further by broiling 1 minute or until browned – watch carefully so as not to burn.



## March is National Eye Donor Month



### FACTS:

- you don't need perfect vision to be an eye/cornea donor
- you may still be able to be an eye/cornea donor after cataract surgery
- the 1st corneal transplant was performed in 1905
- about 60,000 people in the U.S. received cornea transplants last year
- the cornea is the eye's outermost layer. It is the clear, dome-shaped surface that covers the front of the eye

Those who suffer from corneal blindness due to disease, injury or infection may be helped by cornea transplantation. **GIVE THE GIFT OF SIGHT**



**Dr. Mark Nickels presenting at the February TAO meeting**

## Transplant Times

### Submission Deadline

For May/ June 2013 issue:  
April 8, 2013

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

## Contributions

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

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

Dave Johnson  
Norm & Phyllis Breen  
Office Services Unlimited

## Wishes of Wellness To

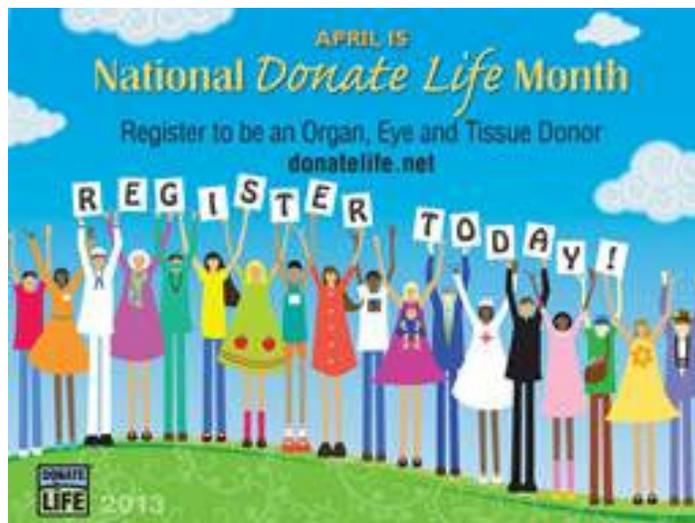
Our healing thoughts and prayers go out to Jeff Spiro, Jerry Runion and Phyllis Breen.

Congratulations and best wishes to Laurie Packard, former membership chairperson, on her kidney transplant!

## Our Sympathies

### Our sincere condolences to :

- Bev Shank and her family  
on the passing of her mother
- Karen Guarino and her family  
on the passing of her brother-in-law
- Kathy Wesline and her family  
On the passing of her husband Jack





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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)