



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

# Transplant Times

April- May, 2014

www.tao-rochester.org

1.888.664.1463

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## Membership Meeting Guest Speakers / Topic

April 21, 2014

Dr. Demme  
Transplant in the Movies

May 19, 2014

Karen Miltner  
Cooking Demonstration  
Christ Episcopal Church Kitchen  
in the basement.  
(See Details on page 5)

## 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 cold weather seems like it wants to hang around forever, but we were all assured that spring is on its way according to the groundhog. I hope that everyone made it through the winter in good shape and am looking forward to spring and summer.

April is National Donate Life Month. Try to spread the word to get your friends, relatives and neighbors to sign up to be organ donors. Every year the need is greater and greater. The total number of people needing organs nationally right now is over 120,000—over 12,000 are New Yorkers. The national average in the U.S. for people enrolled in registries is 48 percent. In New York we are at 22 percent, and in the Finger Lakes area we are over 28 per cent. In the years since my transplant I have heard many stories, not only from recipients but also from donor families. The need is great and without the donor families we would not be here.

Some of the events coming up for Donate Life Month are:

April 2- Donate Life Night with the Amerks; April 4- Harbor House event with the Knighthawks; April 6- River Run; and April 11- Wear Green and Blue Day. Then following in May is the annual Lilac Parade on Saturday the 10th.

It is that time of year again to send in your membership dues. Dues help to mail the newsletter and support other events throughout the year. They also



help with other projects like the comfort bags that are given to transplant patients at Strong Hospital.

TAO is always looking for volunteers, if you are interested in helping out give me a call at 585-425-8032 or email me at [mfelo@rochester.rr.com](mailto:mfelo@rochester.rr.com) and I will get back to you.

Let's all look forward to a warm and healthy Spring and Summer. I hope to see you at the next meeting.

*Matt Felso*

## TAO Donates Frames

The transplant unit 4-3400 at Strong Hospital acquired posters from those submitted over the years to the annual Donate Life Poster Contest sponsored by Rochester Eye & Tissue Bank and Finger Lakes Donor Recovery Network.

The posters needed frames, so TAO jumped on board and investigated purchasing frames or having them made by a member of TAO. Fortunately during an estate sale outing, frame pieces large enough to make frames were found! Matt Felo, TAO president, offered his talents to make the frames. The owner of the sale graciously donated the pieces after learning of our endeavor. Thank you Sue Cimicata! Next, we were on the hunt to have plaques made and Karen Gledhill had a contact — Peter Stummer, who graciously donated the plaques. We are happy to announce the frames are made, plaques are attached and they have been delivered to Tina Blanchard, nurse manager on 4-3400. Please take a look at them on any of your visits to the unit!

Thank you to everyone involved in making this happen! We couldn't do it without the generosity of donations, time and talents!



Framed posters located at Strong Hospital on Transplant Unit 4-3400

## Bit of Trivia

Win a pair of movie tickets.

For those who can name the event at which this bagpiper played, your name will be entered into a drawing for a pair of movie tickets.



Call your answer into TAO @ 1-800-644-1463 by April 30. Be sure to Leave your name and your phone number.

The winner will be notified on May 5 by phone. We will post the winner's name on TAO's website after notification.

Good Luck!

## Welcome New Members

Jane Hogestyn

## Our Sympathies

We extend our sincere condolences to Nancy Metzler and family on the loss of their daughter Hannah.

## Life after Your Transplant: Signs of Rejection

Reprint from WebMD

If you're living with a transplant, "rejection" is a word that can send shivers up your spine. But organ rejection is often not as bad as it sounds. As scary as the word may be, it doesn't mean necessarily that you're going to lose the organ. It often means your medication needs to be adjusted. Once you've established a new medication regimen that works, you can usually go back to business as usual.

But that doesn't mean you can ignore the problem. Be on the lookout for the signs of rejection. Symptoms vary depending on the kind of organ transplant you've had. General signs include:

Recommended Related to Organ Transplant  
Tips for Parents of Children With Organ Transplants

If your child has just had an organ transplant, the last few months -- maybe many more -- have probably been scary and exhausting for your whole family. But things are probably getting a lot better. As your child recovers, you're likely to see a big improvement. You may have noticed it already. And the long-term prospects are good too. Most children who have transplants go on to live pretty normal, healthy lives. Still, many parents in your position feel overwhelmed by their new responsibilities...

Read the Tips for Parents of Children With Organ Transplants article

- Pain at the site of the transplant
- Feeling unwell
- Crankiness (in children)
- Flu-like symptoms
- Fever
- Weight changes
- Swelling
- Change in heart rate
- Urinating less often

See your health care provider right away if you have any of these symptoms.

Organ rejection can be acute or chronic. It's fairly common to have an episode of acute rejection within a year of your transplant. Sometimes, acute rejection leads to chronic rejection. This is when an organ slowly loses its ability to function.

Rejection becomes less likely over time. But you're never quite out of the woods. It may develop even years after the surgery. That's why it's key to keep on top of your condition and get regular checkups.

## Lilac Festival Parade Float Saturday, May 10



Transplant recipients, candidates, donor family members and living donors are needed to ride on the Donate Life float this year. It's a great opportunity to show the community that transplantation works. It also gives us the chance to say thank to those who support organ, eye and tissue donation and to remember, honor and thank all donors and their families.

Total time commitment—typically meet @ 9 a.m. and you are on your way home by 12:30 pm. The above photo is our 2013 float.

Those interested please contact Karen Guarino at [kguarino@rehepb.org](mailto:kguarino@rehepb.org) or call (585) 272-7890.

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**New York Marking Devices Corporation**  
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**Laser Link Rubber Stamps**  
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 Rochester, NY 14620  
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 Cell (585) 303-0808  
 email: [Peter@nymarking.com](mailto:Peter@nymarking.com)  
[www.NYmarking.com](http://www.NYmarking.com)



## February's Featured Speaker . .



Joe Panzarella from Astellas discussed Prograf and new anti-rejection options at the February meeting.

## Membership Dues

Just a friendly reminder that your annual membership dues are now due. Please submit your dues upon receipt of this newsletter. Use the form on the back page to fill out completely, even if you are a renewal. We update the membership list, email list and anniversary dates from these forms. You may also receive an email reminder.

### Membership benefits:

- newsletter
- monthly meetings
- guest speakers on transplant topics
- annual summer picnic
- annual holiday party
- a network of pre and post transplant recipients for support
- support group meetings
- and more!

Dues help to sustain TAO—it's programs, services and activities. What a bargain for \$20 a year!

Dues help to: underwrite the annual picnic and holiday party; cover meeting facility space rental; provide light meals for monthly meeting attendees, cover insurance, website and phone line costs, and more.

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

TAO members and friends enjoyed a proper Irish-themed dinner for St. Patrick's Day at the March meeting.



## Save the Date . . .

Monday  
May 19, 6:30 PM  
Cooking Demonstration

TAO along with Kidney Cares presents a Cooking Demonstration by Democrat and Chronicle's food writer Karen Miltner (pictured right) at Christ Episcopal Church Kitchen in the basement.  
(Handicap Accessible)



Please RSVP by May 12 to Debbie at 377-6028.

We want to have enough food for everyone and need to have a count for shopping and preparing. Walk-ins will be welcome, but are encouraged to RSVP. Thank you!

Monday  
June 16 5:30 P.M.  
TAO Annual Picnic  
Buckland Park Lodge  
1341 Westfall Road  
Details to follow

### Shopping at Amazon?

Don't forget, TAO can benefit from your purchases . Simply go to [www.tao-rochester.org](http://www.tao-rochester.org) and click on the Amazon widget and do your shopping!

## Support Group Meetings

### "Open Airways" - Lung Gathering Group

Thursday, April 17 @ 12 noon  
Winfield Grill - 647 Winton Rd. Rochester, NY  
(Between East Main St and Browncroft Blvd.)  
- and -

May Luncheon - Location and Date TBD  
(Check the TAO Website for updates)

### HEART Transplant/VAD Support Group

Thursday, April 10 @ 6:30 p.m.  
Theresa Cadieux, NP, on 7-3400 Heart Failure Unit  
- and -

Thursday, May 8 at 6:30 p.m.  
Dr. Christine Hay, Program Director  
Infectious Diseases Fellowship

### All Heart Transplant/VAD

Meetings held at 7th floor conference room  
near 7-3400 Corridor unless otherwise indicated

## United Network for Organ Sharing

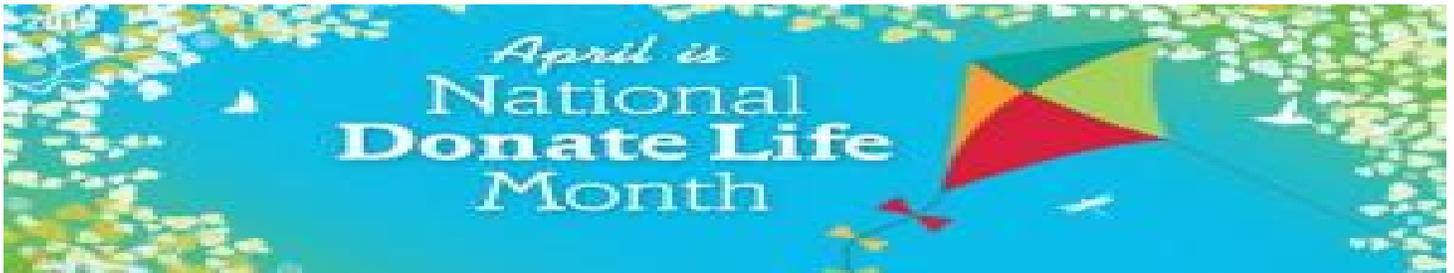
Candidates listed as of 3/25/2014

99,737	Kidney
15,743	Liver
3,806	Heart
2,020	Kidney/Pancreas
1,630	Lung
1,177	Pancreas
255	Intestine
47	Heart/Lung

121,778 TOTAL

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

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



Wednesday, April 2

### Donate Life Night with the Amerks

Rochester Americans Vs. Syracuse Crunch with the evenings focus being "Donate Life" to promote organ & tissue donation. For more information or to purchase tickets to an Amerks game, visit [www.amerks.com](http://www.amerks.com) or call 1-855-GO-AMERKS.

### Friday, April 4 Harbor House event with the Knighthawks @ Blue Cross Arena

Rochester Knighthawks vs. Minnesota Swarm, 7:30 pm

Rochester Knighthawks want to help local charities raise funds and awareness for their cause while allowing ticket holders to enjoy a fun night out watching the back-to-back NLL Champions.

Here's How it Works: The Rochester Knighthawks will sell tickets for \$10 each (regularly priced at \$25) with \$5 from each sale going back to the charitable organization. The organization that raises the most money through the sale of Knighthawks tickets will have the amount matched by the Rochester Knighthawks. We want to be the organization that gets the match amount!

Ticket orders can be taken over the phone or made in person by contacting Derek Anderson at the Rochester Knighthawks office at: (585) 454-4295, ext. 3042. There is an online order form allowing orders to be placed easily. Just follow this link:

[https://www.formstack.com/forms/knighthawks-give\\_back](https://www.formstack.com/forms/knighthawks-give_back) The tickets will either be mailed to the individual or be at Will Call depending on the date.

It's important to mention Harbor House of Rochester!

### Sunday, April 6, River Run

To raise awareness for organ transplant patients and families at UR Medicine's Strong Memorial Hospital Transplant Units, the Friends of Strong volunteer organization is inviting individuals and teams to partake in the 13th annual Rochester River Run/Walk 5K, Sunday, April 6, at the Roundhouse Shelter at Genesee Valley Park. The race will begin at 10 a.m.

Friday, April 11 Wear the Green and Blue

During this day, the public is encouraged to wear blue and green, hold events and fundraisers, and partner with local restaurants, malls, media, and community organizations in an effort to spread awareness about organ, eye and tissue donation and transplantation.

Don't forget to visit  
and like our Facebook  
Page



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

## 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 and \$100s.

## Join a Committee

Sunshine, Newsletter,  
Membership, Awareness  
Interested?

Call 1.888.664.1463

## Transplant Anniversaries

James Graczyk	Liver	April	2002
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
Merrillan Thomas	Kidney	April	2010
G. Murray Thomas	Kidney	April	2010
Asya Zarkhi	Kidney	April	2003
Ginger Zimmerman	Heart	April	1998
Patricia Bianchi	Liver	May	2002
Norman Breen	Heart	May	2007
Amber Castle	Kidney	May	1999
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 To

Geoff Foley  
Debbie Yendrzski

## Transplant Times

### Submission Deadline

For June / July 2014 issue:  
May 5, 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.

Charles Lundeen  
Mike Swete  
Rita Lesnick  
Rich Forbes  
Dave Johnson  
Bev Shank

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

President	Linda Barnard
Matt Felo	Chris Barry MD, Ph.D.
Vice President	Geoff Foley
Debbie Yendrzski	Karen Gledhill
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Membership	Karen Porterfield
Norman Breen	



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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 New Member \$100 Institution 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.