



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

# Transplant Times

December, 2013 - January, 2014

www.tao-rochester.org

1.888.664.1463

### Inside this issue:

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### Membership Meeting Guest Speakers / Topic

- December  
No TAO Meeting
- January 11, 2014  
Annual Holiday Party  
(Details inside)

### TAO Meets

**3rd Monday of the Month**  
**6:30 P.M. (NEW TIME)**  
 Christ Episcopal Church  
 Fellowship Room  
 36 South Main Street  
 Pittsford, NY

### A Message from the President

I hope that everyone had a good Thanksgiving and remembered everyone that helped us to be able to celebrate the day.

December is upon us with the hustle and bustle of the holiday season. I would like to remind everyone of a few upcoming events.

December 11 is ROC the Day. Remember that TAO's number for you and your family to make your United Way donations is 2493.

On December 21 from 9:00 am until 10:00 pm we will have our Christmas gift wrapping at Barnes and Noble. We are looking for volunteers to help out with gift wrapping at the table. Contact Bev Shank at 244-1536 if you are interested.

January 11 is the annual Holiday Party at Joey B's at Packett's Landing in Fairport. Please RSVP by January 4, 2014 by sending your check with names and the number of people attending to TAO, P.O. Box 23552, Rochester, New York 14692-3552. (See article on page 6 for more information.)

Congratulations to Richard Perez for his recent Dove Award for his work with Friends of Strong and his selection to be a rider on the Donate Life float in the Rose Parade on New Year's Day. Join us for a send off at the Strong Memorial Hospital main lobby at 11:00 am Monday, December 16.

I would also like to give special



recognition to Norm Breen for his dedication to our organization. He goes above and beyond not only with his time producing our newsletter and business cards, but also his work on membership.

Kathy Wesline has turned over her duties as Treasurer to Deana Dillon. Thank you Kathy for all the work you have done as treasurer.

If you would like to volunteer for any of our committees, please contact us through our web site or email me at [mfelo@rochester.rr.com](mailto:mfelo@rochester.rr.com) and I will forward your information to whoever is in charge of that committee.

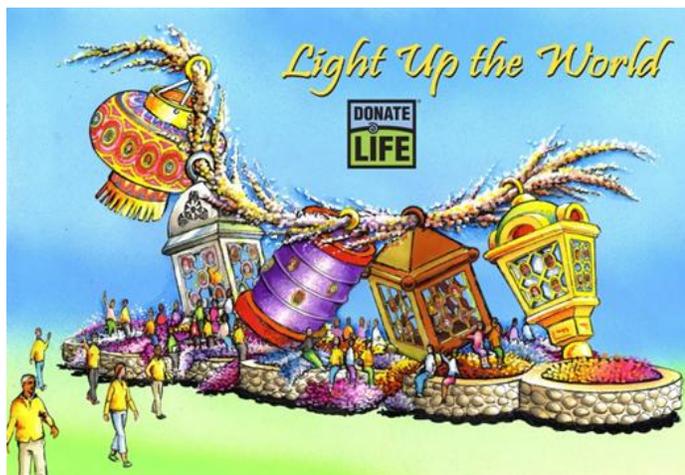
I would like to remind everyone that all are invited to our meetings and gatherings; you do not have to be a member to attend.

Have a Happy and Healthy New Year!

**Matt Felo**

**New Start Time for Meetings is now 6:30 PM**

## 2014 Donate Life Float to Inspire Rose Parade® Viewers to *Light Up the World* as Lifesaving Donors



More than 70 organizations supporting Donate Life America's lifesaving mission unveiled their 11th Donate Life Rose Parade float: "*Light Up the World*," a festival of beautiful lanterns which will inspire viewers worldwide to save and heal lives through organ, eye and tissue donation. The Donate Life float and its honored participants are the centerpiece of a national campaign that leads up to the 2014 Rose Parade.

"We were inspired by the theme of the 125th Rose Parade, 'Dreams Come True,' to reflect on how our dreams are illuminated by the examples of others," said Bryan Stewart, chairman of the Donate Life Rose Parade Float Committee and vice president of communications at [OneLegacy](http://OneLegacy.org), the non-profit organ and tissue recovery organization serving the seven-county greater Los Angeles area. "Through their life-changing experiences, individuals and families touched by organ and tissue donation and transplantation shine a light on us all. Transplant recipients radiate with gratitude and renewed life thanks to the gifts of organ, eye and tissue donors; families of deceased donors rekindle their spirits by carrying on their loved ones' dreams; and both living and registered donors are beacons of hope to patients who aspire to live longer, fuller lives. Like lanterns illuminating the night sky above or the path before us, those who give and receive the gift of life light up the world with their compassion and courage."

The 2014 Donate Life Rose Parade Float entry features a festival of lanterns illuminating 30 riders – all grateful organ and tissue transplant recipients – and 12 living organ donors walking alongside to demonstrate their ongoing vitality. The float's five enormous lanterns are adorned with 72 memorial florigraph portraits of deceased donors whose legacies of life shine brightly. The riders are seated throughout a dedication garden filled with thousands of roses bearing personal messages of love, hope and remembrance.

Since its debut on New Year's Day 2004, the Donate Life Rose Parade float has become the world's most visible

campaign to inspire people to become organ, eye, and tissue donors. The campaign began as an idea expressed in a letter by lung recipient Gary Foxen of Orange, Calif., who wanted to show gratitude to donors who make life-saving transplants possible. Now, in addition to the 40 million viewers who view the Rose Parade in the stands and on TV, hundreds of events are held in cities and towns around the country to put the finishing touches on florigraph portraits and present dedicated roses to donor families and community partners that play a role in making donation possible.

The 2014 Donate Life float is built by Phoenix Decorating Company from a design by Dave Pittman and is coordinated by Donate Life America member OneLegacy. Each year, the Donate Life float campaign is supported by more than 140 official sponsors from coast to coast, including organ and tissue recovery organizations, tissue and eye banks, hospitals, transplant centers, state donor registries, funeral homes, donor family foundations and affiliated organizations. Joining OneLegacy as top-level benefactors are the Dignity Memorial® network, North America's largest network of funeral, cremation and cemetery service providers; the American Association of Tissue Banks (AATB); Donate Life America; the Orange County based Donate Life Run/Walk Committee; The Order of St. Lazarus; SightLife; and TBI/Tissue Banks International. To date all 30 recipient float riders, 12 living donor walkers and 62 of 72 florigraphs have been sponsored.

"Every single person who takes action to be a donor gives hope to the nearly 120,000 people across America waiting for their dream – a life-saving organ transplant – to come true," said Stewart. One person can save up to eight lives through the donation of lifesaving organs – heart, kidney, liver, lungs, pancreas and small intestine – and help 50 people or more who need corneas to see, skin to heal from burns, and bones and connective tissue for common knee, back and dental surgeries. In addition, approximately 6,000 lives per year are saved by living kidney and liver donors.

The Donate Life Rose Parade Float's family of sponsors urges viewers to help make dreams come true for more than one million people in need of life-saving and healing organ, tissue and cornea transplants. Join America's 110 million registered donors so that everyone whose life and livelihood depends on a transplant can have one. Sign up when renewing your driver's license or by visiting [www.DonateLifeAmerica.org](http://www.DonateLifeAmerica.org). Further information about the Donate Life float can be found at [www.donatelifefloat.org](http://www.donatelifefloat.org).

*Editor's note: Rochester's own Richard Perez (liver recipient) has been selected to ride on the Donate Life Float*

## Program matches donors, recipients

By Annette Jiménez/Catholic Courier

ROCHESTER -- Pam Heiple could barely hold back her tears as she spoke of a thank-you letter that she received from the recipient of the kidney she donated in June.

Heiple and her husband, Mike Atkinson, are among the first pairs participating in a new kidney exchange program at the University of Rochester Medical Center. Since her kidney was not "medically compatible" with Atkinson, who was in need of a transplant, Heiple donated hers to a person at New York Presbyterian Hospital.

The kidney Atkinson received from a 36-year-old man was transported to Rochester aboard a red-eye flight from San Francisco. This is Atkinson's second transplant operation; his body rejected a kidney donated by his brother more than year ago, he explained.

Heiple and Atkinson were links in a chain of 10 surgeries that were all successful, said Heiple, a nurse practitioner at Highland Hospital.

"It's like a miracle," she said.

Receiving a thank-you letter from William, her kidney recipient, was a surprise, she explained, as the donors in the program are not told anything about who will receive their kidneys. The man's wife also donated a kidney.

"It is important for people to realize how wonderful it feels to make a difference in someone's life," said Heiple, 60. "Somebody is walking around with my kidney."

The couple hopes more people learn about this new program.

"I think this is a tremendous opportunity to help someone you are not medically connected to," said Atkinson, 62. "This opens up the possibility of more transplants and people to get helped off dialysis. ... It eliminates the need to find a match because the system finds a match."

And the number of lives that could be saved through the multiple pair program is incredible, said Dr. Carlos Marroquin, a URMIC transplant surgeon.

The kidney exchange program has been around in other hospitals in the country since 2000, and the professors who developed the algorithm for the program won a Nobel Prize in economics, he said.

"The potential impact for patients with kidney disease is enormous," Marroquin noted. "And when you consider the economic impact (for health care), it's tremendous."

While rates of mortality have decreased for transplants of such organs as heart and liver, those rates are increasing for people on the waiting list for kidneys, Marroquin said. Nearly 120,000 people nationally are on waiting list for organs -- more than 97,000 are waiting for a kidney, according to <http://optn.transplant.hrsa.gov/latestData/rptData.asp>.

For patients not yet part of this program, which has only been in place at Strong Memorial Hospital for less than a year, the next best option continues to be an organ from a person who has died, known as "cadaveric transplantation," he said.



Pam Heiple (left) donated a kidney and her husband Mike Atkinson (right) received a kidney as part of a new transplant program at the University of Rochester Medical Center.

But whichever transplant procedure takes place, the process is safe and thorough, noted local doctors, donors, recipients and families. Stressing the safety of the donor is especially important because of an incident that was reported over the summer at St. Joseph's Hospital in Syracuse, advocates say.

While initial news reports stated that a woman woke up as she was being taken to a procedure to donate her organs, Rob Kochik from the Finger Lakes Donor Recovery Network said that was not the case.

"The patient was never brain dead ... we were not even close to recovering organs from that patient," said Kochik, the network's executive director. "When it was determined her condition changed, all procedures related to preparation for organ donation stopped. We were no longer part of that process."

Fortunately for the organization, people who support organ donation remain supportive, he said, adding that they understand that the primary role of medical personnel is to save lives.

The Syracuse case "just points out (the need for) our continued efforts to try and help the public be as informed as we possibly can -- to get the important facts out," Kochik said.

Anyone considering organ donation should inform their families, one of the most important steps they can take, he said.

Beyond that, they should consider registering through the network's registry or by signing their driver's license, he added. In New York, new legislation called "Lauren's Law" requires that everyone actively consider that step when they renew their licenses, Kochik said.

Prior to the law's passage, a person renewing his or her license could skip signing the space required to approve of organ donation. Now, a person will need to check a box next to either "yes" or "skip" instead of leaving the signature space blank, he said.

"The question is carefully worded to give everyone the opportunity to say yes or, if they're not ready, to skip that question," Kochik said. "We think that will increase (organ

*(continued on page 4)*

*Program matches donors, recipients*  
(from page 3)

donation) number enrollments. We want to make it more efficient."

The legislation again highlights the importance of taking the time to think about and discuss this difficult topic, he said. But a person who takes the step to register also makes the decision easier for their families if that situation arises, Kochik said.

"You have to think about this ... that I don't want my family to be burdened with that decision," he added. "I don't think we (donor organizations) have demonstrated how amazing it (organ donation) is. ... Each of us that makes that personal decision can save up to eight lives."

Helene Ehmann has lived the trauma and "gift of life" of donating a loved one's organs. Her son, Scott Conrad, died of a drug overdose on March 10, 2010. He was 29.

Because her son had spoken to his siblings and registered as a donor, they were able to donate his kidneys, liver and heart when doctors informed the family that, after a multitude of tests, he was determined to be brain dead, Ehmann explained.

"That's why we try to tell everybody how important it is to have all those discussions before (such a tragedy strikes)," she said. "Because none of us know. ... And when you're in crisis, your mind is going all ways."

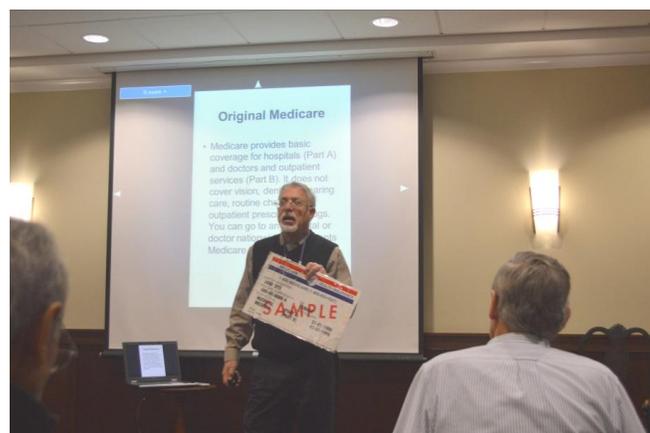
## Membership dues for 2014 are due.

Your dues help sustain your organization and provide you with an information packed newsletter every two months. If you attend meetings, it covers your meals, and the rental of our conference meeting facility. It underwrites the picnic and holiday party, covers insurance costs, website and phone line. What a bargain for \$20 a year!

You will see a reminder on the back of the newsletter and a membership form. Please fill it out completely, even if you are a renewal, we update the member list, email list and anniversary dates from these forms. You also may get an email reminder.

Thank you for sending your dues in a timely manner. You will receive a postcard as an acknowledgement of receipt of your dues.

## TAO MEETINGS . . .



Ron Brandwein of Lifespan provided a review and update of Medicare plans during the November meeting.



TAO Members and guests enjoyed a Thanksgiving themed potluck at the November meeting.



Doug Doehring (left) from Genentech receiving a Certificate of Appreciation from Board president Matt Felo at the TAO October meeting.

## ONCE DENIED A KIDNEY, N.J. GIRL NOW THRIVES

Kim Painter  
Special for USA TODAY

Five-year-old Amelia Rivera is thriving and growing, three months after getting a kidney from her mother, Chrissy. "She's more active; she moves around more; she's more vocal," says Chrissy Rivera, 38, a high school English teacher from Strafford, N.J.

Her -husband; - Joe, a 41-year old real estate agent, says, "She's getting bigger; she's getting stronger; she's more alert."

The Riveras say they shudder to think what might have happened to their girl by now if they had accepted the verdict of a doctor in early 2012. They say that doctor, from a leading children's hospital, told them that even though Amelia's kidneys were failing, she was a- bad candidate for a transplant — because she was "mentally retarded."

Amelia, who has a rare genetic condition called Wolf-Hirschhorn syndrome, does have intellectual disabilities, along with various physical problems, but the Riveras found it shocking and unacceptable that her mental capacity could determine whether she lived or died.

So Chrissy turned Amelia's case into a cause: She went to a website usually seen only by others in the small Wolf-Hirschhorn community and wrote about that encounter at Children's Hospital of Philadelphia.

"I expected it to be seen by 10 or 20 people," Chrissy says. Instead, it went viral and inspired 50,000 people to sign a petition at Change.org, demanding that the hospital allow the transplant. Medical ethicists weighed in — and generally agreed that although transplant centers had to consider patients' health and ability to thrive, it wasn't right for anyone to be denied just because they had a mental disability.

A few weeks later, the family and the hospital released a joint statement saying a transplant was under discussion. Hospital officials apologized for what had happened, saying it was never their policy to deny transplants on the basis of intellectual ability.

Later, the family announced that Chrissy had qualified as Amelia's donor. The surgery was done July 3. The Riveras say they are happy with the care Amelia has received. The family declined to discuss how the surgery was paid for.

In a statement, the hospital said: "We appreciate the role the Riveras have played-in helping us recognize opportunities for improvement and believe we are a better institution as a result. We look forward to providing Amelia and her family the very best of care long into the future.'

But that happy ending does not mean that the fight Amelia inspired is over.

In the months since Amelia's story became public, Chrissy says, "a lot of people have reached out to us personally to share similar stories, to tell us heartbreaking stories of how their loved ones were denied simple medical care, dental care, eyeglasses — because medical professionals felt that this. person's quality of life wasn't good enough to get this care."

## Support Group Meetings

### "OPEN AIRWAYS" - LUNG Gathering Group

Thursday, December 19 at 12 noon.  
Winfield Grill - 647 Winton Rd. Rochester, NY  
(Between East Main St and Browncroft Blvd.)  
- and -

Thursday, January 16 at 12 noon.  
Hicks & McCarthy - 23 S. Main St. Pittsford, NY

### HEART Transplant/VAD Support Group

Thursday, December 5 at 6:30 p.m.  
Annual Holiday Party (by invitation only)  
- and -

Thursday, January (-) at 6:30 p.m.  
Topic and actual date TBA - Check your mail!

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

## Join a Committee

Sunshine, Newsletter,  
Membership, Awareness  
Interested?

Call 1.888.664.1463

## United Network for Organ Sharing

*Candidates listed as of 11/17/2013*

98,575	Kidney
15,876	Liver
3,657	Heart
2,041	Kidney/Pancreas
1,603	Lung
1,175	Pancreas
259	Intestine
48	Heart/Lung

120,649 TOTAL

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

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

## Save the Date . . .

### ROC the Day

Wednesday, December 11

Throughout the day, television and radio media will be urging people to donate to not-for-profit organizations. Please mention to your co-workers and friends that they can make a one-time donation to TAO via the United Way by using our number (2493).

### Celebration and Send off for Richard Perez

Monday, December 16 at 11:00 a.m.

Strong Memorial Hospital Main Lobby  
Richard will be representing our transplant community in the New Year's Day Rose Bowl Parade.

### Barnes & Noble Gift Wrapping

Saturday, December 21

Pittsford Plaza, Monroe Ave., please contact Bev Shank at (585) 313-8271 if interested in wrapping gifts. This is an opportunity for TAO to be seen in the community, raise awareness and promote donor registration. There will be six 2 hour shifts, 2 people wrapping. All supplies are provided.

### TAO Annual Holiday Party

Saturday, January 11, 2014

Joey B's, Packett's Landing, Fairport, NY.  
(Handicap accessible)

12 Noon - Social hour

1:00 pm - Dinner

\$15 per person TAO underwriting part of cost.

RSVP by January 4

Send check to:

TAO

PO Box 23552

Rochester, NY 14692-3552.

Include the number of people attending on the check.

Check out Facebook and the TAO website for up to the minute details.

Don't forget to visit  
and like our Facebook  
Page



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

## Holiday Shopping?

During this holiday season please remember TAO when ordering on Amazon. Go to the TAO website, click on the Amazon widget and place your order.

Tops cards are available and make great gifts. They come in \$25 and \$50 increments. Call Bonnie at (585) 391-3555 to order Tops cards.



### Heather C.M. Rogers

*Partner, Manager of Default Services*

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Flu Season is here!  
Get Vaccinated!

## Our Sympathies

We extend our sincere condolences to:  
The family of Nancy Thompson

## Transplant Anniversaries

Larry Buck	Kidney	December	2000
Richard Forbes	Liver	December	2007
Mark Hackett Jr.	Liver	December	2010
Bonnie Haefner	Kidney	December	2005
Rick Juskiewicz	Kidney	December	1996
Ruth Maines	Liver	December	1990
Stephen Odai	Liver	December	2001
Beverly Shank	Liver	December	2005
Claudia Ciresi	Liver	January	1996
Jane Clewell	Liver	January	2005
Helen Cox	Kidney/Pancreas	January	1996
Dan Ditulio	Liver	January	2003
Dawn Meschi	Kidney	January	2001
Jude Nunciato	Liver	January	1993
Anne Marie Scroger	Liver	January	2007
Pat Stewart	Kidney	January	1994
Guy Valone	Kidney	January	2009

## Welcome New Members

Marsi Rohde  
Earnest Porter

## Wishes of Wellness To

Phyllis Breen

## Transplant Times

### Submission Deadline

For February / March 2014 issue:  
January 6, 2014

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

## Contributions

We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO.

Donations:  
Office Services Unlimited  
Bev Shank

In memory of Nancy Thompson:  
Shirley Tuites  
Paul & Danis Raymond  
David & Becky Chatley  
Sherman & Beverly Sanford  
Charles & Claudia Best  
Glenda Hooker  
Akron Faculty Association

In Kind:  
Bliss Owen  
Heather Rogers

If we omitted you, please let us know so that we may post in the next issue. THANK YOU.

## 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

## Board of Directors & Officers

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Don't forget your 2014 Membership dues! Help support the TAO 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.