



Transplant Times

December 2016/January 2017

A newsletter of the Transplant Awareness Organization of Greater Rochester

www.tao-rochester.org | 1.888.664.1463

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Membership Meeting Guest Speakers / Topic

December 2016

- No Meeting
Happy Holidays

January 14, 2017

- Holiday Recognition Dinner

A Message from the President

Another year is coming to a close and TAO is looking forward to the New Year! The holidays are coming to and I hope they are filled with love and family!

TAO will be gift wrapping at Barnes & Noble in Webster this year. If you'd like to take a shift please read the information inside. This provides an opportunity to spread awareness and doubles as a fundraiser for TAO.

We are preparing for our annual Holiday Recognition Dinner and hope that you will all join us. Many people are involved in keeping this organization going and this is an opportunity to give thanks to those involved. The luncheon is held in lieu of our monthly meeting.

It's time to pay our dues! The monies are used for member meetings costs, the newsletter, comfort bags and blankets for patients. We are able to support transplant related events such as the River Run, Transplant Games and Harbor House to name a few. Your dues are vital to our organization.



This is a tough time of year to stay healthy so please do what you need to do, please get your flu shot.

The TAO Board will be meeting and making plans for the new year, we hope you'll join us at a future meeting or event.

Best wishes for safe, happy and healthy holidays!

Debbie Gendrzewski

Visit & like our Facebook Page
www.facebook.com/TaoOfRochester



SHARE IT WITH OTHERS

Ask your friends to like us!

TAO Meets

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

TAO Providing support, understanding, education & resources . . .

Pink PanTee Open



Monday August 1, 2016, the Pink PanTee Open was held at Victor Hills Golf Club. The 26th annual tournament had 111 women participants.

The raffle benefits the Transplant Fund at URMC Strong which aids transplant recipients and their families with needs that are not covered anywhere else. Diapers have been purchased, a refrigerator so meds could be stored, parking costs, utility bills have been paid.

TAO members, Debbie Yendrzkeski, Linda Barnard, Karen Guarino and Marlene Begy, pictured above enjoyed the day, evidenced by their smiles!

Barnes & Noble Gift Wrapping

On Sunday December 18, TAO will be gift wrapping at Barnes & Noble, 1070 Ridge Rd., Webster, Webster Town Center. We will be there from 9am-3pm and are looking for people to fill the shifts. We need 2 people per shift. Each shift is about 2 hours. Please contact Debbie at 377-6028 if interested.

The gift wrapping provides an opportunity to bring awareness about TAO and organ, eye and tissue donation. The monetary donations aid with TAO's fundraising.

We hope you'll join us wrapping and if not, stop by while you are shopping!



Holiday Recognition Dinner

Join us for the annual Holiday Recognition Dinner on Saturday January 17, 2017. Start the new year with fellowship and good food at Joey B's, 1325 Elmwood Ave, in Brickstone. We will meet at noon and dinner will be served at 1:00.

Please send a check for \$18 per person to TAO, PO Box 23552, Rochester, NY 14692-3552 by January 8, 2017. Include the names of who will be attending.

If you would like to make a donation or "round up" to provide a ticket for a person in need, please indicate that on your check and thank you!



2017 Membership Renewal

It's that time of year again – time to renew your TAO membership! Thank you for your past support and for renewing now so we can continue to have the impact you've come to expect from TAO.

Thank you for your continued commitment to TAO. We are counting on you to renew your membership by filling out the form on the back of this newsletter. Additionally, please use the form to indicate if you wish to continue receiving the newsletter.

Norm Breen
Membership Chair



Coping Emotionally After an Organ Transplant

When most people think about getting an organ transplant, they focus on the obvious physical aspects: the illness, the operation, and the healing. They're less likely to think about the emotional impact. But that can be profound too, both for you and the people around you.

Nearly all people who receive a transplant, experts say, feel elated and experience a sense of relief and hope after a surgery that goes well. But with time, that initial optimism may be tinged with other feelings. You may start to worry about your condition coming back. You may be afraid of organ rejection. Or you may fixate on the uncertainty of the future.

It's perfectly natural to have these feelings. But if these worries take over your life, you need to do something about it.

Guilt After an Organ Transplant

Guilt is a common reaction people have after a transplant. Patients often report thinking a lot about the donor and feeling guilty about benefitting from the donor's death. This feeling can be especially strong for people who became very ill while waiting and prayed or hoped for an organ to become available. After the procedure, some get the feeling that they had been wishing for someone else to die.

One way people come to terms with these feelings is by focusing on the fact that for both the donor family and the recipient the transplant is one way to get a sense of meaning from a death. That understanding, the experts say, can be a source of comfort.

For many people, getting in touch with the donor family can help. To respect privacy, organ donation organizations won't allow you to get in direct contact without the donor family's agreement. But you can at least write a letter that your health care team can pass on to them.

Organ Transplant and Family Issues

Problems with family present another emotional hurdle for many people after a transplant. In most cases, transplants happen rather suddenly, so it's not something you can plan for. As a result, your home life may be turned upside down. Also, you won't be able to predict how you'll feel afterwards.

In addition, the steroids you will likely be taking can have the effect of a mood amplifier. In the first few weeks, especially, when the doses are highest, the medicine will wind you up and make it hard to sleep. The sudden changes in the family -- and in your behavior -- can be extreme. Just keep in mind that recovery is a process that needs adjustment and time.

Organ Transplant Disappointment and Frustration

Organ transplants are a very successful therapy, and most people who get them live normal lives. But there still may be bumps in the road to recovery. For some people, those bumps can be hard to handle.

For one thing, you need to keep your expectations from getting too high. It will take time to get back to normal. Not being prepared for that reality can cause disappointment and contribute to depression.

The recovery time can be especially difficult if your

transplant is a preemptive transplant. Most people who get a transplant have been very sick and feel much better as soon as the transplant is done. But it's the opposite if you get a preemptive transplant. You may have been on the verge of organ failure. But you may not have had any symptoms before the operation. As a result, you'll feel worse during recovery than you did before you had surgery, and that can make coping difficult.

Getting Help After Organ Transplantation

As you adjust to an organ transplant, some of these feelings may bother you less. Part of living with a transplant is accepting uncertainty.

Experts say it's important to stay optimistic while at the same time accepting that it's impossible to know exactly what's going to happen.

But while living with some uncertainty is necessary, you should never accept depression or constant anxiety as inevitable. If you feel that you're becoming depressed or chronically anxious, talk to your health care provider. Get help.

Many people also find that support groups can make a big difference. In everyday life, you don't run into many people who have had a transplant. By joining a support group, you get to talk to people who are going through the same things that you are. Just meeting people in your position can make a big difference.

WebMD

2018 DONATE LIFE TRANSPLANT GAMES

Gathering in the summer of 2018, thousands of individuals touched by organ, tissue and corneal donation will experience the sights and sounds of Salt Lake City, Utah for the Donate Life Transplant Games.

The Games will be held from August 2 - 7, 2018.

Produced by the Transplant Games of America, and hosted by the Utah Sports Commission, Intermountain Donor Services, the University of Utah Solid Organ Transplant Program, and Visit Salt Lake, the 6-day event will carry on many of the traditions from previous events and will very likely include some new exciting activities.

Now that the bid award has been announced, there are many more details to be worked through over the coming months. Please save the date and stay tuned for exciting details as we plan what we expect to be a great event.



community events Save the Date . . .

Sunday, December 18
Barnes & Noble Gift Wrapping
1070 Ridge Rd., Webster
Webster Town Center



Saturday, January 14, 2017
Holiday Recognition Dinner
Joey B's at Brickstone, 1325 Elmwood Ave
Noon Social Hour
1 PM Dinner
Send a check for \$18 per person to:
TAO, PO Box 23552, Rochester, NY 14692-3552
by **January 8, 2017**.

Include the names of who will be attending.
If you would like to make a donation or "round up" to provide a ticket for a person in need, please indicate in the memo portion of your check.

United Network for Organ Sharing

Candidates listed as of 11/11/2016

99,352	Kidney
14,633	Liver
4,076	Heart
1,822	Kidney/Pancreas
1,450	Lung
964	Pancreas
275	Intestine
45	Heart/Lung

119,821 TOTAL

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

www.unos.org

TAO October Meeting



Debbie Yendrzkeski, TAO President presenting a Certificate of Appreciation to Dr. Christine Hay. She addressed unexplained fevers in transplant recipients.

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

President	Debbie Yendrzkeski	Jeffrey Alexis, MD
	Linda Barnard	Linda Barnard
Vice President	Erin Collins	Erin Collins
	Gretchen Collins	Matt Felo
Treasurer	Karen Guarino	Karen Guarino
	Bonnie Haefner	Bonnie Haefner
Secretary	Amy James	Amy James
	Sue Muto	Judy Munn
Membership	Janice Odenbach	Janice Odenbach
	Norman Breen	Karen Porterfield, LMSW

Transplant Anniversaries

Larry Buck	Kidney	December	2000
Carol Comfort	Kidney	December	2003
Argie Mae Davis	Kidney	December	2015
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
Martha Rossi	Kidney	December	2013
Beverly Shank	Liver	December	2005
Cynthia Taillie	Kidney	December	2014
Diane Burgio	Liver	January	2014
Claudia Ciresi	Liver	January	1996
Jane Clewell	Liver	January	2005
Helen Cox	Kidney/Pancreas	January	1996
Daniele Ditulio	Liver	January	2003
Roger Duryea	Kidney	January	1995
Arthur Lisi	Liver	January	2013
Dawn Meschi	Kidney	January	2001
Michelle Teichner	Kidney	January	1996
Jude Nunciato	Liver	January	1993
William Reagan	Kidney	January	2016
Anne Marie Scroger	Liver	January	2007
Ron Secor	Double lung	January	2015
Pat Stewart	Kidney	January	1994
Guy Valone	Kidney	January	2009

Our Sympathies

Florence Eve and family on the death of Donald

Wishes of Wellness

Our healing thoughts and prayers go out to:

Larry Rosner
Tom Barbera
Bernice Eblovi
Bonnie Haefner
Benjamin Smeenk
Cindy DeShane
Norm Breen
Chuck Lundeen



Contributions

Dennis & Carol Wittman in memory of Maria Aponte

Office Services Unlimited

TAO www.tao-rochester.org

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

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

A To promote organ and tissue donation awareness.

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

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

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

"If You're Not Taking Your Medication, You're Taking a Chance"

ABC's Medication Adherence Program Helps Monroe County Residents Improve Medication Management

By Melissa Molongo

"Medication adherence" means taking medication at the timing, dosage, and frequency prescribed by your health care provider. Medication adherence, also known as medication compliance, is one of the most important health maintenance behaviors for people with daily medications. Unfortunately, many struggle to achieve it regularly. Medication non-compliance can occur for many reasons, including when people struggle with timely pickup of medications at the pharmacy, refilling prescriptions on time, skipping, stopping or taking partial doses, taking the wrong amount of a prescribed medication, or taking medication at the wrong time. On the other hand, when complying with medication instructions, it can reduce the risk of hospitalization, severe health episodes, and even death. Additionally, good medication adherence can save money in the long run with less doctor and hospital bills.

For transplant recipients, medication adherence is especially important. It has been found that 20% of transplant recipients do not comply with their medication. Non-adherence can be a matter of life and death for this population, or the difference between a vibrant and a chronically ill life. For example, poor medication compliance among transplant recipients shortens allograft survival and can lead to costly chronic renal replacement therapy.

For Americans with chronic conditions, the CDC and Excellus reports that half of Americans with daily medication do not practice proper medication compliance. Many people simply have not made taking their medicine part of their daily routine, so they often forget to take their medication when they should. Others skip doses because they are trying to save money or looking to avoid unpleasant side effects from their medication. Some do not believe the medication is really helping or do not experience physical symptoms of their condition that would alert them to take their medication. High blood pressure, for example, is known as the "silent killer" because there are often no symptoms. As a result, many hypertensive patients do not take their medication regularly.

In Rochester, Action for a Better Community has a unique community health program that is dedicated to improving medication adherence and management for local residents. Funded by a grant from Excellus BlueCross BlueShield's Community Engagement efforts, the Medication Adherence Program (MAP) is a free service that works one-on-one with individuals on incorporating simple reminder tools into their daily routine and discusses the impact of medication compliance on daily and long-term health outcomes. The program, free to any Monroe County resident, involves meetings with participants in their homes, local library, or wherever they are comfortable and provides tools such as a pillbox, erasable medication chart, and regimen calendar. A skill-building intervention, MAP's goals are to help participants become more independent with and confident about their medication management. Participants are encouraged to personalize their usage of the provided reminder tools and are asked to report on their activities just once a month over the phone. Having engaged with over 300 people over the past two and a half years, the

(Continued on page 7)

2017 Donate Life Float Depicts Spectacular Polynesian Catamaran, Celebrates Organ Donors and Recipients as "Teammates In Life"



This year's entry, *Teammates in Life*, reflects the parade's theme "Echoes of Success" by reminding us that no one succeeds alone. We all thrive by working together and pulling in the same direction.

Donors save the lives of grateful recipients and help families heal, and it is the large community of registered donors that makes it possible to save thousands of lives across the country each year.

The 2017 float depicts a spectacular Polynesian catamaran, which will be propelled by a team of 24 organ, eye, and tissue transplant recipients rowing in unison with strength gained from their donors.

The sails of the vessel will feature 60 floral portraits of donors interwoven with Polynesian designs and patterns. Just as the donors' gifts empower the lives of others, the sails help power the catamaran on its journey. Twelve living donors will walk alongside the float carrying flowers in celebration of the life they have given to others and the quality of life they continue to enjoy themselves. The ocean waves will showcase 1,000 white Akito roses, individually dedicated in memory of specific donors. Vibrant i'iwi and 'amakihi birds perch amongst a lush landscape of tropical flowers and palm trees while a pair of tikis, representing light and life, abundance and peace, peer out of the jungle. The float will exude life with colorful, exotic blooms grown in Hawaii especially for the occasion.



**Flu Season is here!
Get Vaccinated!**

transplant Support Group Meetings

"Open Airways" - Lung Gathering Group

Thursday, December 22 @ 12 noon

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

Thursday, January 19 @ 12 noon

Hong Wah Restaurant, 1802 Penfield Road, Penfield

Heart Transplant/VAD Support Group*

Thursday December 15 @ 6:00 pm

Transplant/VAD Holiday Party

Flaum Atrium

Invite to follow with more information

Thursday, January 12 @ 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.

(Continued from page 6)

MAP model has proven to be extremely effective for people of all backgrounds, medical condition, and age. Seventy percent of MAP participants reported improved medication compliance within a month of the initial consultation with the majority continuing their improved habits over the following two months. These results indicate that improving medication adherence is an achievable goal within a short period of time and with minimal yet effective intervention. Considering the impact that medication adherence can have on health outcomes for those with a chronic health condition, MAP is an important resource for Rochester area transplant recipients.

Action for a Better Community's Medication Adherence Program (MAP) has rolling enrollment and is free. Interested in learning more, signing up, or making a referral?

Contact ABC's Health Resource Coordinator at 585-325-5116 Ex. 3403 or mmolongo@abcinfo.org. MAP is funded by a grant from Excellus Blue Cross BlueShield.



Sponsored by **Excellus** 

Welcome New Members

Shawn Ferguson

Loren Taurisano

Maria Leoto



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AmazonSmile is a website operated by Amazon with the same products, prices and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice.

Go to smile.amazon.com and follow the instructions to designate Transplant Awareness Organization as your choice. Thank you!

Transplant Times

Submission Deadline

**For February/ March issue:
January 7, 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

Donations 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) _____

Address _____ City _____ State _____ Zip _____

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*.