



Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

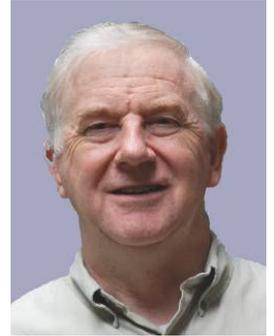
Providing support, understanding, education and resources for transplant recipients, candidates and their families.

July / August 2012

www.tao-rochester.org

1.888.664.1463

A Message from the President



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Membership Meeting Guest Speakers / Topics

*July / August:
No Meeting -
Enjoy the Summer!*

TAO Meets

**3rd Monday of the Month
Christ Episcopal Church
Fellowship Room
36 South Main Street
Pittsford, NY**

Dear TAO member, this will be my last note for the newsletter before my term as TAO President expires. It has been a privilege to serve in that capacity the past two years and I look forward to continuing to support TAO in other ways in the future. In this last letter I would like to briefly look back at the past two years and share my thoughts on what I think have been positives for the organization and where there have been some minor disappointments.

As I think about the TAO mission to support the local transplant community, I believe TAO continues to make a positive contribution in a variety of ways. We distribute our newsletter to more than two hundred TAO members, as well as to doctors' offices and clinics in the area. Two of our board members, Debbie Yendrzkeski and Norm Breen are the principals responsible for pulling together the content for the newsletter, and in printing and distributing what I think is a very professional publication given the modest size of the TAO organization. Our effort to offer interesting and educational material both through the newsletter and through speakers at our monthly meetings has hopefully been a positive for the membership. In the last year or so we also have tried to organize monthly luncheons for organ candidates and recipients with specific transplants. The purpose has been to provide another forum to share personal experiences and information that may be helpful to individuals both in staying healthy and also in dealing with the common

challenges associated with a particular organ transplant. The luncheons for lung candidates, recipients and caregivers have been especially successful.

At the end of 2010 the board searched for a more comfortable environment for our monthly meetings and in 2011 we moved our meetings out of the Al Sigl Center to a meeting room at Christ Episcopal Church in the village of Pittsford. The room is large, comfortable and free of the frequent interruptions that were a problem during our time at the Al Sigl center. Like the Al Sigl center, the facilities at Christ Church are also handicap accessible. While no location is convenient for every member, overall I believe this change of venue has been a major positive.

On the volunteer front, TAO members continue to contribute many hours to the support of various initiatives within the Rochester and Finger Lakes transplant community. This includes great support of visitation and clinic programs at the University of Rochester Medical Center by some TAO members. Importantly, TAO continues to be involved with the Rochester Eye and Tissue Bank and the Finger Lakes Donor Recovery Network. Members support those organizations' efforts to increase organ and tissue donation registrations in the area and in helping to educate members of the community about organ and tissue donation, particularly the youth, through

Continued on page 2

Message from the President (continued)

presentations of personal experiences at local schools and colleges.

I also feel very positive about steps that we have taken as an organization during these past two years to plan for long term financial stability. The board has committed itself to creation of balanced budgets and we have managed the organization's activities accordingly. As part of that commitment we have taken steps to develop new sources of revenue beyond membership dues and memorials. In the past year these initiatives included a Tupperware sale and sale of Delta Sonic car wash gift cards during the Christmas season. Along with the Tops gift cards that we have traditionally offered, we have become an Amazon affiliate where we derive financial benefits whenever a member makes a purchase through Amazon.com. We have also held a very successful euchre tournament. More of each of these initiatives is planned for the future, along with TAO nights at local eateries. Beyond these endeavors, TAO has also been a grateful recipient of generous donations from local groups such as the Z-Car Club of Rochester and the United Way, in addition to many donations from individuals.

One area in which I would like to have seen more progress is in attracting larger numbers of members to our monthly meetings. There are likely many possible reasons for the sometimes limited attendance. Some members I know have difficulty driving at night; for others the chosen evening is not a good one and, for yet others, the location is not as convenient as it might be. We would be grateful for your ideas as to how we might encourage better meeting participation.

Another area that we recognize needs improvement is our web site. The site has not received a major update in some years and I believe can be improved as a vehicle for TAO communications to its members in the future. In that regard, I am delighted to report that following a request in our last newsletter we received offers of help to redesign our site from two TAO members. Work is now underway to completely rework the site. My sincere thanks to the two individuals who volunteered, Thanh Nguyen and Jeff Travis.

Let me close by thanking my fellow TAO board members for their support during my tenure as president. My thanks also go to you - our TAO members - for your ongoing interest and involvement in the organization. Whether a recipient, a candidate, a living donor, donor family, or a caregiver, I hope that TAO is contributing positively in some small way in your life. Please let us know if you have ideas as to how we might improve our support in the future.

My best to all of you.
Stay well!

Geoff Foley

Board Elections 2012

Spring is election time for the TAO organization. A number of board positions are open. These represent either reelection for expiring terms or open positions due to retirement of a current board member. We traditionally run a single slate for the TAO board elections, i.e. there is a single nominee for each of the open positions. While the election for each board position is not contested, we ask you to vote "Yes" or "No" for the slate of the nominees by email to: Geoff21@yahoo.com. This is your organization and your input is greatly valued.

The following are the nominees for two-year terms for this year's election:

Linda Barnard – caregiver for heart transplant recipient (current term expiring, up for re-election)

Norm Breen – heart transplant recipient (current term expiring, up for re-election)

Geoff Foley – double lung transplant recipient (current term expiring, up for re-election)

Karen Gledhill – kidney transplant recipient (for a first term – Karen is a former TAO board member and previously served as president)

Bev Shank – liver transplant recipient (current term expiring, up for re-election)

President's note: I am very grateful to the nominees identified above for their willingness to serve on the board, as well as those board members whose terms are ongoing. Their dedication and time commitment to help the Transplant Awareness Organization carry out its mission to support organ transplant families (candidates, recipients and donor families) in the Rochester area is enormously appreciated. I want to express particular gratitude to Jerry Runion, past president of TAO, whose term is expiring. Jerry has made many important contributions to TAO over the six years he has served. Many thanks Jerry for all you have done.

Transplant Times

Submission Deadline

**For September/October 2012 issue:
Monday, August 6, 2012**

Articles /ideas email to:

auggeday@aol.com or send by mail to:

TAO, PO Box 23552, Rochester, NY 14692-3552

Hoping for a Kidney Transplant.....?

The solution we found might work for you

Diagnosed with polycystic kidneys my wife Linda was headed for dialysis and finally started going to the Dialysis Center in the Fall of 2008 for treatment. It was only treatment of the problem, which added to the burden of traveling 25 miles one way four times a week, knowing that this may never change.

After several months the opportunity of home hemo-dialysis presented itself. The privacy of our own home and on our schedule was intriguing, so we started. After converting a room in our house into a mini clinic and months of successful treatments, countless home visits from the coordinating nurse, and endless hours of help from a small platoon of supporting friends and family (you know who you are), multiple deliveries of supplies... and even a couple of trips to the ER when things went wacky...it just so happened with dumb luck, Linda heard a story on the evening national news.

There was a program offered through the Alliance for Paired Donation for living paired kidney transplants. The interesting part was, this was the very first time we'd heard of it, even with all the doctors, nurses, social workers, and technicians we'd seen, nobody had mentioned it. Why was the only course of action to remain on a strict dialysis program and "hope" for an eventual transplant, and the source for a solution on the evening national news on TV? We registered the next day and went to an orientation at the University of Toledo Medical Center (UTMC).

Next, Linda gave up her place on the long waiting list in Rochester and placed her hope for a transplant with Dr. Michael Rees and the Living Paired Program that included my offer to donate a kidney to someone else and maintain this paired chain.

While continuing dialysis at home and diligently maintaining good health, the good news came at a follow up visit to Toledo. A match had been found for Linda and surgery could be scheduled. Since her donor lived in North Carolina and unable to travel; the kidney was transported to Toledo for her operation there. No more dialysis, no more asking friends to sit for 3-4 hours during treatment, and a quality of life back that had been slipping away for 3-1/2 years.

Dr. Rees assured me he'd call me someday, and 9 months later he did.

He located a recipient and set aside some time for surgery if I was still willing to fulfill my commitment - which of course I was willing to do. In May of 2012, I donated a kidney to a young man from Michigan that I met for the first time while being prepped for the OR. It was pretty emotional to say the least. His family was

super-appreciative, warm and very loving. He was sent home a few days later and last I knew, doing great. The chain will continue further via his family member donating soon to someone else.

Linda is doing great and I'm fully recovered too. The dialysis machine and makeshift clinic home is only a memory. We've opened our pool and planted a backyard garden for the first time in years.

God bless the 6:30 news story about the living paired kidney program and all the many folks that made this SOLUTION possible.

Sitting on a dialysis machine thinking "is this how it's going to be?" is a tough situation. Being proactive, not only offers hope for the patient, but also holds the larger strength for the caregiver, being able to actually offer life changing help, which is priceless.

A quality of life is yours, no one else's. Don't put up with just being on a waiting list when there may be a better answer.

Contact information is offered here for details about the program and the support groups we found that offered guidance and supplied financial help.

If our story is similar to your situation or someone you love, don't wait for it to be suggested, look into it, it may make ALL the difference.

Blessings, Glen & Linda Cone
glcone11@gmail.com



www.paireddonation.org: Alliance for Paired Donation

www.transplantliving.org: United Network for Organ Sharing

www.livingdonorassistance.org: National Living Donor Assistance Center

www.retb.org: Katie's Star Memorial Fund
University of Toledo Medical Center UTMC 419-383-3419

Ask for the Renal Transplant Coordinator.

Would you like to share your transplant experience?

The *Transplant Times* is looking for your story. TAO has found that candidates and recipients gain useful knowledge from hearing about real life experiences. Please submit your story to auggieday@aol.com or mail it to TAO, PO Box 23522, Rochester, NY 14692, include your name and a contact number.

Organ Donation Awareness Proclamation Presented to URM Center Transplant from the Monroe County Legislature

Last Fall, Dr. Barry met Monroe County Legislator Josh Bauroth (District 24) at a political fundraising event. Always eager to get the word out about the crisis of organ donor availability here in Monroe County, New York State, and nationally, Dr. Barry began telling Josh about the tragic discrepancy between people awaiting transplants and the number of registered donors. Josh graciously offered to arrange for a Monroe County Legislature proclamation to be presented to URM Center Transplant in order to raise awareness about organ donation, to celebrate URM Center's efforts in this regard and, most importantly, to honor organ donors, their families and transplant recipients. The proclamation was first presented in the County Legislature on April 17, 2012 (see photo) to Drs. Chris Barry, Mark Orloff (Chief of the Division of Solid Organ Transplant and Hepatobiliary Surgery at URM Center), and donor mother Helene Ehmann. It was again presented by Mr. Bauroth at the URM Center for Transplantation's River Run on April 22nd, 2012. Below is the text of the proclamation.

We are very grateful to the entire Monroe County Legislature, in particular President Jeffrey R. Adair, Joshua Bauroth (District 24), Justin Wilcox (District 14) and John Lightfoot (District 25) for acknowledging and supporting this very important cause. We will continue to work with the Legislature and other local government representatives to advocate for organ donation awareness and to celebrate the miracle of transplantation.

Monroe County Legislature

Whereas: Organ donors are true modern day heroes that selflessly put themselves on the line for the betterment of those around them. A single organ donor can save up to eight people's lives and dramatically improve the lives of up to 50 people through tissue donation. Donors and

recipients do not need to be a perfect match and thanks to modern medicine, age, health & pre-existing conditions do not immediately preclude someone from being a potential donor; and

Whereas: There are some very tough statistics that advocates and patients are faced with: there are nearly 113,000 people waiting for an organ transplant in the United States, 10,000 of which are citizens of New York State. Tragically, 18 people die every day while awaiting a transplant. Thankfully, the University of Rochester Center for Transplantation and area organizations have been working diligently to raise awareness, sign up more people to be donors, and raise money to support patients & their families; and

Whereas: Since 1996, the Transplant Center has performed thousands of successful kidney, liver, pancreas, heart, tissue and cornea transplants. Strong Memorial Hospital also takes on the daunting task of assisting patients before, during and after a transplant. The costs and responsibilities associated with treatment can be crippling to patients and their families, which is why the Rochester River Run/Walk was established in 2002 to raise money for patient treatment and care; and

Whereas: The real praise still lies with transplant patients, donors, their families and caretakers. The strength, courage, dedication, patience, resolve and selflessness that they display is a constant inspiration to the entire community.

Now, Therefore, Let it Be Known, that we, Jeffrey R. Adair, President, Joshua Bauroth, Legislator—District 24, Justin Wilcox, Legislator—District 14, and John Lightfoot, Legislator—District 25, on behalf of the entire Monroe County Legislature on this day, April 17th, 2012, do hereby honor

The University of Rochester Center for Transplantation, Transplant Patients, Organ Donors, their Families & Caretakers in Monroe County

For their efforts to raise awareness of the extreme importance of organ donation and for their incredible courage in the face of daunting adversity.



L-R: Justin Wilcox (14th District), Josh Bauroth (24th District), John Lightfoot (25th District), Helene Ehmann (donor Mother), Mike (Helene's husband), Chris Barry and Mark Orloff.

Facebook Timeline Updated to Enable Users to Share Donation Decision

Facebook has launched an upgrade to its timeline profile structure that asks users to check their donation status and directs them to the Donate Life America website where one can click on one's home state and enroll. Facebook users can now share their donation decision to be an eye, organ and tissue donor on the Timeline.

Christopher Taylor Barry, MD PhD, "We in the transplant community are very happy that the good people at Facebook are encouraging its 900 million members to consider becoming organ donors. This is a perfect vehicle for all of us to begin the conversation about organ donation and transplantation, learn more about what is exactly involved, and to start having thoughtful conversations with our friends and loved ones about the subject. Hopefully, many people will be moved to register their intentions to become an organ donor and thousands of lives can be saved or improved."

Here are some other great resources and media coverage of this exciting new partnership:
[Step by step guide to adding donor status on Facebook](#)
[Facebook Post](#) to share on your Facebook Timeline
[Mark Zuckerberg's Blog Post](#)
[Mark Zuckerberg's Interview](#)

All [ABC Coverage](#) on the Initiative

<http://www.nytimes.com/2012/05/01/technology/facebook-urges-members-to-add-organ-donor-status.html>

(Note: Underlined links are enabled at our website: www.tao-rochester.org)

Board of Directors & Officers

President	<i>Linda Barnard</i>
<i>Geoff Foley</i>	<i>Chris Barry MD, PhD</i>
<i>GeoffF21@yahoo.com</i>	<i>Norman Breen</i>
Vice President	<i>Matt Felo</i>
<i>Debbie Yendrzeski</i>	<i>Karen Guarino</i>
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<i>Kathy Wesline</i>	<i>Amy James</i>
Secretary	<i>Janice Odenbach</i>
<i>Bev Shank</i>	<i>Karen Porterfield</i>
	<i>Jerry Runion</i>

Transplant Anniversaries

PHILIP RONZO	LIVER	July	1996
GIULIO VERDE	HEART	July	1998
CHERYL HELFER	KIDNEY	July	2002
RICHARD PEREZ	LIVER	July	2003
RICK CLARK	KIDNEY	July	2004
CINDY DESHANE	LIVER	July	2005
BONNIE GOTTORFF	KIDNEY	July	2005
JOANNE TUCKER	LIVER	July	2006
PATRICIA RIDGE	KIDNEY/PANCREAS	July	2006
JOHN ODELL	LIVER	July	2010
SHAWN PANGBURN	LIVER	July	2011
DANIEL KLIMEK	CORNEA	July	2011
DAVID SPIRO	LIVER	August	1997
REBECCA SNYDER	HEART	August	1998
MOIRA MILLER	LIVER	August	2005
LISA FAUCZ	KIDNEY	August	2008
TOM FUOCO	HEART	August	2008

Contributions

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

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

Mary Magdalene Church

In Memory of Herbert L. Phillips:

Dan & Suzi Phillips

Kathleen & Steven Speno

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

Our Sympathies To...

The family of Ivan Tzontchev.

Lilac Parade

The Lilac Parade was held on Saturday, May 5, under sunny blue skies. The Council for Donation of Organs & Tissues (C-DOT) which is comprised of several agencies from the Rochester and Syracuse areas, TAO included, sponsored a floral decorated float expertly pulled by Janice Odenbach. Thank you Janice for pulling the float without incident for so many years, it is greatly appreciated.

Those riding on the float included donor families, liver, heart, lung, cornea and kidney recipients along with their caregivers. The response from the crowd was very moving. You'd hear, "oh, wow" and then applause. The parade is always the first Saturday of the Lilac Festival in May. Interested in riding next year? Contact Karen Guarino at 585-272-7890 to have your name added to the email distribution list. It's a great way for the general public to see recipients, remember and honor all donors and their families and raise awareness of eye, organ and tissue donation. If you missed the parade you can watch it on channel 108 YNN on demand.

C-DOT is in need of "borrowing" a flat bed for next year's parade. If you have access to one, please contact Karen Guarino at kguarino@rehpb.org



TAO April Meeting

Members of the Finger Lakes Donor Recovery Network (FLDRN) and the Rochester Eye and Tissue Bank (RETB) presented an update on the topic of What's New in Organ, Eye and Tissue Donation.



Amy James (FLDRN)



Rob Kochik (FLDRN)



Karen Guarino (RETB)

United Network for Organ Sharing

Candidates listed as of 6/21/2012

- 92,682 Kidney**
- 16,011 Liver**
- 3,212 Heart**
- 2,160 Kidney/Pancreas**
- 1,641 Lung**
- 1,288 Pancreas**
- 263 Intestine**
- 52 Heart/Lung**

114,756 TOTAL

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

www.unos.org

Join a Committee
 Sunshine , Newsletter,
 Membership, Awareness
 Interested?
 Call **1.888.664.1463**

Save The Date . . .

TAO Dedication at the Maplewood Rose Garden Saturday, July 21, 2012
More details to follow.

TAO Organ Specific Support Groups

"OPEN AIRWAYS" - Lung Gathering Group

- Monday, July 9, 12 Noon Mike's Diner
 - Thursday, August 23, 12 Noon Mike's Diner
- Contact Joanne Schum at 585-671-7635 or twoluckylungs@juno.com if interested in attending.
MIKE'S NEW YORK DINER is at 3423 Winton Place (S. Winton Road Area, and Brighton Henrietta Town Line Road area)



The URMC is proud to support the Indian Community Center and the production of *Where there's a Will*

**Save the Date
September, 28, 2012**

for a very special Bollywood style Gala
and celebration of the
20th Anniversary of the Liver Transplant Program
At the University of Rochester Medical Center

We are excited to announce that Bollywood superstar and former Miss World PRIYANKA CHOPRA will deliver the keynote address and share her passion about organ donation. Ms. Chopra is a world famous actress, singer-songwriter and an internationally known humanitarian.

To receive an invitation for this event please send an email to idoktor@admin.rochester.edu or call 585-275-9827

MEDICINE of THE HIGHEST ORDER

Warm Hearts Made Up for the Chilly Weather at the Rochester River Run

Even though the weather didn't cooperate, more than 300 runners, walkers and participants came out to the Roundhouse Shelter on Sunday, April 22, at Genesee Valley Park for the 11th annual Rochester River Run/walk 5K. In spite of the rain and chill, the run raised more than \$10,000 for transplant patients and families at Strong Memorial Hospital.

A highlight of the day was a brief ceremony at the Riverbend Shelter prior to the race which recognized donors, recipients and families. Donor parent, Helene Ehmann, received a proclamation from Josh Bauroth (District 24) of the Monroe County Legislature proclaiming April 22 as Organ Donation Day. The proclamation had been made earlier in the Legislature on April 17. Celebrants also marked April as Donate Life Month. Also attending the ceremony were URMC transplant surgeons Mark Orloff, Chris Barry and Carlos Marroquin.

This year's event saw the increase of pre-registered participants, making this year's Rochester River Run the biggest ever. Organizers noted that the convenience of online registration made it easier to sign up.

Organizers of the event want to thank everyone who worked so tirelessly on the planning of the Rochester River Run, but the event could not have grown into the success it has without the runners, walkers and participants. Organizers are especially grateful to everyone who came out in spite of the poor weather. Friends of Strong organizer Melanie Oldfield said that the size of the turnout reflected the importance of organ transplant and the impact it can have on families.





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Transplant Awareness Organization of Greater Rochester PO Box 23552 Rochester, NY 14692-3552

If you have a change of address, or you would like to be removed from our mailing list, please send an e-mail to:

Subscriptions@tao-rochester.org

Or a written request to:

TAO PO Box 23552 Rochester, NY 14692-3552



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)