



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

# Transplant Times

June - July, 2014

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

**1.888.664.1463**

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## Membership Meeting Guest Speakers / Topic

**June 16, 2014**

**TAO Annual Picnic  
(See Details on page 5)**

**July and August  
No Meeting**

## 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



Well it looks like Spring has finally sprung, at least I think so. Easter was a beautiful day and the weeks ahead look promising. The temperature is supposed to rise but we must all remember, we live in New York and it can change at any second.

We have a busy month coming up. TAO's annual picnic is right around the corner on Monday, June 16 at 5:00 pm at the Buckland Park Lodge, Brighton, NY. The Transplant Games golf tournament is on Sunday, June 22 at Wildwood Country Club. August 17 is Donate Life night with the Rochester Red Wings. On 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.

Election Time is here! Ballots for new board members are in this month's member's newsletter. Your vote counts! It is important that your voice is heard! Please vote.

As some of you know, Gerry Bluff passed away on Easter Sunday. He was a lung recipient, a member of TAO, and was a good friend to many. Our condolences go out to his wife Diane and family.

Even though TAO doesn't meet over the summer months, your Board is busy preparing for the upcoming year. If you have some ideas, suggestions for

speakers or demonstrations that you would like feel, free to email me at [mfelo@rochester.rr.com](mailto:mfelo@rochester.rr.com) and we will try to schedule it in the future.

Have a great spring and a terrific summer.

*Matt Felio*

## Skin Cancer in Transplant Recipients

Patients who have received an organ transplant have a higher risk for developing skin cancers, in some cases up to 65 times the risk, compared with non-transplant patients. In particular, transplant recipients have a significantly increased risk of developing squamous cell carcinomas. SCC is more likely to spread (metastatic SCC) in organ transplant recipients, and may lead to the death of the patient.

Organ transplant recipients are also at increased risk for other types of skin cancers, particularly melanoma. These may occur on any site on the body. All histological subtypes are seen. Melanoma can be very difficult to diagnose in organ transplant recipients, leading to a low threshold to excise any unusual or changing lesion. Melanoma tend to be thicker and more advanced on diagnosis than in non-transplant patients and these tumors may behave aggressively in organ transplant recipients.

Preventative measures, early detection, regular skin checks and appropriate early treatment of skin cancers are essential to minimize the harm caused by these cancers.

### Why are transplant patients at higher risk of skin cancer?

Ultraviolet (UV) exposure is the major factor in the development of skin cancers in both transplant and non-transplant patients. Transplant patients require the long-term use of immunosuppressant medications to prevent organ rejection but they impair the capacity of the immune system to repair or destroy UV damaged cells, allowing damaged cells to develop into cancers. It is also possible that the immunosuppressant medications directly cause cancer generating changes in cells. Additionally, human papilloma virus (HPV), which causes warts, may also be involved in the development skin cancers in transplant recipients.

### Who is at the highest risk of skin cancer?

Patients who have been receiving immunosuppressant medications for longer periods of time tend to have the highest incidence of skin cancers. Other risk factors for skin cancer include:

- Older age (possibly due to greater cumulative sun exposure)
- History of skin cancers or pre-cancerous lesions before the transplant
- Fair skin (Fitzpatrick skin type I-III)
- History of significant UV exposure from sun or sunbeds
- Infection with the HPV (wart) virus
- Low CD4 cell counts
- Heart and/or lung transplant recipients (who tend to have higher levels of immunosuppressant medication)

### Preventing skin cancer in transplant patients

Being sun-smart is absolutely vital for transplant patients. The incidence of skin cancers may be greatly reduced by following preventative measures whenever out of doors, including:

#### Always wear sunscreen

Sunscreen should be rated SPF30+, and should be broad spectrum (blocking both UVA and UVB radiation). You should apply sunscreen 15-30 minutes before going outside and then again immediately before going outside. Sunscreen needs to be reapplied regularly during the day (2-hourly in sunny weather, otherwise 3 to 4-hourly). Daily application to the face and hands regardless of your intended activities should be considered.

#### Avoid sun exposure

This is especially important during the middle of the day, between 11 am and 4 pm, when UV radiation levels are at their highest. If you are outdoors during these times, stay in the shade. Check the weather reports to find out ultraviolet index or sun protection alerts – take these seriously.

#### Cover up well

Wear with long sleeved shirts and pants. Dark colored, tightly woven material provides the most UV protection. If possible try to wear sun protective clothing that has an Ultraviolet Protection Factor (UPF) rating of 40-50+.

#### Always wear a hat when outdoors

Choose a hat with tightly woven material that shades your face, nose, neck and ears.

#### Wear sunglasses

Sunglasses provide the best protection to the delicate skin around the eyes. Choose glasses that are close fitting with large lenses. Wrap around style glasses provide the best protection.

#### Detecting skin cancers

Early detection and treatment of cancerous and pre-cancerous skin lesions is essential to minimize the harm caused by skin cancers. Transplant patients should perform a skin self examination every month, concentrating particularly on areas that are normally most exposed to sunlight, such as the backs of the hands, forearms, head and neck, upper chest and back and, in women, the lower legs. They should report any new lesions to their dermatologist promptly.

## 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!

## Care for Others – and you, too!

### The Doctors

*Reprint from USA Weekend March 7-9, 2014*

Remember: To be a caregiver to others, it's important that you also tend to your own health.

It's a noble job — taking care of an aging parent, chronically ill spouse or disabled family member. And more than 65 million Americans are serving as caregivers for loved ones, preparing meals, taking over household duties, managing doctor appointments and medications, and in some cases providing full-time assistance.

As rewarding as the role can be, caregiving is also tough, in many ways relentless, and often physically and emotionally draining. Surveys have shown that more than half of caregivers feel overwhelmed; they also report higher levels of stress than the average person, according to the American Psychological Association. But to care for others effectively, you have to look after your own well-being too. Some strategies to help keep you happy and healthy:

**Recognize the warning signs of stress.** If you're irritable or exhausted most of the time, have trouble sleeping, are more forgetful or lose interest in activities you used to like, it could indicate you're under too much stress, which over time can harm your health. If you have a history of depression, pay even closer attention to the red flags— a new, small study suggests that caregiving itself doesn't necessarily cause depression but may raise the risk for those who have vulnerability toward it.

**Change the things you can.** Identify your sources of stress. Maybe you're trying to do too much; perhaps there are family disagreements or financial worries. Focus on matters over which you have control and then take a small step toward a solution, the Family Caregiver Alliance suggests. Even meeting a friend for coffee once a week or calling a financial planner can help alleviate some anxiety and stress.

**Accept help.** According to some estimates, nearly one in five caregivers provides more than 40 hours of care per week. A friend could pick up groceries or run an errand; someone else could freeze some extra meals for you or even take the person you care for on a short walk a few days a week.

**Seek support.** Maintaining a strong support system is key to managing the stress of caregiving, experts at the Mayo Clinic say. Set aside time each week to connect with family or friends, and consider joining a support group, which can be a good source for encouragement and advice from others in similar situations.

**See your doctor.** Studies have shown care-givers are more likely to have a chronic illness, and rate their health as fair or poor. As impossible as it may feel to find the time, it's important to see your physician for checkups and screenings. Tell him you're a caregiver, and mention any health concerns or symptoms you have.

*"The Doctors" is an award-winning national TV show*

Advice from

**THE DOCTORS**

## Welcome New Members

Thomas & Lora Laine  
Maria & Didkine Correa  
John Interlichia Jr.  
Dianne Burgio  
Yolanda Porter  
Martha Rossi  
Mary Hickey

## April's Featured Speaker . .



(L) TAO President Matt Felo with Dr. Richard Demme whose topic was "Transplants in the Movies"

## Diet and Transplantation

If you have a new organ transplant, you are probably wondering if your diet will differ from the one you followed before your transplant. You can get help in planning your diet after transplant from your doctor and dietitian.

### Do I need to be on a special diet?

Yes. After an organ transplant, your diet still plays a big role. If you were on dialysis and had a kidney transplant, you may find that this diet is easier to follow than the one you were on for your dialysis.

### Will any of my medicine affect my diet?

Yes. Your diet will be affected by the use of the medicine you need to prevent rejection of your transplant. Some common anti-rejection medicines that may affect your diet include:

- steroids (prednisone)
- cyclosporine (Sandimmune, Neoral, Gengraf)
- tacrolimus (Prograf)
- azathioprine (Imuran)
- mycophenolate (CellCept).

This list will continue to grow as new medications are developed. These medicines may change the way your body works in different ways.

### Will I gain weight?

Many people have a better appetite after they get a transplant, and they gain unwanted weight. Weigh yourself often. Limit high-calorie foods such as fatty foods, sweets, pastries and other foods rich in fat or sugar. You can help control your calories by eating:

- raw vegetables and fruits
- lean meat, skinned poultry and fish
- nonfat dairy products
- sugar-free drinks like diet soda.

Controlling your weight will lower your chance of having problems such as heart disease, diabetes and high blood pressure. If you gain unwanted weight, you will need to exercise more and follow a low-calorie diet. Ask your doctor to refer you to a dietitian to plan low-calorie meals and snacks.

### What about my cholesterol and triglyceride levels?

Fat (cholesterol or triglyceride) levels in your blood may be high. High levels of cholesterol and triglyceride can cause heart disease. There are many steps you can take to lower the fat and cholesterol in your blood.

### What about foods high in carbohydrates?

You should know some important facts about foods high in carbohydrates:

Carbohydrates come from sugars and starches.

They provide fuel and energy for your body.

When you take steroid medication, it is hard for your body to use extra carbohydrates. This can lead to high blood sugar levels and may cause diabetes.

### Do I still need to follow a low-salt diet?

Most people still need to limit salt after they get a transplant, although it is different with each person.

Transplant medicines, especially steroids, may cause your body to hold on to fluid, and salt makes this problem worse. Increased fluid in the body raises blood pressure. Controlling blood pressure is very important to your transplant. Your doctor will decide how much sodium is best for you.

### What about protein?

Protein is important for the following reasons:

It builds and repairs muscles and tissues

It helps you heal after the transplant operation

Your protein intake will need to be higher than normal right after your transplant to help build up the muscle tissue that will be broken down by the large doses of steroids. Later, you can return to moderate amounts of protein.

### What about potassium?

As long as your transplant is working well, you should be able to take in normal amounts of potassium from your food. However, some transplant medicines can increase your blood level of potassium, while other medicines may decrease it.

### Are calcium and phosphorus a problem?

You may need to pay close attention to your calcium and phosphorus levels. If you have been ill for a period of time, your body probably lacks the balance of calcium and phosphorus needed for healthy bones, especially if you had kidney disease. In the months after your transplant, your doctor will check for possible bone loss and talk to you about the best way to keep your bones as healthy as possible. In the meantime, every adult needs about two servings a day from the dairy group (low fat milk, cheese and yogurt). Unless your doctor or dietitian has told you not to use these foods, try to include them in your meals. Your doctor may decide you need more calcium and phosphorus than your diet provides and may tell you to take a supplement. You should not start any supplements on your own as this could cause problems with your transplant.

### What if I have diabetes?

After a transplant, your new diet may be higher in protein and lower in sugars due to the effects of steroids and other medicines. Work with your doctor and dietitian to keep your diet and blood sugar in good control.

### Where can I get more information

More information about diet after a transplant can be found in the free brochure "**Nutrition and Transplantation.**" You can obtain a copy by calling 1.855.NKF.CARES (1.855.653-2273).

*Source: National Kidney Foundation*

## Save the Date . . .

### TAO Summer Picnic

**Monday, June 16 5PM**

Join us for the Annual TAO Picnic! The Social Hour begins at 5pm with Dinner at 6pm. We'll be serving freshly barbecued chicken, hamburgers, and hots, together with sides, salads, desserts, and soft drinks. Adults - \$10, Children (under 15) - \$5

Make your reservation by June 9th by mailing your check to TAO, P.O. Box 23552, Rochester, NY 14692-3552. Please include name of attendees and the number of adult/children.

Buckland Park Lodge, 1341 Westfall Road (between Winton Road and S. Clinton Ave.) Note, this is different from last year's location

### Transplant Games Golf Tournament

**Sunday, June 22** at Wildwood Country Club located in Rush New York, \$400 per foursome.

Email Vathxira Inthalasy ,Vathxira@gmail.com, to set up your foursome. We will take individuals and figure out teams for those player. The price includes t-shirt, 18 holes + cart, and range balls beforehand. Lunch will be at Wildwood and dinner/prizes/awards at Otter Lodge following the tournament.

For those who would like to sponsor a hole it is \$100.00 per hole.

### Harbor House Celebration Picnic

**Sunday, July 27 at 1pm - 4pm** at the Burgundy Basin Outdoor Pavilion. Tickets ar \$20.00 per person payable to Harbor House of Rochester. Includes picnic lunch and soft drinks and two live bands. Send payment to Harbor House of Rochester, 89 Rossiter Road, Rochester, NY 14620

**Sunday, August 17 Donate Life Night** with the Rochester Red Wings.

**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.

## 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.

### 7th Annual Kicks4Kidneys Charity Soccer Tournament

**Saturday, July 26 11AM** at Honeoye Falls-Lima High School,83 Church St., Honeoye Falls, NY.

For information contact:

Tim Parks: 585-259-8324 or Jamie Friello: 585-568-9548

Proceeds benefit the Rochester area organ recipients participating in the 2014 "Transplant Games of America"

## Support Group Meetings

### "Open Airways" - Lung Gathering Group

**Thursday, June 19 @ 12 noon**

Winfield Grill - 647 Winton Rd. Rochester, NY (Between East Main St and Browncroft Blvd.)

- and -

**Thursday, July 17 @ 12 noon**

Hicks and McCarthy - 23 S. Main St., Pittsford

### Heart Transplant/VAD Support Group

**Thursday, June 12 at 6:30 p.m.**

Dr. Mark Nickels, Psychiatrist for Transplantation at Strong Memorial Hospital

- and -

**Thursday, July 10 at 6:30 p.m.**

Speaker and Topic TBA

### All Heart Transplant/VAD

Meetings held at 7th floor conference room near 7-3400 Corridor unless otherwise indicated

## United Network for Organ Sharing

*Candidates listed as of 5/17/2014*

**100,748 Kidney**

**15,728 Liver**

**3,978 Heart**

**2,043 Kidney/Pancreas**

**1,651 Lung**

**1,188 Pancreas**

**264 Intestine**

**56 Heart/Lung**

**122,748 TOTAL**

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

**www.unos.org**

# Senator Nozzolio Announces Lifesaving Yellow Dot Program

Continuing his strong commitment to protecting the health and safety of all New Yorkers, State Senator Mike Nozzolio is working to make the public aware of the lifesaving Yellow Dot program. This free program is designed to provide first responders with important medical information that can save the lives of accident victims.

“The Yellow Dot initiative is a free program designed to help first responders provide lifesaving medical attention during the first “golden hour” after a vehicle crash or other emergency. A Yellow Dot in the



driver’s side rear window of a vehicle will alert first responders that vital medical information is stored in the glove compartment. Our brave volunteer firefighters, first responders and police officers represent the best of our local communities and this important program will provide them with the information they need to save the lives of accident victims,” said State Senator Mike Nozzolio.

## How Yellow Dot Works

1. The Yellow Dot kit contains a personal information card and a Yellow Dot decal. Complete both sides of the personal information card as fully as possible, in pencil. Attach a recent photo of yourself and place it in a visible location in your car's glove compartment.
2. Complete one card for each person who regularly occupies the vehicle. See below to request additional medical information forms.
3. Place the Yellow Dot decal on the rear driver’s side window to alert first responders to look in the glove compartment for your medical information.
4. Update the card annually yourself or bring it to your annual medical checkup. If you sell your car, remove the Yellow Dot sticker.

A Yellow Dot kit can also be used to alert those who respond to an emergency in your home. Simply place a Yellow Dot decal on or beside your front door and place a completed card for each occupant in a clear plastic freezer bag and place in a visible location in the freezer compartment of your refrigerator.

**Yellow Dot kits are available for free at local county Sheriffs’ Offices:**

**Cayuga County Sheriff’s Office**  
7445 County House Road, Auburn, NY 13021  
(315) 253-1222

**Monroe County Sheriff’s Office**  
130 South Plymouth Avenue Rochester, NY 14614  
(585) 753-4178

**Ontario County Sheriff’s Office**  
74 Ontario Street, Canandaigua, NY 14424  
(585) 394-4560

**Seneca County Sheriff’s Office**  
6150 State Route 96, Romulus, NY 14541  
(315) 220-3200

**Tompkins County Sheriff’s Office**  
779 Warren Rd, Ithaca, NY 14850  
(607) 257-1345

**Wayne County Sheriff’s Office**  
7376 Route 31, Suite 1000 Lyons, NY 14489  
(315) 946-9711

“After a car accident, every second counts! That is why I am working aggressively to inform local residents about this lifesaving program. Individuals can request a free Yellow Dot kit by going to [www.nysheriffs.org/yellowdot](http://www.nysheriffs.org/yellowdot) or by contacting my office toll free at 1-888-568-9816. As State Senator, I will continue my efforts to support programs and initiatives that help our first responders save lives and prevent tragedy,” said Senator Mike Nozzolio



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

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



**SHARE IT WITH OTHERS**

## Transplant Anniversaries

Bernice Eblovi	Liver	June 2002
Matthew Felo	Lung	June 2007
Kevin McCorry II	Bone Marrow	June 2004
Dick Miller	Heart	June 2007
Mike Yendrzski	Liver	June 2002
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
Dean Kiefer	Kidney	July 2012
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

## Wishes of Wellness To

**Kathy Wesline**  
**Bob Munn**  
**Richard Perez**

## Transplant Times

### Submission Deadline

**For August - September 2014 issue:**  
**July 7, 2014**

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

## Contributions

Thomas & Lora Laine  
 Bernie Pierce  
 Kathy and Thanh Nguyen

## 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

## Our Sympathies

### **We extend our sincere condolences to:**

Nancy Metzler and family on the loss of their daughter Hannah.

Diane Bluff on the passing of her husband Jerry Bluff.

## Board of Directors & Officers

<b>President</b>	Linda Barnard
	Chris Barry MD, Ph.D.
<b>Vice President</b>	Geoff Foley
	Karen Gledhill
<b>Treasurer</b>	Karen Guarino
	Bonnie Haefner
<b>Secretary</b>	Amy James
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Subscriptions@tao-rochester.org

Or a written request to:

TAO PO Box 23552 Rochester, NY 14692-3552



Don't forget your 2014 Membership dues! Help support TAO's Mission



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.