



# Transplant Times

June/July 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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## A Message from the President

The summer months are fast approaching. A time of graduations, weddings, picnics and family celebrations. Take these few short months and enjoy life. Smell the flowers and the fresh cut grass. Don't forget your sunscreen though! As recipients we realize the need for sunscreen and protecting our skin against one of the most prevalent cancers.

We hope you will join us for the annual picnic, details are enclosed. Friends and families are encouraged to come. We have an enclosed lodge so we can be comfortable rain or shine.

Election time is here and we are asking you, the members, to vote for the board members by sending in the enclosed ballot sheet.

The TAO board will be busy preparing for the fall speakers and events. If you have any suggestions for speakers/topics please let us know. If you'd like a certain event to happen, again let us know.



I'd like to take a moment to thank two outgoing advisors, Karen Porterfield and Amy James. They have both served for a number of years and are moving on to other ventures. Also past president, Matt Felo is stepping down. I personally appreciate their time, input and effort to help TAO grow and thrive. Thank them if you get a chance!

We do not meet in July or August but we look forward to seeing you all in September and I hope that you all have a safe, healthy and fun summer!!

*Debbie Gendrzewski*

## Membership Meetings

Guest Speakers / Topic

### June

- Annual Membership Picnic  
Details on pg. 4

### July

- no meeting

## TAO Meets

**3rd Monday of the Month  
6:30 P.M.**

Christ Episcopal Church  
Fellowship Room  
36 South Main Street  
Pittsford, NY



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

## TAO Board Nominees

**Marilyn Moran** - I would like to give some of my time for a "cause". I've known about TAO for years, through the Yendzski's experience.

I personally have had several tissue and bone grafts in my mouth and ear over the past few years. I have served on boards and have been affiliated with organizations in the past.

I am a Dental Hygienist, previously taught and served as the Director at Rochester Dental Assistant School. I have volunteered at the Food Closet, Hospice, and served on the Habitat for Humanity Fund Raising committee.

Through my church I have been vestry officer, Chairperson for several committees. I was involved with Neutral Ground Support Organization as a board member for many years, chairperson for the social committee, secretary, past president, facilitator and on the emergency phone line. I feel I could help with this organization in some capacity.

**Bonnie Haefner** - long time board member and kidney recipient

**Debbie Yendzski** - long time board member and caregiver

**Karen Gledhill** - long time board member and kidney recipient

**Gretchen Collins** - vice president and kidney donor

**Judy Munn** - board member and caregiver

Please vote! Ballot is enclosed. Mark your ballot, fold, tape and mail!



## Rochester River Run/Walk 5K

The 16th Annual Rochester River Run/Walk 5K took place on Sunday, attracting more than 1,000 participants and raising about \$40,000.

The fundraiser event supports patients awaiting and recovering from organ transplant surgery at Strong Memorial Hospital. Money raised at last year's fundraiser, money went directly to supplement patient care needs with emergency financial assistance.

Following a ceremony commemorating donors and transplant recipients, runners departed for the scenic 5K along the Genesee River—crossing through Genesee Valley Park and the University of Rochester campus.

Race participants received sunscreen packets compliments of TAO. TAO is very proud to be a sponsor of such a fine event!

Each year UR Medicine's transplant programs serve hundreds of heart, liver, pancreas and kidney patients from across Upstate New York. In addition to current transplant recipients, Strong provides ongoing care for patients who continue coming to Rochester for medical care related to their transplant. More than 100 patients have received assistance through River Run funds over the past three years alone.



TAO's vice president, Gretchen Collins (kidney donor) and board member and Gretchen's daughter, Erin Collins (kidney recipient) at the TAO table at the River Run.

## Guest Presenters



**Dr. MaryAnne Lester** receiving her certificate of appreciation from TAO President Debbie Yendrzkeski, after her presentation about oral health in a transplant recipient, pre and post transplant.

## Lilac Festival Parade

The rainy skies held off for another successful Lilac Parade. The Lions Eye Bank of Rochester along with the Transplant Awareness Organization (TAO) sponsored a float full of recipients and their families. The float was beautifully decorated by the riders. They thanked people as they traveled the parade route. We hope you'll join us next year!



**WELCOME**  
 Our newest members to TAO  
 Vicki DeRue



*Brain Death, Circulatory Death and Munchkin Death — What is Dead Enough?* was the topic for the May meeting.

**Dr. Richard Demme** presented the ethics behind brain death and transplant. Check our website for the PowerPoint presentation.

## events Save the Date . . .

**Monday, June 19**

### **TAO Annual Picnic**

The Lodge at Buckland Park  
1341 Westfall Rd

Social Hour 5:30 pm

Dinner 6:00pm

Adults \$12 / Children \$6

RSVP by June 11

### **RSVP by sending a check to :**

TAO

PO Box 23552

Rochester NY 14692-3552

## United Network for Organ Sharing

*Candidates listed as of May 18, 2017*

<b>97,758</b>	<b>Kidney</b>
<b>14,477</b>	<b>Liver</b>
<b>3,977</b>	<b>Heart</b>
<b>1,696</b>	<b>Kidney/Pancreas</b>
<b>1,419</b>	<b>Lung</b>
<b>927</b>	<b>Pancreas</b>
<b>270</b>	<b>Intestine</b>
<b>41</b>	<b>Heart/Lung</b>

**117,920 TOTAL**

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

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

## Transplant Support Group Meetings

### "Open Airways" Lung Gathering Group

**Thursday, June 15 @ 12 noon**

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

**Thursday, July 20 @ 12 noon**

Hong Wah Restaurant, 1802 Penfield Rd., Penfield

### Heart Transplant/VAD Support Group\*

**Thursday, June 8 @ 6:30 pm**

Transplant Coordinator Liz Powley, FNP  
Post Transplant Care and Recovery

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

TBA

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



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

**S**

## CONTRIBUTIONS

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

Jeffrey Alexis  
Chuck Lundeen

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

### 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.

Please don't flush your drugs!



## Board of Directors & Officers

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

## Wishes of Wellness

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

Laurie Packard  
Bernice Eblovi  
Jerry Runion  
Vicki DeRue  
Joe Dunn  
Jan Sharp  
Rose Mary McNitt  
Dave McNitt  
Jerry Muto



## Our Sympathies

To Lia Stephenson on the passing of her husband, Jerry.

## 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, \$100s.  
Contact Bonnie Haefner at (585) 391-3555

## What Makes Someone Donate a Kidney to a Stranger?

By Lenny Bernstein  
The Washington Post

Would you donate a kidney to someone you've never met? The idea is layered with soul-searching judgments — questions of risk and benefit, sacrifice and selfishness, not to mention the physical pain of the surgery itself.

But a small number of people have done this, and researchers at Georgetown University are studying them, providing a window on altruism in a world seemingly dominated by a me-first philosophy.

"Extraordinary altruists," as the researchers call them, come from all age, race and socioeconomic groups. Some are religious, others are not. But unlike almost everyone else, they don't see less value in a stranger's life than in the life of a close friend or relative, the researchers found. And they are genuinely puzzled that the rest of the world doesn't view other people the same way.

"They don't see it as something necessarily heroic or that they should be given praise for," said Kruti M. Vekaria, a doctoral student in psychology who was part of the team that conducted a study published Friday in the journal *Nature Human Behavior*. "They think it's something everybody should do."

When asked directly why they would give up a kidney to a perfect stranger, "they see it as an obvious choice," added Abigail A. Marsh, a psychologist at Georgetown who led the research team. "They just seem politely puzzled. They have trouble answering the question."

Altruism is difficult to study because most generous acts, such as giving to charity, carry some benefit for the donor (a tax break, for example). And small, kind gestures, such as holding a door open, are partly determined by social norms. But undergoing a surgical procedure and increasing one's own risk of future health problems is "painful, costly, non-normative, exceedingly rare and meets the most exacting definitions of costly altruism," the authors wrote.

"When we're personally touched by something, that's when we react to it," said Angela Cuzzo, a 49-year-old from Albany, N.Y., who gave a kidney to a 25-year-old woman in Bakersfield, Calif., seven years ago. "We should take it upon ourselves to be a little more forthcoming and pay it forward before we're personally touched by it." Cuzzo said that she was single with no children and going through a minor midlife crisis when she overheard a co-worker discussing his sister's fourth kidney transplant. She began to research the idea of giving a kidney and discovered that she could participate in a chain kidney donation if she gave to a stranger. In that arrangement, organizers try to maximize the number of

kidneys donated by having a friend or relative of each recipient give an organ to someone with whom they are a match, but strangers can donate as well.

"I just really needed to make sure that before I left this Earth I could somehow contribute," Cuzzo said. Her donation eventually went to the California woman, not the co-worker's sister.

Rob Upham, who gave a kidney to a woman in 2009, said he first thought about the idea after watching a news report on chain kidney donations. The oldest person in the chain was 72.

"I just thought 'why hadn't this dawned on me before? I have two healthy kidneys and I can possibly save someone's life, or at least improve the quality of somebody's life,'" said Upham, 52, director of human resources for an organization that provides services to Rhode Island's homeless.

He said he sees nothing extraordinary in what he did and never worries about his own health. No one in his family has had kidney problems.

"Most people live in a wooden house. It might burn down. You still live in a wooden house. Life is filled with risk," he said.

Upham said he met the woman who received his kidney in the hospital, three days after the transplant. She died three months later of a stroke. But he has no regrets. He went to her funeral, where he was called "an angel" during the eulogy.

Vekaria said about 2,100 people had given kidneys to strangers out of a total of about 147,000 live donations at the time the research was conducted.

There is a drastic shortage of transplant organs in the United States. According to the United Network for Organ Sharing, 97,727 people are waiting for kidneys as of this week, and an additional 20,000 need livers, hearts, pancreases or other organs.

Previous research by Marsh has established that extraordinary altruists have larger than normal amygdalas, a portion of the brain involved in compassion. (Psychopaths have smaller than normal amygdalas, she said). In brain scans, that part of altruists' brains also appears to be more active than in average people when they are considering questions of altruism, she said. But that doesn't explain much, because the technology used to visualize brain activity is relatively crude and compassion for others is learned as one goes through life, she said. In the current study, the team compared 21 kidney donors with 39 control subjects. First, they asked them to place avatars representing family, friends, neighbors and strangers on a computer screen at distances from an avatar for themselves, to test their views of "social distance" — whether they consider themselves closer to strangers than most people do. They found that there is no significant difference between altruists and others.

*(Continued on page 7)*

(continued from page 6)

Then the researchers asked people to play a money allocation game. In each round, they could keep larger sums for themselves by declining to give part of the money to another person — a family member, a friend or a stranger, for example. Or they could give some money away, resulting in less for themselves.

The altruists consistently placed more value on strangers than ordinary people did. The altruists gave as much money to very distant strangers as control group members gave to a good acquaintance, for example.

That helped researchers conclude that the altruists simply don't value strangers less than they value people they are close to. "They don't tend to view a stranger or even an acquaintance as any less deserving of resources," Vekaria said.

In an article that accompanies the study, Tobias Kalenscher, who studies comparative psychology at Heinrich Heine University in Düsseldorf, Germany, praised the research for its insights on altruism. But he noted that it still does not explain *why* altruists hold such views of strangers. And he wondered whether the outcome of the experiment might have been different if the study had used real money.

Still, he wrote, "In today's zeitgeist of nationalist protectionism and populist individualism, this news inspires hope for the future."

Extraordinary altruists receive no benefits from their donation and face some costs. The kidney donors often receive pressure from family and others who worry about their health. Some of their loved ones express concern that the organ won't be available if a relative needs it in the future, Marsh said. Cuozzo, who married after her donation, said her husband has told her that he would have strongly opposed the idea if he had known at the time. Cuozzo did not discuss her decision with family and close friends until she was about to undergo surgery. Most were supportive, but without the enthusiasm she felt. One who works in health care was openly opposed.

"I like to say that maybe I'm a little more compassionate and that has at times" been a disadvantage, she said. At work, Cuozzo, a graphic designer, said she is sometimes not assertive enough and has paid a price professionally.

"I've often had people say 'you've got to stop thinking about everybody else and focus more on yourself,'" she said.

At 49, she remains in good health, her day-to-day existence largely unchanged by the donation, she said. Except that "it was the most amazing experience of my life to this day," she said.

## Transplant Anniversaries

Thomas Clark	Kidney	June 2007
Bernice Eblovi	Liver	June 2002
Kristin House	Kidney	June 2014
Kevin McCorry II	Bone Marrow	June 2004
Dick Miller	Heart	June 2007
Larry Rosner	Kidney	June 2014
Karen Lee Sommer	Liver	June 2006
Ralph M. Toscano Jr.	Cornea	June 1990
Mike Yendrzeski	Liver	June 2002
Rick Clark	Kidney	July 2004
James Connolly	Liver	July 1990
John Dedloff	Heart	July 2011
Cindy Deshane	Liver	July 2005
Matthew Felo	Lung	July 2007
Bonnie Gottorff	Kidney	July 2005
Cheryl Helfer	Kidney	July 2002
Dean Kiefer	Kidney	July 2011
Daniel Klimek	Cornea	July 2011
John Odell	Liver	July 2010
Richard Perez	Liver	July 2003
Patricia Ridge	Kidney/Pancreas	July 2006
Philip Ronzo	Liver	July 1996
Jerry Runion	Kidney	July 2011
William Sprenger	Heart	July 2015
Joanne Tucker	Liver	July 2006
Giulio Verde	Heart	July 1998

## Transplant Times

### Submission Deadline

**For August/September issue:  
July 8, 2017**

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



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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

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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*.