



Transplant Times

A newsletter of the Transplant Awareness Organization of Greater Rochester

August/September 2018

www.tao-rochester.org | 1.888.664.1463

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Membership Meetings

Guest Speakers / Topic

August

- No Member Meeting

September

- Richard Demme, MD

Living Will & Advanced Directives

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

I hope everyone is enjoying the warm summer that we are having!

I personally have been recovering from surgery and am doing well yet I look forward to being 100%!

We don't meet during the summer months but we are busy preparing for the fall. We had a very informative last season and look forward to the upcoming one. We are planning on changing a few of our regular events and hope you will support us.

The weather didn't cooperate for our annual Holiday Recognition Dinner so we are giving in to the weather and planning a "bring your favorite dish" party. It will be more casual, family friendly and inexpensive. The Board feels that the price may be a deterrent to participation and we would like to remove that factor.

We also are looking for member participation for the River Run. Raffle items are donated to help



raise money and TAO would like to donate. It will be a themed basket and the details will come at a later date, stay tuned!

Our election results are in and posted in this newsletter. If at any time you choose to join our board or pass along new ideas suggestions, we welcome it!!

We hope to see you at a future meeting/event, the Board puts a lot of effort into the planning! Enjoy the last days of summer!

Debbie Gendrzewski



Visit, like our Facebook Page
www.facebook.com/TAOfRochester

TAO Providing support, understanding, education & resources . . .

TAO Picnic

After a day of threatening rain, the annual TAO picnic was held under sunny skies. The lovely lodge at Buckland Park had a beautiful breeze going through it as TAO members enjoyed a delicious meal and conversation.

Our thanks go out to JR Dewhirst and his great cooking skills, to Judy Munn for making all the arrangements and baking a delicious chocolate cake, and to Bev Shank for securing the location, it's such a great spot. Thank you to Melanie Runion for her help in the set up.

A lot of work goes into making a successful event. We hope you will join us at a future event. If there is something else you'd like us to do, please let us know!!



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Amazon shoppers can help support TAO by using [Smile.Amazon.com](https://www.smile.amazon.com) to make their purchases.

Amazon Smile 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 Amazon Smile, the Amazon Smile Foundation will donate 0.5% of the purchase price of eligible products to TAO.

Go to [smile.amazon.com](https://www.smile.amazon.com) and follow the instructions to designate Transplant Awareness Organization as your choice. **Thank you!**



Save the Date!

When: Saturday, September 29, 2018
 Time: 6:00 PM
 Where: Monroe Golf Club
 Price: \$75.00 per ticket

Mark your calendar for our annual **"And the BEAT goes on..."** fundraiser. Maureen Maguire, news anchor for channel 8 will host the event. She will be joined by Chris D'Orso who will be the auctioneer for the evening.

Heavy hors d'oeuvres will be served including carved turkey and sirloin, with rolls, a potato bar, selection of fresh veggies, cheese and hand-passed epicurean delights.

The evening activities will include basket raffles, a silent and live auction, our chocolate hearts raffle, wine toss and Adopt-A-Day campaign.

To purchase tickets go to: <https://www.brownpapertickets.com/event/3484449>
 Or mail a check with your ticket order to:

Harbor House of Rochester
 89 Rossiter Road
 Rochester, NY 14620

Be sure to include a return address so we can mail you your tickets!

*Please note that the event is cocktail attire and bar is cash only.

Transplant Anniversaries

Lisa Faucz	Kidney	August	2008
James Graczyk	Liver	August	2008
Moira Miller	Liver	August	2005
Cosimo Palermo	Liver	August	2014
Shawn Pangburn	Liver	August	2016
David Spiro	Liver	August	1997
Loren R. Taurisano	Liver	August	2016
Thomas Vitti	Heart	August	2014
Lisa Abbey	Heart	September	2008
Tom Arcara	Heart	September	2005
Ernst Baier	Kidney	September	2000
Marianne Benvenuti	Liver	September	2006
James Connolly	Kidney	September	2011
Marcia J. Marcheson	Liver	September	2008
Tom Neary	Lungs (2)	September	2017
Joanne Schum	Lungs (2)	September	1997
Debbie Vernam	Kidney	September	2004

Transplant Times

Submission Deadline

**For October/November issue:
 September 8, 2018**

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

We welcome your personal story and feel our members appreciate hearing about other's journey. So write your story and send it to us, a picture is always welcomed too!



Upcoming Events

Sunday August 5– River Run

Roundhouse Shelter, Genesee Valley
Park,

99 Elmwood Avenue

Event Schedule

6:30 a.m. On-site registration through 7:30
a.m.

8:00 a.m. Start for Runners

8:05 a.m. Start for Walkers

9:00 a.m. Awards Ceremony

9:30 a.m. Ceremony for donors and recipients

Saturday September -

"And the Beat Goes on ..."

Fundraiser to benefit Harbor House of
Rochester

6:00 PM

Monroe Golf Club

Tickets: \$75.00

(Details on Page 3)

United Network for Organ Sharing

Candidates listed as of July 19, 2018

94,920	Kidney
13,797	Liver
3,968	Heart
1,626	Kidney/Pancreas
1,433	Lung
891	Pancreas
248	Intestine
50	Heart/Lung

114,362 TOTAL

www.unos.org

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

Transplant Support Group Meetings

"Open Airways" Lung Gathering Group

- **Wednesday, August 15 @ noon**
Porterhouse, Packett's Landing, Fairport
- **Wednesday, September 19 @ noon**
Hong Wah, Penfield Rd. , Penfield

Heart Transplant/VAD Support Group

- **Thursday, August 9 @ 6:30 pm**
No meeting
- **Thursday, September 13 @ 6:30 pm**
Speaker & Topic TBA

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

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

S



Wishes of Wellness

Our healing thoughts and prayers go out to:

Dave Spiro
Bonnie Haefner
Mike Swete
Tina Swete
Lisa Faucz



Welcome to Chuck Lundeen and Melanie Runion to the TAO Board! We look forward to new ideas and to your help!

Thank you to the returning board members for their continued support!

CONTRIBUTIONS

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

Cosimo Palermo

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: TAO

Board of Directors & Officers

President	Debbie Yendrzeki	Jeffrey Alexis, MD
Vice President	Gretchen Collins	Linda Barnard
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Secretary	Sue Muto	Bonnie Haefner
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		Marilyn Moran
		Judy Munn
		Janice Odenbach
		Melanie Reunion

Richard Perez Receives Recognition in Washington D. C.

Long-time Friends of Strong volunteer and liver transplant recipient, Richard Perez, had spent two days in Washington D.C. exchanging inspirational stories with dozens of unsung heroes from across the nation when he found himself sitting at the iconic Mayflower Hotel. He was thinking about the public service volunteers he had met when the award ceremony began, which recognized the very best among them for their efforts to make positive, lasting changes in their communities.

Richard was caught off-guard when his son pulled him back to the present. "Dad, they're talking about you," Rich Jr. whispered to his father. Suddenly, Richard heard former U.S. Secretary of Education Arne Duncan call him to the podium to accept one of only five Jacqueline Kennedy Onassis Awards for Outstanding Public Service Benefitting Local Communities. The award is given out each year by the Jefferson Awards Foundation, the nation's most prestigious and longest-standing organization dedicated to inspiring and celebrating public service.

Throughout the years, Richard has helped more than 700 liver transplant recipients, 2,000 people who have undergone a transplant evaluation and innumerable family members who have turned to him for reassurance. They come from all over Upstate New York and Northern Pennsylvania.

"These patients often wait years for a lifesaving donor organ to become available," said Roberto Hernandez- Alejandro, M.D., director of Solid Organ Transplant at Strong Memorial Hospital. "He knows and understands the patient perspective and he provides a level of reassurance that is different from that of our clinical team members."

For those who've come to know Richard well throughout the past 14 years, his recognition among the very best volunteers in our country comes only as a mild surprise. "With all his service here at Strong Hospital and throughout our community, Richard brings awareness to the

importance of organ donation and boosts up those he meets and volunteers with every day," said Sandy Arbasak, Friends of Strong Director. "His unwavering determination to bring forth the good in others is, undoubtedly, just one reason he received this prestigious recognition."

Throughout his life, 63-year-old Webster resident Richard Perez feels blessed by the love and support he's received from the Rochester community. His list of blessings include a serendipitous career in retail and then financial security and starting a family with his late wife, Maria, which led to their son and recently twin grandsons. But among his greatest gifts, Richard says, is a life-saving liver transplant in 2003 at UR Medicine's Strong Memorial Hospital (SMH).

Given a rare second chance at life, he embarked on a new mission and purpose—to help educate our community about organ donation and transplant, as well as providing comfort, support and comradery to fellow transplant patients.

Even before he received his own transplant, Richard seemed to know, intuitively, that there was a need in Rochester's Donate Life community—a calling—that he wanted to fill. "I was sitting across the table from my surgeon, Dr. Mark Orloff, listening to the prognosis, and learned how contingent my survival was on a donor and how rare that there would be a viable liver available, given that participation in the organ donor registry is so low," he remembers. "I asked him right then if there was anything I could do to help change that." By June 2004, while he was busily helping raise awareness and get folks registered as organ donors, he also expanded an official volunteer program with SMH's Friends of Strong to help comfort patients and families who were now experiencing the same transplant journey that he and his family had also traveled.

Since then, he's volunteered more than 5,000 hours at SMH to make their lives just a little more bright. The transplant volunteer program, with Richard leading the charge, now includes at least eight volunteers at any given time—all of whom are fellow organ transplant recipients who *(continued on page 7)*

(Continued)

can offer comfort, hope and inspiration to those who face the same daunting obstacles they themselves have overcome.

Richard continues volunteering throughout the Rochester area to help bring greater awareness and support for organ donation. He works to recruit those he meets to register for the New York State Donate Life Registry.

"This has been an amazing experience," Richard says. "I am extremely honored to receive this award, and it's really thanks to everyone around me for making it possible. All organ donors, my fellow volunteers, the staff at Friends of Strong, the Organ Transplant programs at Strong Memorial Hospital, Finger Lakes Donor Recovery Network, Harbor House, Karen Guarino from Lions Eye Bank of Rochester, my fellow transplant recipients from across upstate New York and beyond. I'm so incredibly thankful for everyone's support."



Richard Perez (L) with former Secretary of Education - Arne Duncan

Tops Never Stops

Tops cards help TAO raise money.

The Tops Gift Card Program allows our non-profit 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, \$100s.

Contact Bonnie Haener at (585) 391-3555

Prescription Disposal

Do you have unwanted or expired prescription drugs? If so, stop by the Webster Town Hall, 1000 Ridge Rd., Webster, NY.

There is a box in the lower level where you can deposit any expired or unwanted drugs.

You can also drop off unwanted prescription drugs in the locked container at the Irondequoit PD, Monday through Saturday from 8 a.m. until 11 p.m.

Additionally, there are drug drop boxes located at the Brighton, Gates, Greece and Ogden police departments. The Livingston County Sheriff's Office also has a drug drop box located outside the sheriff's office.

Please don't flush your drugs!



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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

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

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*.