



# Transplant Times

April - May 2015

A newsletter of the Transplant Awareness Organization of Greater Rochester

www.tao-rochester.org | 1.888.664.1463

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**Membership Meeting Guest Speakers / Topic**

**April 20**  
Matthew Williams, PT  
*Benefits of Physical Therapy*

**May 18**  
Sherrif F. Ibrahim, MD, PhD  
*Dangers of the sun for Transplant Patients*

**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

The snow and record breaking cold weather make it seem like winter wants to hang around forever. I hope that everyone has made it through the winter in good shape and are looking forward to spring and summer.

Sadly, TAO has lost a former President, Dennis Stenshorn. We'd like to extend our sympathies to his family. Dennis was awaiting a heart/lung transplant.

April is National Donate Life Month. Try to spread the word to get your friends, relatives, and neighbors to sign up to be organ, eye and tissue donors. Every year the need is greater and greater. The total number of people waiting for organs nationally right now is over 123,300. Over 10,330 on the waiting list are New Yorkers and 488 are from the Rochester area.

Look on line to see a new ad that the Ad Council has produced, entitled "Pass Life On". The link is on our website or you can go to [passlifeon.com](http://passlifeon.com). It is very well done and I have seen it on TV a couple of times. I feel it is very effective.

At our April meeting, Matthew Williams, a Physical Therapist at the University of Rochester Medical Center, will talk about the need for and the benefits of physical therapy. A light meal will be offered prior to the discussion.

The speaker at our May meeting will be Dr. Sherrif Ibrahim, a dermatologist who performs MOHS surgery. Dr. Ibrahim will discuss the dangers of the sun, especially for transplant patients. We will have a light meal at this meeting.

There are many projects that could use



a volunteer. If you have some spare time and would like to volunteer please give me a call at 585-425-8032 or send me an email at [mfelo@rochester.rr.com](mailto:mfelo@rochester.rr.com) and I will point you in the right direction. Some of the projects may take few hours and others longer.

We are looking forward to seeing everybody at the next member meeting. Come and share your story and meet another recipient or a donor family. Until then, stay warm and healthy.

*Matt Felo*

## Transplant Anniversaries

Geoff Foley	Bilateral lung	April	2005
James Graczyk	Liver	April	2002
Joseph Heil	Liver	April	2011
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
Daniel Pszczolkowski	Heart	April	2011
Penny Sayles	Kidney	April	1998
Linda Marie Serenka	Kidney	April	2001
Scott Stewart	Kidney	April	2013
G. Murray Thomas	Kidney	April	2010
Merrillan Thomas	Kidney	April	2010
Asya Zarkhi	Kidney	April	2003
Ginger Zimmerman	Heart	April	1998
Patricia Bianchi	Liver	May	2002
Norman Breen	Heart	May	2007
Carol Comfort	Kidney	May	1994
Marilyn Isenberg	Liver	May	2007
Bonnie Patten	Liver	May	1995
Barbara Robida	Liver	May	2002
Phil Sinaguglia	Kidney	May	2004
Marilyn Sottile	Liver	May	2005
Nancy Thompson	Liver	May	1993

## Wishes of Wellness

### Our healing thoughts and prayers go out to:

Norm Breen

Benjamin Smeenk



## Our Sympathies

Matt Felo on the passing of his sister Carleen

Irene Stenshorn on the passing of her husband and former TAO President  
Dennis Stenshorn

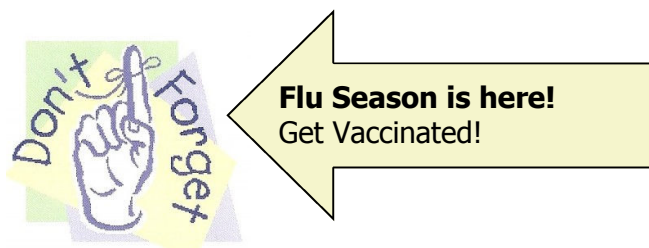
Bonnie Haefner on the passing of her brother  
Michael Ferrauilo, Sr.

## Welcome New Members

Stacie Poromon

## Contributions

Geoff Foley



## 2015 Membership Renewal

It's that time of year again – time to renew your TAO membership! Thank you for past support and for renewing now so we can continue to have the impact you've come to expect from TAO.

**YOUR** renewed membership ensures we can continue the support, programs and activities needed in the transplant community. We continue to hold our dues at \$20 (family/individual).

Members can be found at UR Strong Hospital supporting pre and post transplant patients and their families. We have member meetings, social gatherings, a website, publish a newsletter, and yes, we are on Facebook!

Your dues help in ways such as:

- Comfort Bags
- Event promotional items
- Support for the newsletter
- Annual membership picnic
- Holiday recognition dinner

Thank you for your continued commitment to TAO. We are counting on you to renew your membership by filling out the form on the back of this newsletter. Additionally, please use the form to indicate if you wish to continue receiving the newsletter.

Norm Breen  
Membership Chair



## There is Life After Kidney Disease

*Carol Pfuntner, a transplant recipient since October 9, 2001 has now canoed all fifty of our states and one Canadian Province.*

I have shared this adventure with my caregiver, now husband, Bill. What a wonderful time seeing the USA.

Life is good after a transplant. Our canoeing, for years, was to and from the American Association of Kidney Patients' Conventions and the National Rifleman Association meetings. Five years ago we expanded our canoeing to baseball's spring training in Florida and Arizona, then just canoeing the great states along the way. We have a beautiful nation. Our last state to canoe was Hawaii.

My kidney failure was due to toxicity from prescription medicines. My kidneys were at 9% usage when my primary doctor referred me to a nephrologist in 1997. Due to a strict kidney diet suggested by the nephrologist, I stayed off dialysis for three years until February 14, 2001 which was my start date for dialysis.

HOPE is what we as dialysis patients must have. Never give in. All is possible. BELIEVE and it can happen.

I moved to New York State to work for Jesus. My "new" life was given to me by someone that had died; now I live and serve my Lord.

I have a support group for anyone with kidney disease or just has questions. We meet the last Friday of each month. I can be contacted at my home in Dansville, NY, 585-335-2279.

## 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. Contact Bonnie Haefner at (585) 391-3555

**The more we sell, the more we earn.**  
The cards are available in \$25s, \$50s and \$100s.

## Visit & like our Facebook Page

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



**SHARE IT WITH OTHERS**

**WE NOW HAVE 290 LIKES!**

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

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**To act as a support group for transplant candidates, transplant recipients and their families.**

**To provide education and information on transplantation issues that surround it.**

**To promote organ and tissue donation awareness.**

***All potential transplant recipients, candidates, family and friends are welcome. Meetings are held monthly and include programs of interest to the transplant community.***

## community events

**Save the Date . . .****Sunday, April 12**

14th Annual Rochester River Run/Walk 5K  
**Genesee Valley Park, Rochester**  
 Elmwood Ave and Moore Rd

10:00 a.m. Fee - \$30 in advance or \$35 the day of the race.  
[signmeup.com/105351](http://signmeup.com/105351)

**Contact: Kathy Thompson**

**(585) 273-3881** for Registration forms, or visit Friends of Strong Office. First Floor SMH.

**Saturday, May 9**

Lilac Parade Tailgate continental breakfast, 8:30 - 9:15 am; 9:15 am- 10:15 am decorate float onsite/ Need recipients & donor families to ride/walk. Starts @ 10:30, ends at 12:15 pm.

**Contact Karen Guarino for details @ 585-272-7890 or [kguarino@rehpb.org](mailto:kguarino@rehpb.org)**

**April 10 : Amerks Donate Life Nite**

Contact Finger Lakes Donor Recovery Network

**Monday, June 15**

TAO Annual Picnic  
**Buckland Park, 1341 Westfall Rd., Brighton**  
 (between Winton Road and S. Clinton Ave.)

5 p.m.

Adults - \$10,

Children (under 15) - \$5

Make your reservation by June 6 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.

**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

**Support Group Meetings****"Open Airways" - Lung Gathering Group**

**Thursday, April 16 @ 12 noon**

Jeremiah's - 2164 Fairport Nine Mile Point Rd. Penfield

**Thursday, May 21 @ 12 noon**

Hicks and McCarthy - 23 S. Main St. Pittsford

**Heart Transplant/VAD Support Group**

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

Dr. Leway Chen - Director of the Heart Failure and Transplant Program

**\* Thursday, May 14 @ 6:30 p.m.**

Melissa Guerin - LMSW Social Worker for the Heart Failure/Transplant/Total Artificial Heart Program

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

**United Network for Organ Sharing**

*Candidates listed as of 3/6/2015*

<b>134,621</b>	<b>Kidney</b>
<b>15,856</b>	<b>Liver</b>
<b>4,108</b>	<b>Heart</b>
<b>2,057</b>	<b>Kidney/Pancreas</b>
<b>1,664</b>	<b>Lung</b>
<b>1,085</b>	<b>Pancreas</b>
<b>243</b>	<b>Intestine</b>
<b>39</b>	<b>Heart/Lung</b>

**134,621 TOTAL**

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

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

**Transplant Times****Submission Deadline**

**For June - July 2015 issue:**

**May 4, 2015**

**Articles /ideas email to:**

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

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

## Flying High or Possibly Low on Oxygen?

Article from: *Lung Foundation – Australia*

*Contribution authors:*

*Sharon Lagan BSc CRFS, Respiratory Scientist,  
Department of Pulmonary Physiology & Sleep Medicine,  
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Physician, Department of Pulmonary Physiology & Sleep  
Medicine, Sir Charles Gairdner Hospital, Perth, WA*

Flight has become an accepted form of travel for so many of us in Australia. If your lungs and heart are in reasonable shape, then the conditions within the aircraft cabin are something our bodies can deal with. However, if you have respiratory or heart disease, the environment in a plane can pose a potential problem.

The concentration of oxygen that we breathe at sea level is around 21%. Unless you were born at high altitudes (e.g. the Sherpa near Everest), your body tends to work best with this oxygen level. With altitude, the pressure (and effectively the amount) of oxygen available in the air rapidly diminishes. The human body could not survive at the heights that planes travel at – between 9,000-12,000 meters (30-40,000 feet). To overcome this, plane cabins are pressurized, making the conditions around the same as standing at an altitude of 2,400m (approximately 8,000ft). This equates to breathing an oxygen concentration of around 15%. This is not ideal, but in response our hearts and lungs work a bit harder to pump enough oxygen around our bodies to allow us to happily wander around the cabin. Not all planes are the same and the cabin pressure (and therefore the available oxygen level) will alter over the course of the flight. In addition, newer planes do not necessarily have better cabin pressures, although commercial aircraft must adhere to a minimum standard.

When measured using an oximeter, your oxygen levels (SpO<sub>2</sub>) whilst on a flight are ideal if maintained above 90%. If you have severe lung or heart disease then the additional work to maintain adequate oxygen concentrations may put your body under undue stress. At an SpO<sub>2</sub> of significantly less than 90%, things can get hard, particularly on long haul flights when you will need to move from your seat. Mild exercise may cause your oxygen levels to fall rapidly, leaving you feeling unwell or extremely short of breath.

For those who need oxygen during air travel, there are options to help you on your journey. If pre-arranged, some airlines can provide supplementary oxygen. Some also let you take your own oxygen concentrator on board, which can be very useful if you think you may need supplementary oxygen at the other end of your journey.

So how do you know how your body is going to respond to these low oxygen levels?

Before undertaking a flight, it is a good idea to speak to

your doctor or specialist and if needed, they can arrange for a High Altitude Simulation Test (HAST) to be performed at a lung function laboratory. During this test, you will be fitted with a mask and will breathe the same oxygen level (approximately 15%) as you would during air travel. Your oxygen saturation level (SpO<sub>2</sub>) will be monitored with an oximeter to see how your body responds. Some labs may also perform blood tests to ascertain the amount of oxygen in your blood stream. If your oxygen levels fall too low during this test, then supplementary oxygen can be added to see if that helps to maintain a healthy SpO<sub>2</sub>. When completed, the doctors overseeing the test will provide a recommendation of whether additional oxygen will be of benefit to you in flight. In some cases, doctors may recommend that a person should not undertake air travel.

If supplementary oxygen is suggested, then that is the time for you to spring into action and listed below are a number of things you will need to do:

Contact your airline to find out their policy on flying with oxygen. Some airlines e.g. some budget airlines will not supply oxygen, nor allow you to take concentrators on board.

There are forms available from each airline that will need to be completed with the assistance of your referring doctor. These forms must be submitted BEFORE travel.

Remember to ask about any additional charges involved.

Organize oxygen well in advance and follow up with the airline before travel to make sure that everything is in place.

Ask to be seated as close to the toilets as possible to minimize the distance needed to walk there.

Take your own nasal prongs as well as spare batteries, chargers and adaptors if using a concentrator.

Arrive at the airport early and allow extra time to clear check points in case someone has a query about your concentrator.

Remember, you cannot use the drop down oxygen masks they talk about during the safety demonstration, as these are strictly for emergencies.

Air travel and more importantly your destination can be fun, but it is important to recognize that you might need a little more assistance than you have previously. Before you book a ticket for air travel, ask your doctor if he/she thinks you may need additional oxygen inflight. Allow enough time before travel to have a HAST test (there may be a wait time for an appointment at lung function labs) and research which airlines will accommodate your needs. When you have the recommendation from your doctor, contact the airline well in advance and follow up just before travel. Lastly...don't forget your passport and to have a great trip!

### 14<sup>th</sup> Annual Rochester River Run/Walk 5K

The Friends of Strong and the Strong Memorial Hospital Transplant Programs Fourteenth Annual River Run is scheduled for Sunday, April 12, 2015 at Genesee Valley Park. Help celebrate and raise awareness for organ transplant patients and families in our community. There will be a ceremony honoring organ donors and recipients prior to the start of the race/walk.

There will also be a raffle featuring beautiful baskets donated by transplant team members and hospital units, so bring your extra cash!

The day kicks off with the registration table opening at 8:00am. We hope to see you there!

### TAO Communication

TAO is trying to keep you informed and up to date by sending weekly emails. Please look for the notices. They will come from TAO Communication. If there are any changes, cancellations we can keep you informed and up to the minute. When renewing your dues please include your email address. These are held strictly confidential and are not shared!

### March Meeting - corned beef dinner



### Something to Think About

Many of us have put together estate plans that identify how we would like our assets to be distributed after we pass away.

Whether or not you have already put together your last will and testament, we would like to encourage you to consider remembering the Transplant Awareness Organization by designating a modest gift for the organization's benefit in your estate plans.

The ability of a charitable organization like TAO to both expand its offerings, and to sustain its programs over the long term, depends in part on its ability to fund those programs and to build savings to carry it through the inevitable "rainy days" that occur from time to time.

Your estate-planning attorney can explain the various options that exist for making such a gift. We thank you sincerely for your consideration.

### Interested in going to the Transplant Games?

Need more information? Come to the next meeting on Tuesday April 14, 6 PM at the Finger Lakes Donor Recovery office, Corporate Woods, Building 30, Suite 220.

### April 17 is Wear Blue & Green Day

During this day, the public is encouraged to wear blue and green in an effort to spread awareness about organ, eye and tissue donation. Send us your photos!

### Board of Directors & Officers

**President**

Matt Felo

Jeffrey Alexis, MD

**Vice President**

Debbie Yendrzeski

Linda Barnard

**Treasurer**

Karen Gledhill

Geoff Foley

**Secretary**

Bev Shank

Karen Guarino

**Membership**

Norman Breen

Bonnie Haefner

Amy James

Janice Odenbach

Karen Porterfield, LMSW

# Your Periodontal health and Organ Transplantation

## What you need to know to thrive!

Organ transplantation is becoming more and more predictable because of technological advances, increased knowledge base and surgical experience. The transplant team does an individual potential organ recipient evaluation prior to surgery and determines if they are a good candidate and how to minimize risk factors that could lead to failure of the transplant. One of the main reasons for organ transplant failure is due to rejection and the second major reason is infection. It makes sense then that all potential factors be assessed and addressed prior to surgery such as stabilizing diabetic control, helping the patient quit smoking and stabilizing gum disease.

### **Gum Disease:**

In the US alone 47.2 percent of adults 30 and older have periodontal disease which is 65.7 million Americans. Periodontal or gum disease is highly preventable and treatable, yet it remains one of the most prevalent conditions around the world. So what is periodontal disease? Periodontal disease is a catch all term for gingivitis and periodontitis. Gingivitis is the swelling and bleeding of gum tissue but generally is reversible with a good home care regimen including brushing and flossing. Periodontitis is swelling and bleeding of the gum tissue but also includes loss of the supporting bone that holds your teeth in your jaw bone which is not reversible. Gum disease starts with bacterial plaque which is a sticky film that starts to form around your teeth within hours of eating. It can become hardened tartar (calculus) in as little as 48 hours if not removed and is difficult to remove with your regular toothbrush. Since gum disease doesn't necessarily hurt you may not know you have it!

Periodontists are important team members to consult with before; during and after organ transplantation because they can help minimize risk factors such as gum disease (gram negative bacterial infections) and tooth decay before they become problematic. The last thing an organ recipient needs while recovering surgery or after is a gum abscess or a toothache. There are more and more clinical studies that show that favorable transplant outcomes are directly related to how patients "train" for their transplant surgery. What I mean by that is that the patient should be an active participant in preparation... just like training for a marathon. So... in terms of oral health how do you get yourself ready? A visit with a periodontist is a perfect place to start and most people don't realize that you do not need a referral.

Periodontists are specialists in gum disease and can determine your current gum health. If you have periodontal disease it is imperative to treat it before you have your organ transplant as if left untreated can be a source of gram negative bacteria systemically and potential graft infection. Besides gum disease other common oral manifestations in transplant patients are

viral, bacterial and fungal infections and gingival hyperplasia due to the anti-rejection drugs and anti-hypertensives (ex: Cyclosporine and calcium channel blockers like Procardia). There is also a higher risk of developing oral malignancy.

So empower yourself and take the next step in achieving and maintaining your health by following these simple recommendations:

- See a periodontist and find out what your risk level is so you can address concerns
- Get a sonic toothbrush... it fights plaque better than your manual one and brush 2-3 times a day for 2 minutes at a time
- Floss or use little brushes 1x day... to get in between your teeth where food tends to get stuck
- As your transplant team probably informed you there are no elective dental procedures that can be done for post-organ transplant patients for 3-6 months so be proactive.

Remember health is the new wealth!

Be well,

Maryann

Mary Ann Lester, DMD

Board Certified American Academy of Periodontology

Private Practice, PHS Dental Implant and Periodontal

Surgical CTR,

Rochester, NY, [www.phsmile.com](http://www.phsmile.com)

Clinical Instructor University of Rochester, Eastman

Institute of Oral Health

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## **April is National Donate Life Month.**

There are ways YOU can help raise awareness of the need for organ, eye and tissue donation. One way is to share your own story with others whenever you have the opportunity.

Believe it or not, many people don't know much about transplantation, or have never met anyone who has had a transplant.

Another way is to write a letter and submit it to the op-ed page of the newspaper. They accept letters online these days. Or, distribute Donate Life Registry enrollment forms to family, friends, neighbors, co-workers and others interested and wanting to sign up.

To get a supply of brochures with enrollment forms call the Rochester Eye & Tissue Bank at 585-272-7890 or Finger Lakes Donor Recovery Network at 585 – 272-4930.

If you have another idea on how to recognize Donate Life Month, please let us know, send photos and we'll publish in the next Transplant Times.



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Return Service Requested

If you have a change of address, or you would like to be removed from our mailing list, please send an e-mail to: Subscriptions@tao-rochester.org Or a written request to: TAO PO Box 23552 Rochester, NY 14692-3552

Dues are due for your membership for 2015! Help support TAO's mission.



TAO / Rochester Membership Application

No one is denied membership because of financial considerations

DUES: \$20 Family / Individual \$100 Business / Organization 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)

Check here if you do not wish your transplant anniversary date to be published in the Transplant Times.