



# Transplant Times

April / May 2017

A newsletter of the Transplant Awareness Organization of Greater Rochester

[www.tao-rochester.org](http://www.tao-rochester.org) | 1.888.664.1463

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## Membership Meetings

Guest Speakers / Topic

### April 17

- Mary Ann Lester, DMD  
Organ Transplantation and Gum disease: What you need to know to thrive

### May 15

- Unconfirmed at press time.  
Please check the TAO website and your email.

## 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

April is Donate Life Month. What does that mean? It is your chance to spread awareness about organ donation, how important the donor registry is and transplantation.

How can I spread awareness? Talk to your loved ones, friends and co-workers about your personal experience and how organ donation touched your life. Speak at your place of worship. Talk to your pastor about setting up a donor registry table after services. Before doing this though, please take the time to get educated to the facts of donation. Unfortunately, myths and misinformation are the big reasons why people do not register. We certainly do not want to contribute to this. Write a short article for your local newspaper about your experience, why you needed a transplant and how it's changed your life. Many don't realize that transplantation works, they may not realize they know someone that has been touched by organ, eye or tissue donation.

Did you know that donor bone is used in dental procedures and other surgeries such as hip replacements? That many athletes are functioning in their sport due to tissue or ligament



donation? I met two teachers in one classroom that were walking and standing due to ligament replacement, thanks to a deceased donor.

There are many recipients walking amongst us. It's not always the life saving organ transplant that is impacting a life. For one that can't see anything but a blur, a corneal transplant can help them see more clearly.

The general population might not realize the impact that their decision to donate can make and we have the opportunity to change that.

Spring is in the air, let's spring into action and make a difference.

*Debbie Gendrzewski*



Visit, like our Facebook Page  
[www.facebook.com/TAOofRochester](http://www.facebook.com/TAOofRochester)

## Why Me?

While reading my February-March 2017 issue of the *Transplant Times*, I saw my name in the Transplant Anniversaries column...Elaine Schultz-Liver-March 2015. While that date is always etched in my mind, seeing it in print brought back a flood of memories.

I had been rushed by ambulance from a hospital in Buffalo, NY to Strong at the end of February 2015 with only a few days left to live. It was truly a miracle that a liver became available and a match was made. I was oblivious to all that was going on around me, but I know that my husband and both of our sons were there praying for me as I underwent the 9 hour surgery. The weeks following were rough ones, but the amazing doctors (namely Dr. Orloff and Dr. Kashyap) and staff helped me physically and mentally to get through the days one by one...until on April 15th I was able to go back home to Elba, NY.

Since that time, I have had some complications and have been in and out of Strong for various procedures. I will forever be grateful for my wonderful doctors, unforgettable nurses, the incomparable transplant clinic team and the always friendly and encouraging staff.

I, as I'm sure most transplant patients, have always wondered *why was I given a second chance? Was I suppose to be doing something for a greater cause...if so what is it?* After recently seeing the movie "A Dog's Purpose", where the viewer learns that the dog's purpose is just to be and enjoy life...BE HAPPY. I think that lesson applies to all transplant recipients also... **be content, be grateful, be happy.**

- Elaine Schultz



## National Donate Life Month

Across the United States in April, National Donate Life Month features local, regional and national activities to help encourage Americans to register as organ, eye and tissue donors, and to celebrate those who have saved lives through the gift of donation.



Friday April 21 is wear **Blue & Green** Day. Wearing blue and green is a way to promote organ, eye and tissue donation. In the past people have painted their nails, decorated their office, made food such as cookies, cupcakes decorated in blue and green.

This is a fun way to start a conversation about organ donation and educating people about the importance of registering in the donor registry.

Be creative and share your pictures with us!

## Our newest members to TAO

WELCOME

**Paula DelSanto** recently joined TAO. Originally from Hyde Park, she has resided in Brooklyn, NY for over 30 years. On a particularly fateful day, she saw a story on her local news channel regarding a need for a kidney for a recipient with a special blood type. She was so moved by the story that she took steps to determine if she could be a match for the recipient—and she was! Paula gave the ultimate gift by donating one of her kidneys in July of 2016. After a six week recovery period, she was able to return to work as an accountant for the Treasury Department. She continues with a healthy life style and enjoys participating in half marathons, traveling, and taking Disney cruises.

**Rob Taylor** is a heart transplant recipient of almost 18 years. He had his transplant at Loyola Medical Center in Maywood, Illinois.

Rob enjoys being a philanthropist and worked many years in a number of positions involved with fundraising for charitable organizations in both the Chicago and Boston areas.

Although Rob spent many years away from his home town, he returned to his roots in Conesus, NY in 2006. He is currently semi-retired and works part-time at the Wadsworth Library in Geneseo. In addition, he spends special time as a moderator at the Congregational Church in his community.



**Molly Huff** of Molly's Yoga Corner spoke to TAO members at the February meeting about Mindfulness & Meditation. She demonstrated some basic yoga moves and chair yoga and invited all in attendance to try.

TAO president Debbie Yendrzkeski is presenting her with a certificate of appreciation after her demonstration.



**Dr. Jeffrey Alexis, MD** was our guest speaker for the March meeting. His presentation on Advances in Heart Transplantation will be available to view on our website: [www.tao-rochester.org](http://www.tao-rochester.org)

community events  
**Save the Date . . .**

**Friday April 21**

Blue & Green Day

**Sunday April 23**

16th Annual Rochester River Run  
For details: [www.riverrun.urmc.edu](http://www.riverrun.urmc.edu)

**Sunday May 7**

Comedy Night to benefit the Solid Organ Transplant Programs of Strong / URMC  
For details: (585) 319-2572

**Saturday May 13**

Lilac Parade  
For details: [kguarino@lebrochester.org](mailto:kguarino@lebrochester.org) or  
(585) 272-7890

transplant  
**Support Group Meetings**

**"Open Airways" Lung Gathering Group**

**Thursday, April 20 @ 12 noon**

Jeremiah's - Rt. 250, Fairport Nine Mile Point Rd., Penfield

**Thursday, May 18 @ 12 noon**

Hong Wah Restaurant, 1802 Penfield Rd., Penfield

**Heart Transplant/VAD Support Group\***

**Thursday, April 13 @ 6:30 pm**

VAD Specific Support Group  
Invite to follow for VAD patients

**Thursday, May 11 @ 6:30 pm**

Advanced Heart Failure Program Director  
Leway Chen, MD, MPH

\* 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 March 17, 2017

98,025	Kidney
14,363	Liver
3,989	Heart
1,729	Kidney/Pancreas
1,393	Lung
932	Pancreas
273	Intestine
45	Heart/Lung

**118,100 TOTAL**

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

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



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

**G** Act as a support group for transplant candidates, recipients & their families.

**O** Provide education and information on transplantation issues that surround it.

**A** Promote organ/tissue donation awareness.

**L**

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

## Riders needed for Lilac Festival Float

Come join The Lions Eye Bank of Rochester and TAO at the Lilac Festival Parade, Saturday, May 13.

Organ, eye and tissue transplant recipients interested in riding on the Donate Life float in this year's Lilac Festival Parade, please contact Karen Guarino for information and details at (585) 272-7890 or kguarino@lebrochester.org.

We will start the day with a tailgate breakfast, proceed to the parade site to decorate the float and then enjoy the parade.

Please contact Karen by May 1, 2017.



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**Amazon shoppers can help support TAO** by using Smile.Amazon.com to make their purchases.

**AmazonSmile** is a website operated by Amazon with the same products, prices and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice.

Go to smile.amazon.com and follow the instructions to designate Transplant Awareness Organization as your choice. **Thank you!**

### Board of Directors & Officers

<b>President</b>	Debbie Yendrzeski	Jeffrey Alexis, MD
<b>Vice President</b>	Gretchen Collins	Linda Barnard
<b>Treasurer</b>	Karen Gledhill	Erin Collins
<b>Secretary</b>	Sue Muto	Matt Felo
<b>Membership</b>	Norman Breen	Karen Guarino
		Bonnie Haefner
		Judy Munn
		Janice Odenbach
		Karen Porterfield, LMSW

## Our Sympathies

To **Donelle Evans**  
on the death of his Mother

## Wishes of Wellness

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

Laurie Packard  
Bernice Eblovi  
Benjamin Smeenk  
Jerry Runion



## Comedy Night

**Combat Comedians** present a huge comedy show to benefit the Solid Organ Transplant Programs at Strong Hospital / U of R Medicine Sunday May 7 from 5 pm-7 pm at the Comedy Club, 2235 Empire Blvd. Webster, NY.

Comedians from the Army, Navy and Marine Corps will be performing and hosting. Ralph Tetta will be headlining. This event is organized by Dave DiFranco, a living kidney donor.

The funds raised at the event will go towards the Transplant Patient Needs fund. Join us for an evening of laughs and fun.

Tickets are available at the Comedy Club in Rochester, Sue's Creature Comforts in Ontario and at the URMC Transplant Office.

For more information contact (585) 319-2572.



**Flu Season is here!  
Get Vaccinated!**

## NY State Donate Life Registry opens to 16 & 17 year olds

Legislation allowing 16 and 17 year-olds to register their intent to donate organs, eyes and tissues when applying for a driver's license, learner permit or a non-driver ID took effect on Tuesday, February 14.

"Allowing young adults to express their desire to make life-saving donation is critical to expanding the New York State Organ Donor Registry and saving lives," said Adam Bello, Monroe County Clerk. "Many young people who visit our office for a learner's permit won't be presented with another opportunity to enroll until their first driver's license renewal eight years down the road. That eight-year gap effectively keeps thousands of potential donors off the registry. This is a giant step forward to filling that gap. Our staff is going to make a serious effort to make sure that everyone visiting a Monroe County DMV is making an informed decision on organ donation."

While the new rules allow 16 and 17 year olds to enroll, parents retain the rights to notification and final authorization until the enrollees turn 18.

Monroe County Auto License Bureau offices issued 41,217 new permits, licenses and IDs and;17,037 of the new documents issued were permits. Permits are largely issued to newly eligible 16 and 17 year-olds.

New York is now one of 48 states that allows young adults to register as donors. There are nearly 10,000 New Yorkers waiting for organ transplants and thousands of others that will be in need of cornea or tissue transplants.

## Transplant Times

### Submission Deadline

For June / July issue:  
May 7, 2017

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

## Thomas Starzl, pioneering transplant surgeon, dies at 90

Thomas E. Starzl, whose bold vision, boundless energy and unflagging self-confidence resulted in dramatic and pioneering advances in organ transplantation and anti-rejection medicines that saved thousands of lives, died in his sleep Saturday, March 4 at his home in Oakland. He was 90.

Dr. Starzl performed the world's first liver transplant in Denver in 1963 and Pittsburgh's first liver transplant in 1981 after moving here at the end of 1980. He was the surgeon who performed the world's first heart-liver transplant in 1984, replacing those organs in Stormie Jones, a



Texas girl who died in 1990 at age 13. And, in 1987, he led the five-organ transplant operation on Tabatha Foster, who survived for six months.

During his years in Pittsburgh, Dr. Starzl achieved international renown and celebrity status for those high-profile transplants and transformed the University of Pittsburgh Medical Center into the busiest transplant center in the world.

Dr. Starzl's work on drugs to prevent organ rejection also resulted in much higher success rates for organ transplants. In 1989, Dr. Starzl and John Fung, then a colleague and now director of the University of Chicago Transplantation Institute, developed FK506 (better known as tacrolimus), still the most widely used immune-suppressant drug in the world.

- Pittsburgh Post-Gazette

## JOIN OUR BOARD

Do you want to get more involved with the transplant community? Do you have some extra time? TAO is looking for board members. The board meets every other month for one hour prior to the general membership meeting.

If you have an interest or want to learn more call 1-888-664-1463. TAO holds monthly meetings from September to June on the 3rd Monday of the month from 6:30 to 8:00 pm.

Meetings offer time for social interaction with other members, along with a scheduled speaker at many. Refreshments are provided and guests are welcome. The January meeting is reserved for a Holiday Party and the June meeting for a Picnic.

## 2017 Membership Renewal

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

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

## Transplant Anniversaries

Tiffany Conboy	Kidney	April	2014
Wayne Dickinson	Kidney	April	2008
Geoff Foley	Bilateral Lung	April	2005
Joseph Heil	Liver	April	2011
Doug Hemingway	Heart	April	2008
Fred Knewstub	Heart	April	2014
Nicholas Latona	Kidney	April	2016
Donald J. Leone	Liver	April	2009
Chuck Lundeen	Liver	April	2008
Susan Maglisco	Liver	April	2010
Sharon Mooney	Kidney	April	2010
Bernie Pierce	Lungs (2)	April	2011
Daniel Pszczolkowski	Heart	April	2011
Penny Sayles	Kidney	April	1998
Linda Marie Serenka	Kidney	April	2016
Jerry Stephenson	Liver	April	2016
Scott Stewart	Kidney	April	2013
G. Murray Thomas	Kidney	April	2010
Merrillan Thomas	Kidney	April	2010
Kirk Wilson	Liver	April	2016
Asya Zarkhi	Kidney	April	2003
Ginger Zimmerman	Heart	April	1998
Patricia Bianchi	Liver	May	2002
Norman Breen	Heart	May	2007
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

## CONTRIBUTIONS

**We are grateful to those individuals and organizations that generously contribute to TAO.**

Settlers Club



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***It's time to renew your membership for 2017!  
Help support the TAO mission***



# TAO / Rochester Membership Application

*No one is denied membership because of financial considerations*

- DUES:**
- New Member
  - Renewal
  - \$20 Family / Individual
  - \$100 Business / Organization
  - unable to make dues payment at this time

Donations 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) \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone ( ) \_\_\_\_\_ E-mail \_\_\_\_\_

- Candidate
- Recipient
- Family Member
- Donor Family
- Friend
- Professional
- Business / Organization

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*.