



# Transplant Times

June - July 2015

A newsletter of the Transplant Awareness Organization of Greater Rochester

www.tao-rochester.org | 1.888.664.1463

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## A Message from the President



Summer is upon us and it feels great not to have to put on a jacket or coat to go outside. If you do go out, remember to use sunscreen even on overcast days. Enjoy the summer activities but be aware of the dangers in our surroundings, such as ticks (Lyme disease) and mosquitoes, (West Nile virus) and of course the sun which can cause skin cancer to name a few.

Our *Donate Life* table setup at the mall went well. It was good to talk to some of you who had transplants and visited our table. We handed out a lot of information about our group, organ and tissue donation, and the transplant games. If anyone is interested in volunteering for TAO sponsored events, please call me at 585-425-8032 or you can email me at mfelo@rochester.rr.com and I will be happy to give you more information.

Coming up on June 15 is the annual TAO picnic which is being held at the Buckland Lodge on Westfall Road in Brighton. Make your reservation by June 6 by mailing your check to TAO, P.O. Box 23552, Rochester, New York 14692-3552. So mark your calendar for a good time. This event is not just for transplant recipients but for living donors, donor family members and pre-transplant families.

Election Time is here! Ballots for new board members are in this month's member's newsletter. Your vote counts! It is important that your voice is heard! Please vote.

If you are interested in going to the Transplant Games in 2016 in Cleveland,

consider coming to the next transplant games meeting. You can reduce the cost of your stay in Cleveland by volunteering to help raise money at Finger Lakes Transplant Games events. The events are fun and you can meet other transplant recipients, donor families, living donors, and people waiting for a transplant. Watch our website for the June meeting. I have been asked by many people about the games and the June meeting will be a chance to find out more. Check out our website and newsletter for information on upcoming events.

I hope to see you at the TAO picnic. Have a great summer!

*Matt Felio*

## Membership Meeting Guest Speakers / Topic

### June 15

TAO Annual Picnic  
*Buckland Park*  
*(Details Inside)*

### July - August

No Meeting

## TAO Meets

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

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

## Transplant Anniversaries

Bernice Eblovi	Liver	June	2002
Matthew Felo	Lung	June	2007
Sheldon Kristin	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
Michael Yendrzieski	Liver	June	2002
Rick Clark	Kidney	July	2004
James Connolly	Liver	July	1990
John Dedloff	Heart	July	2011
Cindy Deshane	Liver	July	2005
Bonnie Gottorff	Kidney	July	2005
Cheryl Helfer	Kidney	July	2002
Dean Kiefer	Kidney	July	2012
Daniel Klimek	Cornea	July	2011
John Odell	Liver	July	2010
Shawn Pangburn	Liver	July	2011
Richard Perez	Liver	July	2003
Patricia Ridge	Kidney/Pancreas	July	2006
Philip Ronzo	Liver	July	1996
Joanne Tucker	Liver	July	2006
Giulio Verde	Heart	July	1998

## Welcome New Members

Ron Secor  
Mike & Nancy Postilli

## Wishes of Wellness

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

Bonnie Haefner



## Contributions

Mike & Nancy Postilli

### In Memory of:

**Frank Imburgia**  
Priscilla Imburgia

**Dennis Stenshorn**  
Kathy & Thanh Nguyen

### In honor of:

**Daniel Klimek**  
Ernst Baier

**All transplant recipients and organ donors for the month of April**  
Dr. MaryAnn Lester

**Life**  
Shawn Pangburn

## TAO once again helps sponsor 2015 Rochester River Run

**Dear Matt, Debbie and the entire TAO organization,**

On behalf of the Transplant River Run Committee, I would like to thank you for your generous sponsorship of our event on Sunday April 12, 2015 at Genesee Valley Park. We were fortunate to have beautiful weather and incredible attendance at the 14<sup>th</sup> Annual Rochester River 5k Run/Walk. 2015 was a record breaker. We had more than 600 participants, sold out of raffle tickets, and raised nearly \$20,000!

Thank you for helping honor our organ transplant recipients and donors, as well as their families. All proceeds from the event benefit transplant patients (kidney, heart, liver, pancreas) at Strong Memorial Hospital.

We appreciate you being part of this event and hope you will consider sponsorship again next year. Until then, stay tuned to the Friends of Strong website ([fos.urmc.edu](http://fos.urmc.edu)) or Facebook page for details on next year's race.

With gratitude,  
*Strong Memorial Hospital Solid Organ Transplant Team and Friends of Strong Memorial Hospital*

## New Kidney Allocation System Begins

The new kidney allocation system started on 12/4/14. What does this mean? It should help more people have longer function with their transplanted kidney. It should also help shorten the waiting time for some groups of people who often wait a very long time because they are hard to match with most kidneys.

Instead of the "standard" or "expanded criteria" classifications, every kidney offered will now have a Kidney Donor Profile Index (KDPI) score. This score is associated with how long the kidney is likely to function when compared to other kidneys. Factors considered are: age, height, weight, ethnicity, whether donor died due to loss of heart or brain function, stroke as cause of death, history of high blood pressure, history of diabetes, exposure to hepatitis C virus, serum creatinine level.

Transplant candidates will now be given an individual Estimated Post-Transplant Survival (EPTS) score. This is a percentage score associated with how long the candidate will need a functioning kidney transplant when compared to other candidates. The EPTS is calculated based on facts about the candidate that affect how long you are likely to need a kidney. These factors include: age, length of time spent on dialysis, having received a previous transplant (any organ), current diagnosis of diabetes.

Many people will not see any major change. The time you spend waiting for a kidney is still a major factor in matching. You will not lose credit for any time you have already spent waiting. If you began dialysis before you were listed for a transplant, your transplant waiting time will be backdated to your first dialysis date.

UNOS' Patient Services phone line (888) 894-6361 can provide information about the OPTN and UNOS allocation policy and other resources available to you. Additional information is available online on the following websites:

<http://www.transplantliving.org> <http://optn.transplant.hrsa.gov> and <http://www.unos.org>  
<http://www.srtr.org>

### 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. Contact Bonnie Haefner at (585) 391-3555

**The more we sell, the more we earn.**

The cards are available in \$25s, \$50s and \$100s.

## TAO Communication

TAO keeps you informed and updated by e-mail on important organizational news, upcoming events, and other transplant-related issues that may impact membership.

Please look for these e-mail notices. The subject line will read: **TAO Communication.**

Also, if there are any changes or cancellations that need to be communicated to you regarding a meeting or event, we can keep you informed and up to the minute.

Please include your e-mail address when renewing your membership dues so that you may be able to receive this information. These are held strictly confidential and are not shared!

## Visit & like our Facebook Page

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



**SHARE IT WITH OTHERS**

**WE NOW HAVE 290 LIKES!**

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

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**To act as a support group for transplant candidates, transplant recipients and their families.**

**To provide education and information on transplantation issues that surround it.**

**To promote organ and tissue donation awareness.**

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

## community events

# Save the Date . . .

### Monday, June 15

TAO Annual Picnic

**Buckland Park, 1341 Westfall Rd., Brighton**  
(between Winton Road and S. Clinton Ave.)

5 p.m. Dinner @ 6 p.m.

Adults - **\$10**

Children - (under 15) - **\$5**

**RSVP by June 6 by mailing a check**

Payable to : TAO  
P.O. Box 23552  
Rochester, NY 14692-3552.

Please include name(s) of attendees and the number of adults / children.

### United Network for Organ Sharing

*Candidates listed as of 5/8/2015*

<b>109,706</b>	<b>Kidney</b>
<b>15,775</b>	<b>Liver</b>
<b>4,238</b>	<b>Heart</b>
<b>2,082</b>	<b>Kidney/Pancreas</b>
<b>1,643</b>	<b>Lung</b>
<b>1,085</b>	<b>Pancreas</b>
<b>245</b>	<b>Intestine</b>
<b>40</b>	<b>Heart/Lung</b>

# 134,814 TOTAL

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

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

## transplant

# Support Group Meetings

### "Open Airways" - Lung Gathering Group

**Thursday, June 18 @ 12 noon**

Jeremiah's - 2164 Fairport Nine Mile Point Rd. Penfield

**Thursday, July 16 @ 12 noon**

Hicks and McCarthy - 23 S. Main St. Pittsford

### Heart Transplant/VAD Support Group

**Thursday, June 11 @ 6:30 p.m.**

LVAD Specific Support Group sponsored by Thoratec

**Located in Conference rooms A & B, 2nd Floor above main lobby.**

**\* Thursday, July 9 @ 6:30 p.m.**

TBA

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

## 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**

**Mail to:** TAO  
PO Box 23552  
Rochester, NY, 14692-3552

## Transplant Times

### Submission Deadline

**For August - September 2015 issue:**  
**July 6, 2015**

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

## A Mobile Medical App that Aids Transplant Patients with their Immunosuppression

Efforts to improve immunosuppression have succeeded in achieving previously unthinkable longevity, but we as clinicians have fallen short in recognizing the challenges that these complex medication regimens present. Nevertheless, not taking immunosuppression medication appropriately can result in grave consequences with increased morbidity due to increased rates of rejection and graft loss.

It has been estimated that up to 30% of patients may “miss doses” of their immunosuppression during the first year of transplant. As such, conservative estimates purport that one-half of rejection episodes and 15% of graft losses may be due to these medication errors.

I am a transplant surgeon in New York and in talking with patients over the years; it has become evident that taking medication is not easy. First of all, there are so many! Secondly, these medications need to be taken at all hours of the day and night. It is with this understanding that I have designed ***Transplant Hero***, an iPhone App that looks to focus on some of the most important medications and time them appropriately—so you don’t have to!

***Transplant Hero*** is a beautifully created App that helps transplant patients deal with the seemingly impossible task of taking their immunosuppression in a timely fashion. At the core, ***Transplant Hero*** is an alarm system that alerts the user when it is time to take their medication—but it is so much more! It is an interactive, educational and simple to use tool that offers users positive reinforcement. More recently, I’ve introduced the feature that even allows one to email their immunosuppression regimen to their healthcare provider so as to improve communication between the patient and clinician.

At present, the feedback has been overwhelmingly positive, but you can try ***Transplant Hero*** for yourself by downloading it [free](http://www.transplanthero.com) from the website ([www.transplanthero.com](http://www.transplanthero.com)). As always, feel free to let me know how I can improve the user experience for you.

Throughout my career it has been such a privilege to be a part of such a vibrant community that is bolstered by groups like the **Transplant Awareness Organization**. In many ways, the creation of ***Transplant Hero*** was a means for me to say thank you to all the patients over the years that have supported me as surgeon!

All the best!

Jay A. Graham, MD  
Transplant Surgeon  
Transplant Hero LLC

*“Everyone needs a helping hand”*

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



## Monroe Community College’s Health, Phys. Ed., and Wellness Club Commemorate “2015 Blue and Green Donate Life Day”

Members of the MCC Health, Phys. Ed., and Wellness Club and MCC students commemorate the 2015 Blue and Green Donate Life Day on April 17 by wearing blue and green and gathering to promote the conversation and awareness about organ, eye and tissue donation for transplantation. Currently, United Network of Organ Sharing (UNOS) shows over 134,000 people waiting for a life-saving organ transplant and others awaiting eye and tissue donation.



### Join a Committee

Sunshine, Newsletter,  
Membership, Awareness  
Interested?

Call **1.888.664.1463**

### Shopping at Amazon?

TAO can benefit from your purchases. Go to

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

and click on the Amazon widget

to do your shopping!

## April Member Meeting

The April Member meeting featured Matthew Williams, PT, DPT. He spoke about the importance of Physical Therapy pre-transplant and post. Check out his presentation on the TAO website.



Matt Felo (L), TAO President, presents Certificate of Appreciation to Matthew Williams at the April meeting.

## May Member Meeting

The May Member meeting featured Sharrif Ibrahim, MD, PhD. He spoke of the dangers of sun exposure for transplant patients and preventative measures.



Matt Felo (L), TAO President presents Certificate of Appreciation to Dr. Sharrif Ibrahim at the May meeting.

## Something to Think About

Many of us have put together estate plans that identify how we would like our assets to be distributed after we pass away.

Whether or not you have already put together your last will and testament, we would like to encourage you to consider remembering the Transplant Awareness Organization by designating a gift for the organization's benefit in your estate plans.

The ability of a charitable organization like TAO to both expand its offerings, and to sustain its programs over the long term, depends in part on its ability to fund programs and to build savings to carry it through the inevitable "rainy days" that occur from time to time.

Your estate-planning attorney can explain the various options that exist for making such a gift. We thank you sincerely for your consideration.

## Tops Never Stops

### Tops cards help TAO raise money.

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**The more we sell, the more we earn.**  
The cards are available in \$25s, \$50s and \$100s.

## Board of Directors & Officers

### President

Matt Felo

Jeffrey Alexis, MD

### Vice President

Debbie Yendrzeski

Linda Barnard

Geoff Foley

### Treasurer

Karen Gledhill

Karen Guarino

Bonnie Haefner

### Secretary

Bev Shank

Amy James

Janice Odenbach

### Membership

Norman Breen

Karen Porterfield, LMSW

## National Living Donor Assistance Center

The National Living Donor Assistance Center (NLDAC) reimburses eligible living donors for their travel expenses to the transplant center for their evaluation, surgery and medical follow-up trips. Approved donors receive an American Express card to pay for transportation, food and lodging up to \$6,000. NLDAC will also pay for up to two trips for the donor's support person(s).

There are certain requirements that must be met in order to qualify:

- The donor and recipient must be U.S. citizens or lawfully admitted residents and their primary residence must be in the U.S. or its territories.
- The donor and recipient must meet certain income requirements. Eligibility is based on the household incomes of the recipient and donor.

For more information, please visit the NLDAC website: [www.livingdonorassistance.org](http://www.livingdonorassistance.org) or call their toll-free number: 1-888-870-5002.

## Pharmaceutical Waste Drop Box is now at Webster Town Hall

There is now a CVS Drug Collection unit at the Webster Town Hall! This permanent pharmaceutical waste drop box can be found inside the Webster Town Hall, located at the Police Department entrance, 1000 Ridge Road, during regular business hours of Monday through Friday, 8:30 a.m. – 4:30 p.m. This permanent pharmaceutical waste drop box can be found inside the Webster Town Hall, located at the Police Department entrance, 1000 Ridge Road, during regular business hours of Monday through Friday, 8:30 a.m. – 4:30 p.m.

Items accepted at the drop box include any unused, unwanted or expired medication such as prescriptions, prescription patches, prescription medication, prescription ointments, over-the-counter medications, vitamins, samples and medications for pets.

Items that are NOT accepted include hydrogen peroxide, inhalers, aerosol cans, ointments, lotions, or liquids, thermometers, needles (sharps) and medication from businesses or clinics.

If you do not feel comfortable with your personal information on the bottles, you can remove the pills and put them in a plastic bag for disposal.

Special thanks go to Acting Chief Joseph Rieger and CVS Pharmacy for establishing this for our residents. With their foresight and with our community's cooperation, we can continue to help keep these drugs out of our children's hands and out of our water supply.

## Liver Transplant Allocation Update

In September UNOS held a public meeting in Chicago to discuss potential changes to the way livers are allocated in the United States. We believe changes to the system are necessary in order to ensure that everyone in the country has fair and equal access to organs for transplantation. In particular we support broadening the current regions to expand access to a larger pool of organ offers for our patients.

Prior to the meeting almost 700 people responded to a survey that was organized by UNOS. Nearly 80% of the respondents either strongly agreed or agreed that the ability of all patients to receive timely access to liver transplantation is a component of a fair national organ transplant system. Nearly two thirds of respondents felt that addressing the geographic disparity in liver allocation should be a top priority for the OPTN. More than half of the respondents would support creating larger distribution areas, as long as operational issues were addressed.

There will be further discussions and deliberations before any changes can be made but our program will continue to advocate for improving organ availability for our patients. We will keep you updated as the debate unfolds.

## TAO at Eastview Mall

April 25 was a bright sunny day, both outside and inside the Eastview Mall in Victor as TAO members Matt Felo (President), his wife Sandra and board member Geoff Foley shared information about TAO, organ and tissue donation and the 2016 Transplant Games to mall visitors.



Bill Breen, visiting from Michigan, receives a copy of the Transplant Times from Board President Matt Felo at Eastview Mall.



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Subscriptions@tao-rochester.org  
Or a written request to:  
TAO  
PO Box 23552  
Rochester, NY  
14692-3552

**Dues are due once a year. If you haven't yet paid your 2015 dues, please  
send it in today! Thank you to those who have sent in their dues.**  
*Help support TAO's mission.*



# TAO / Rochester Membership Application

*No one is denied membership because of financial considerations*

**DUES:**       \$20 Family / Individual       \$100 Business / Organization  
 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) \_\_\_\_\_

Check here if you do not wish your transplant anniversary date to be published in the *Transplant Times*.