



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

Transplant Times

May / June 2013

www.tao-rochester.org

1.888.664.1463

A Message from the President

Inside this issue:

- New York Alliance for Donation Legislation Day .. 2
- Check Us Out 3
- After the Transplant 4
- Join us for Dinner 6

Membership Meeting Guest Speakers / Topics

May 20 @ 6 p.m.

Join us for **Movie Night!**
Dr. Richard Demme presents:
"Transplant in the Movies"
Appetizers & Popcorn served!

June 17 @ 6 p.m.

TAO Member & Family Picnic
Details on page 3

TAO Meets

**3rd Monday of the Month at
6:00 P.M. (NEW TIME)**
Christ Episcopal Church
Fellowship Room
36 South Main Street
Pittsford, NY

It is still April as I am writing this and it is Donate Life Month. I'm looking forward to volunteering at health fairs, schools and colleges in the coming year to promote organ, eye and tissue donation. It's also a good time to remember all donors who have helped to extend and make our lives better - doctors, nurses, family and friends - all who have helped us along the way. Without them it would have been much harder to come this far. With all we have been through, we should all take care of ourselves by remembering to take our meds, exercise daily and eat a proper diet.

Looking out my window I can see signs of spring: tulips, daffodils, and crocuses are up. It reminds me that the lilac festival is just around the corner, Spring has almost sprung and Summer can't be far away. I have already tried my angling skills with no luck.

At our last meeting we had a Reiki demo by Susie Szczepanski with the assistance of Lois Foley, wife of former president, Geoff Foley. The talk and demo were interesting and enjoyed by all.

The next meeting is May 20 and it is **Movie Night** with Dr. Richard Demme. His talk will describe how transplants have been featured in movies and he will show clips from some of the movies. Popcorn and appetizers will be served.

The new time for our general membership meeting is now 6 p.m. You are welcome to bring a friend anytime.

TAO's annual picnic, is fast approaching. Save the Date - Monday,



June 17 at 5 p.m., Carmen Clark Lodge, 777 Westfall Road in Brighton.

Please watch your mail and email for a survey we are compiling. We hope to include questions regarding meeting venue, time, day and format. We need your input and welcome it! Remember to visit our re-designed, informative website. There are many interesting things you can learn. You can also check out upcoming events, look at past issues of the newsletter, and find links to other websites.

We are always looking for volunteers. Come to a meeting or e-mail me if you are interested at mfelo@rochester.rr.com. I look forward to meeting you. Have a great Spring and hope to see you at future meetings.

Matt Felo

New Start Time for Meetings is now 6:00 PM

New York Alliance for Donation Legislative Day, April 16

Tuesday, April 16 was New York Alliance for Donations's (NYAD) Legislative Education Day in Albany. Transplant recipients, donor families and caregivers from the area accompanied Karen Guarino from Rochester Eye and Tissue Bank and Amy James from Finger Lakes Donor Recovery Network to Albany to meet with local legislators and to share their personal stories and to ask legislators to support upcoming legislation that will encourage and ease registration in our state's registry.

The presence of those affected by donation and transplant put a face to the cause. During a brief program for all participants, Assemblyman Felix Ortiz spoke about how donation and transplantation has touched his family.

NYAD Executive Director Aisha Tator has reported that, "our collaborative efforts have reaped immediate rewards! Senator Kemp Hannon, Chair of the Senate Health Committee, will be introducing legislation to grant administrative rights to the New York State Donate Life Registry to NYAD through an innovative public/private partnership with the Department of Health. There is still a significant amount of work to be done, but this is a tremendous step forward ."



L to R: Kathy Miller, Cherri Todisco, Karen Guarino, Debbie Yendrezski, Tom and Lindsay Rohrbaugh



L to R: Tim Parks, Tanya Herrold, Gary Guiste, Amy James, Helene Ehmann and Rob Kochik



Nearly 60 individuals participated in Legislative Education Day. Group photo before scheduled meetings.

Save the Date . . .

Saturday, June 15, 2013 @ 6 PM **And the Beat Goes On. . . .**

Fundraiser for Harbor House of Rochester
Doubletree Hotel, Rochester.
Ticket sales begin March 15, 2013
Call 585.473.1779 or visit
www.harborhouseofrochester.org

Monday, June 17, 5 PM **TAO Family Picnic**

Dinner served at 6 PM
Carmen Clark Lodge, Brighton Town Park
777 Westfall Road (West of Clinton Ave.)
To ensure the right amount of food please
RSVP by June 11 to TAO either by email
auggieday@aol.com
Subject: picnic or 585-377-6028
Suggested donation Adults: \$10, Children \$5

Monday, September 16

Fundraiser for Rochester Eye & Tissue Bank
"Brighter Tomorrow" Golf Tournament
Shadow Lake, Penfield, NY
Call Kathy Miller @ (585)272-7980 for details

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.

Hey, Check Us Out!

If you haven't visited the TAO website latterly, we hope you will now. It has gone through a major makeover thanks to members Thanh Nguyen and Geoff Foley. The original site, developed and maintained by Dave Johnson, served the organization well over the years and was instrumental in bringing TAO into the homes of its members and others.

What you'll find on the site is more information - articles of interest to recipients, their families and caregivers; regular communication from local and national healthcare professionals relating to transplant and donation; a calendar of events; volunteer opportunities; links to videos; reviews of monthly meetings along with presenter's PowerPoint presentations (when applicable) and past issues of TRANSPLANT TIMES, our monthly newsletter.

If you are interested in learning more about TAO or thinking of joining, visit the site to view the mission statement, find out where we meet and when meetings start and a membership form you can download, complete and send back.

Also, we want and encourage your feedback. Let us know what you like; what you don't like or what other information you would like to see added to the site. There is a link on the HOME page which gives you the chance to share all or any thoughts about the site with us. We look forward to hearing from you and appreciate your support.

www.tao-rochester.org



Don't forget to visit and like our Facebook Page

www.facebook.com/

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After the Transplant

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Why does organ rejection occur?

Your body has a natural defense system called the immune system that protects you from infection and disease. The immune system defends your body by producing antibodies and "killer" cells that destroy foreign substances (such as viruses and bacteria). Since the donor organ doesn't match your own tissue exactly, your body tries to destroy the transplanted organ by rejecting it. Rejection is nature's way of protecting your body.

What medicines will I need to take?

After an organ transplant, you will need to take antirejection medicines, or immunosuppressants, for as long as you have the donor organ. Because your immune system will try to destroy the new organ, antirejection medicines are needed to decrease your immune system's response so the new organ stays healthy.

Antirejection medicines weaken your immune system and decrease your body's ability to fight infections, cancer, and other diseases. Over the years since organ transplants were first done, these medicines have greatly improved. Researchers are finding out more all the time about how to better regulate the immune system after a transplant. Current medicines still have the potential to speed up illness or create new disease, such as heart problems, diabetes, cancer, and osteoporosis. But these medicines also will save your life by keeping your body from rejecting the donor organ. It is important to take these medicines daily and exactly as prescribed.

Taking medicines daily for the rest of your life is not as hard as it sounds. It may help to talk to someone who has had a transplant and who can give you some assurance that you will be able to make the medicines a part of your daily routine. Over time, probably, fewer medicines will be needed. Additional medicines may be needed now and then to fight infection or other health problems related to your transplant.

In general, the antirejection medicines you will take after an organ transplant include:

Corticosteroids, such as prednisone or methylprednisolone. A high dose of corticosteroid, often methylprednisolone, is given right before your transplant, to decrease your immune system's activity, reduce inflammation, and prevent rejection. High doses of corticosteroids are usually continued for a few days after your surgery and then tapered to the lowest dose that helps prevent rejection. Taking high doses of corticosteroids for just a few days may cause temporary side effects such as high blood pressure, high cholesterol, weight gain, sleep problems, and

anxiety. High doses can sometimes cause more severe side effects, such as extreme agitation, paranoia, and psychosis (trouble telling the difference between what is real and what is not real)-some people may feel "out of it" or have hallucinations while taking high doses of steroids. But these side effects are temporary.

Prolonged use of corticosteroids can cause glaucoma, steroid-induced diabetes, and increase your risk of getting an opportunistic infection (such as pneumocystis pneumonia), which is a type of infection that occurs in people with weakened immune systems. Some experts are finding that some people may be able to avoid use of steroids or to use them sparingly.

Calcineurin inhibitors, such as tacrolimus and cyclosporine. These block the message that causes rejection. You probably will always need to take calcineurin inhibitors, because they are an important part of your lifelong care after a transplant. These medicines are helpful, but they also have potentially serious side effects such as high blood pressure, too much potassium in the blood (hyperkalemia), and kidney problems. These medicines can also cause nausea, vomiting, diarrhea, high cholesterol, tremors, and seizures. And they can put you at increased risk for infection and cancer. There is a great deal of research on the development of newer calcineurin inhibitors with fewer side effects. Ask your doctor for more information if you are having any of these side effects.

Antiproliferative agents, such as mycophenolate mofetil, azathioprine, and sirolimus. Antiproliferative agents prevent the immune cells from multiplying. These antirejection medicines are also an important part of your lifelong care after a transplant. They prevent your immune system from attacking and destroying the donor organ. Common side effects can include nausea, anemia, reduced number of white blood cells (leukopenia), high triglycerides, and intestinal upset. Antiproliferative agents also increase your risk of getting an opportunistic infection, cancer, and other life-threatening conditions.

Monoclonal antibodies, such as daclizumab, basiliximab, and rituximab. These antibodies block the growth of immune cells that are responsible for rejection. They are used early after transplantation with calcineurin inhibitors and antiproliferative agents.

Polyclonal antibodies, such as antithymocyte globulin-equine and antithymocyte globulin-rabbit. Polyclonal antibodies temporarily deplete the body's immune cells. These medicines are used in the hours and days immediately after your organ transplant to prevent your body from rejecting the donor organ. They may also be used again if your body starts to reject the donor organ. They are often used to reduce early use of calcineurin inhibitors, which can have serious side effects. Side effects of polyclonal antibodies include fever, itching, joint pain, and decreased number of white blood cells (leukopenia). Severe side effects may include an increased risk for cancer

Continued on page 5

After the Transplant (continued)

and opportunistic infections, serum sickness (a bad reaction to your own tissues), and a condition that prevents your body from making antibodies that fight infection. You may have to take other medicines to prevent infection or to control other health problems you have (like high blood pressure).

What kind of physical issues will I face after transplant?

Almost immediately after a transplant, many people report feeling better than they have in years. The physical limitations you have will depend on the type of transplant you had, other conditions you may have, and whether your body rejects the donor organ. You will likely not face major physical limitations after you have healed from your transplant.

The daily antirejection medicines can cause some bothersome and sometimes serious side effects in some people. High blood pressure and high cholesterol are common problems after a transplant, although they can be treated with other medicines. You may be at increased risk for getting certain types of cancer and conditions such as diabetes. You will be at higher risk for infections, especially opportunistic infections, because your antirejection medicines will weaken your immune system. Be sure to keep your regular appointments with your doctor or the transplant center so you can be monitored for these illnesses.

What kind of emotional issues will I face?

Having an organ transplant may cause many emotional issues both for you and those who care about you. When your organ comes from a deceased donor, you may sometimes think about that and what it meant to the donor's family. It is common to have some depression after an organ transplant, although not everyone does. If you think you may be depressed, it is important to tell your transplant coordinator, doctor, or someone who cares about you. The earlier depression is treated, the more quickly you will recover and the better you will feel.

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

Support Group Meetings**"OPEN AIRWAYS" - LUNG Gathering Group**

- **Thursday, March 14, at 12 Noon**
Hicks and McCarthy, 23 S. Main St., Pittsford
- **Thursday, April 11, at 12 Noon**
Winfield Grill, 647 Winton Rd North, Rochester
Contact Geoff Foley at 585-383-1559 or
geoff21@yahoo.com if interested in attending

HEART Transplant/VAD Support Group

- **Thursday, May 9, at 6:30 p.m.**
LVAD Group with Thoratec Speakers
Location: Strong Memorial Hospital
ACF - Rooms A & B (Above Main Lobby)
- **Thursday, June 13, at 6:30 p.m.**
Marsha Buckley, NP Palliative Care
Location: Strong Memorial Hospital
7th Floor Conference Room
(Near the 7-3400 corridor)

United Network for Organ Sharing

Candidates listed as of 5/3/2013

96,042	Kidney
15,842	Liver
3,499	Heart
2,118	Kidney/Pancreas
1,696	Lung
1,173	Pancreas
261	Intestine
50	Heart/Lung

118,077 **TOTAL**

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

www.unos.org

ATTENTION MEMBERS.... Come Join Us for Dinner !

No need to cook and rush through dinner any longer before one of TAO's monthly social mixer meetings that serves up pizza, subs or other delectables. TAO is mixing up social gatherings with educational programs for its members.

On March 18, TAO held its first dinner social mixer. Those in attendance dined on delicious pizza and shared personal transplant experiences.

On April 15, TAO members enjoyed an assortment of subs while Susie Szczepanski shared her Reiki techniques with some very fortunate volunteers from the membership.



Susie Szczepanski with volunteer Bonnie Haefner at the April 15 meeting



ABOVE

Members and guests enjoy food and conversation at the Pizza Party March 18



TAO President Matt Felo presenting thank you gifts to Susie Szczepanski at the meeting.

Transplant Times

Submission Deadline

For July/ August 2013 issue:
June 3, 2013

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

Wishes of Wellness To

Our healing thoughts and prayers go out to Gates Orlando, heart recipient.

Transplant Anniversaries

CAROL COMFORT	KIDNEY	May	1994
PATRICIA BIANCHI	LIVER	May	2002
NORMAN BREEN	HEART	May	2007
AMBER CASTLE	KIDNEY	May	1999
ROGER DURYEA	KIDNEY	May	1995
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
BERNICE EBLOVI	LIVER	June	2002
MATTHEW FELO	LUNG	June	2007
KEVIN MCCORRY II	BONE MARROW	June	2004
DICK MILLER	HEART	June	2007
MIKE YENDRZESKI	LIVER	June	2002

Welcome New Members

Daniel Pszczolkowski, Heart recipient

John Dedloff, Heart recipient

Dean Kiefer, Kidney recipient

Join a Committee

Sunshine, Newsletter,
Membership, Awareness
Interested?

Call **1.888.664.1463**

Contributions

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

Herb Reif

Mike Swete

In Memory of **Jack Wesline**:

Mike & Karen McDonald
Gerri & Steve Fox
Sheila Henry
Joanne Morse
Sheila & Joshua Hollander
Carol Yungkurth
Bliss Owen
Ted Howk
Mr. & Mrs. Jon McNally
Dave Johnson
Jim & Dorothy Caswell
Thomas & Barbara Coyle
Richard & Sandra Larson
Linda & Ken Fishell
The Friday Night Stitches:
Jeanne Bringley
Pat Ellis
Michele Gailey
Chris Ghinazzi
Roberta Grainger
Janice Host
Carol Lore
Ruth Nobel
Carolyn Ravello
Norma Roberts
Cindy Salow
Cris Zaffuto

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

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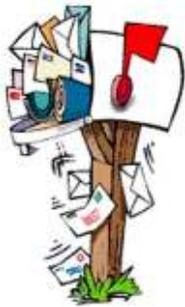


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HAVE YOU RENEWED YOUR MEMBERSHIP FOR 2013? YOUR SUPPORT IS NEEDED!



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)