



Transplant Times

Newsletter of Transplant Awareness Organization of Greater Rochester

May / June 2009
www.tao-rochester.org

1.888.664.1463

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TAO Meets

3rd Wednesday
of the Month
at the
Al Sigi Center
1000 Elmwood Ave.
Corner of South Ave.
& Elmwood Ave.
7:00 to 9:00 pm

Enter Door #5
and
FOLLOW TAO SIGNS

ELECTIONS ARE COMING May 20



The Nomination Committee is looking for candidates to run for six board positions. The term for each is two years. The Board of Directors meets the third Wednesday of the month from 5 - 6:45 pm, prior to the Membership meeting. Six board members will be elected by the general membership. If you are interested contact Sandy McNitt, 359-8015 or sdmcnittot@aol.com before May 20.

Who can be a board member? This position is not limited to the transplant community. We welcome individuals from the business community, health professionals, and others who have a genuine interest in helping ensure the mission of TAO. You must be a TAO member. You will be required to attend monthly board meetings and participate in voting on various issues that help to improve the organization. It is important to do work outside of board and membership meetings, such as participation in Strategic Action Planning Committee projects and in events that support TAO goals (i.e. Lilac Parade, National Donate Life Month and National Donor Sabbath).

Our current nominees are, but not limited to:

Sally Stelljes is running for reelection, a caregiver for her husband, who is a liver recipient. She has just finished a term as a board member. She started a successful volunteer Transplant Clinic program at Strong Hospital with her husband Mike, meeting with potential transplant candidates on their evaluation day. The program is almost three years old. She is also a volunteer for the Rochester Eye & Tissue Bank and Finger Lakes Donor Recovery Network.

Bonnie Haefner is running for reelection to the board member. She is a kidney recipient and has been a TAO member since 2002. She is active in the National Kidney Foundation. She is a volunteer for the Transplant Clinic program at Strong Hospital, and for the Rochester Eye & Tissue Bank and Finger Lakes Donor Recovery Network. She has participated for multiple years as an athlete in the US Transplant Games and has ridden the Council for Donation of Organ and Tissue (C-DOT) float in the Lilac Parade.

(Continued on Page 2)

Membership Meeting Guest Speakers / Topics

April 15:
Kate Norway RN Nurse Leader
6-1600 " Post Transplant Care"

May 20:
Dr. Richard Demme, will present " Transplant at the Movies". Using movies from the 1930's up to the present we'll explore the facts and fiction surrounding transplant as portrayed by Hollywood. Come prepared to be educated and amused. Popcorn will be provided.

June 17:
Annual TAO Picnic (details on page 5)

ELECTIONS ARE COMING May 20 ... *continued*

Janice Odenbach is running for re-election to the board. She has been a member of TAO since 1991, the year her husband became a heart recipient, has served multiple terms. She has attended the US Transplant Games many times, supporting the Upstate NY Team and helping as needed. She also enjoys driving the C-DOT float in the Lilac Parade.

Debbie Yendrzski is running for re-election for board member. She is the wife of a liver recipient. She is active in editing the newsletter, coordinating the blanket project, and serves on the holiday party committee. She is a volunteer for the Rochester Eye & Tissue Bank, Finger Lakes Donor Recovery Network, Strong Hospital, and serves on the Patient Advisory Council, Impressions Committee, and the MPAC (parking committee).

Bev Shank first time candidate is a TAO member running for the board. She is a liver recipient. Pre-transplant she worked as an Assistant Manager for ESL Federal Credit Union and was a teacher for religious education at her church. Since her transplant, she volunteers in the Transplant Clinic program at Strong Hospital and for the Rochester Eye & Tissue Bank and FLDRN. She will participate in the Annual Liver Life Walk in Washington, D.C., with her daughter in May and in a similar walk here in Rochester with family and friends this June.

Jim Fyfe first time candidate is a heart recipient and has been a TAO member since 2007. The past two years he was involved with the Heart Failure/ Heart Transplant fundraiser, And the Beat Goes On. As a recipient and donor family member he volunteers for the

Rochester Eye & Tissue Bank and Finger Lakes Donor Recovery Network. He also has ridden on the C-DOT float in the Lilac Parade.

Mike Stelljes is seeking another term on the board. He is a live donor liver recipient who served on the board as Treasurer, 2005-2007. He started the Transplant Clinic volunteer program at Strong Hospital with his wife Sally. This program has received repeated positive feedback. Mike is interested in being a more integral part of TAO's operation and decision-making process.

NEWS ABOUT VOLUNTEER PROGRAM

Late last fall I received a message from Nancy Metzler, transplant administrator at Strong. Nancy had received e-mail from a woman in Washington State asking about the volunteer program in the transplant clinic at Strong. The person who contacted Nancy had met a young woman who had been a live liver donor for her mom at Strong. During their transplant time they had had interactions with volunteers in the meet and greet program. The contact from Washington was active in the transplant community and was interested in learning how our program had gotten started.

During the ensuing months, communication has been established and information about the program has been sent to the woman. She is working with staff at their transplant center to get a similar program started for potential transplant candidates. We are very proud of our program and the group of volunteers who work the clinic each week. Let's wish the group in Washington much success as they embark on their journey.

Submitted by Sally Stelljes

United Network for Organ Sharing

Candidates listed as of 3/27/2009

| | |
|---------------|------------------------|
| 78,997 | Kidney |
| 15,764 | Liver |
| 2,786 | Heart |
| 2,276 | Kidney/Pancreas |
| 1,964 | Lung |
| 1,548 | Pancreas |
| 215 | Intestine |
| 83 | Heart/Lung |

101,224 TOTAL

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

www.unos.org

New Co-Editor for Transplant Times

The Newsletter Committee is happy to report that we've found a new co-editor! We'd like to introduce Kimberlee Blied, RN, MS, administrator UPMC Nephrology Division/ Kidney and Pancreas Transplant Programs.

She has had 12 years experience in writing and editing legal reports, business related documents and more recently transplant marketing flyers. Kimberlee will be working with the newsletter committee on this issue of the *Transplant Times* and taking the reins from there on in. We'd like to welcome Kimberlee to TAO and look forward to working with her.

Fiber

- Elizabeth Keirstead, RD, CNSD;
Transplant Nutritionist, University of Rochester

Hey, all you label readers...Did you know that:

- By checking the fiber content can make double sure you are getting products to manage your cholesterol, blood sugar and weight?
- Fiber can be a dietary element that provides multiple benefits *ESPECIALLY* for transplant recipients. Your overall nutritional habits can impact the management of hypertension, cholesterol, blood glucose, bone and muscle health.

Do I have your interest, yet?

What can you do and what information should you be looking for on food label?

- Identify Food products containing ≥ 2 grams of fiber per serving.
- Rice, pasta, breads, crackers and chips labels: just because it looks like fiber, doesn't mean it HAS high fiber content. This is especially true of highly processed grains.
- Fresh, canned or frozen fruits and vegetables can provide 2 or more grams of fiber.
- Soymilk and soy products.
- Legume (Lentils), beans, nuts and seeds.

Daily Intake Guidelines: 25-30 grams or more/day (Europeans tend to get 40 grams or more!!).

Foods that are less processed (for example, fresh vegetables) contain more fibrous materials. The downside is that we do not digest this fiber as well. The result can be gas and bloating. Many people consider these side effects as intolerance; BUT, if fiber is increased gradually, these symptoms lessen over time as your body becomes more efficient and used to processing the higher quality fiber.

Benefits:

Gastrointestinal health: Reduces the risk of colon cancer and other gastrointestinal disorders, such

as diverticular disease. Helps to regulate constipation along with proper hydration and exercise.

Heart health: Yes, the Cheerios® commercial is correct!! Lower cholesterol and triglyceride levels are achieved by entrapment of the cholesterol that your body makes. This facilitates that "good" carbohydrates can be released to lower triglycerides.

Weight loss: Adding fibrous foods tend to fill you up, lessening the chance of over portioning. If fruits and vegetables are present with all meals these tend to contain fewer calories than meats and starches. By adding more fiber to meals will stay with you longer and keep hunger at bay.

Blood Sugar Control: High fiber containing carbohydrates, known as "complex carbohydrates" are associated with better glucose control. Substituting a tennis ball size apple will provide more sustained blood sugar levels than 4 ounces of juice. In addition, apple provides more nutrients. It is okay to have juice, just not all the time. A variety of foods with more use of complex carbohydrates is the best.

Products to consider purchasing as higher fiber choices:

Many companies are updating product formulas/recipes. Educate yourself by reading the labels of the products you are currently purchasing before you switch. The following are a few examples of products to try: Dreamfield pasta®, Barilla Pasta®, whole wheat pastas, spelt pastas, Multi grain wheat thins®, Triscuits®, Kashi company® – granola bar, cereal, crackers, cookies etc., Texmati rice®, brown minute rice® (hybrid not quite a brown or white but in between), white bread with whole-wheat flour, oat-meal breads, oat-bran & wheat English muffins and breads Multi grain pretzels and tortilla chips

Got questions?? Contact: Elizabeth Keirstead, RD
CNSD University of Rochester 585-276-3516

Join a Committee

Sunshine , Newsletter, Membership, Awareness
Interested? Call
1.888.664.1463

Blankets from Home

Maria Fiorille started this project in memory of her mother Sharon, a two time liver recipient. TAO is pleased to carry on Maria's project

To date 48 blankets have been distributed to transplant recipients, candidates as well as living donors at Strong. The patients are very grateful for the gift.

TAO has been providing the fleece for the blankets. Norm and Phyllis Breen volunteered their time and made blankets. The Alpha Phi Omega fraternity at SUNY Geneseo made blankets and Get Well cards to be distributed to the patients as a community service project. Thank you to all!

We welcome monetary and material donations. The fleece should be at least one-yard quantities of a solid and coordinating pattern. Monetary donations are made out to and sent to TAO with blanket project noted. Material can be brought to meetings or contact Debbie at 377-6028.

Voice Your Choice

TAO has been surveying our members to determine their needs, wish list for future activities and programs and goals for the group, while updating our membership records. Thank you to all of you who have shared your suggestions with us.

TAO would like to offer you the opportunity to receive the TAO newsletter by e-mail. We are all trying to conserve our resources and this would save paper, printing and postage costs for the organization. We realize some people prefer the hard copy and will continue to make both options available to our members.

The Board is also considering setting up a TAO contact list with members' e-mail addresses. Confidentiality of this list will be maintained. It will NOT be shared with any other organization and will solely be used to update members about upcoming programs, site changes, educational opportunities and need for advocacy for pending legislation. We sometimes hear of events that would be of interest to members after the newsletter has been printed and email provides another avenue we could use to communicate this information.

Please contact Debbie at Auggieday@aol.com, subject: NEWSLETTER if you would like to receive newsletters by e-mail in the future, as well as if you would like to also continue to receive a hard copy. It would be helpful to indicate your choice as follows: Email ONLY, BOTH email and HARD COPY, or HARD COPY only. Secondly, please indicate your preference for having your e-mail address used for communicating TAO updates and reminders.

Would you?

If I were to ask.....

Would You help someone get back onto their feet?

Would You give food to the homeless and hungry?

Would You help an elderly person get out of a chair?

Would You?

I would hope that you didn't need to think about your answer.

Would You help your family or another family survive a natural disaster?

Would You help a total stranger who is lost and needs directions?

Would You help a child in distress or danger?

Would You help a loved one if they were in an accident?

Would You help yourself to a good and healthy life?

Would You?

I would hope you would to all of these and more.

For those should be easy to answer with a yes.

If you can answer yes to these then these next should be a breeze.

Would You help a stranger live life by giving something of yours?

Would You give your loved ones a gift from you?

Would You give your blood and maybe more?

Would You?

Would You give a final gift of life to maybe a loved one?

Would You give that gift to a total stranger who is in need and hope?

Would You give that gift that only you and God from above can give?

Would You?

I know you are wondering what this gift could be?

It is a gift that would bring happiness and set you free.

What gift you ask can do this and more?

That gift would be the ultimate gift.

A gift of life from you to me.

It's a gift of an organ.

It's so easy to do.

Just fill out a card that's all you have to do.

That ultimate gift is for you to become an Organ Donor

So I ask you once again.....

Would You?????

By - John Stapleton

Surplus Medications

Do you have medications that you're not using and don't know what to do with them?

St. Joseph's Neighborhood Center 417 South Ave Rochester (585) 325-5260 will take any medications current or expired. Please drop them off at their location for disposal.

Save The Dates

Donate Flag Raising Ceremony Tuesday, April 21. to recognize Strong Memorial's organ, eye and tissue donors. Meet at 10:30 am at the Crittenden Road main entrance. All are welcome to attend. Reception following with light refreshments. Please contact Karen Guarino at 272-7890 or kguaino@rehepb.com.

Lilac Parade: Saturday May 9th from 9 am to 12 noon. Contact Karen Guarino at 272-7890 or kguaino@rehepb.com. if interested in riding on the float.

"And The Beat Goes On..." Saturday June 13:

This annual fundraiser dinner will be at the Doubletree Hotel, Rochester, NY.

The event benefits the Harbor House, a home for transplant patients and their families, while their loved ones are in the hospital waiting for or recovering from a transplant. The house is scheduled to open this spring. For information and tickets contact 473-1779 or www.harborhouseofrochester.org.

Time: 6:00 pm

Cost: \$40.00 per person/\$400 per table.

Annual TAO Picnic

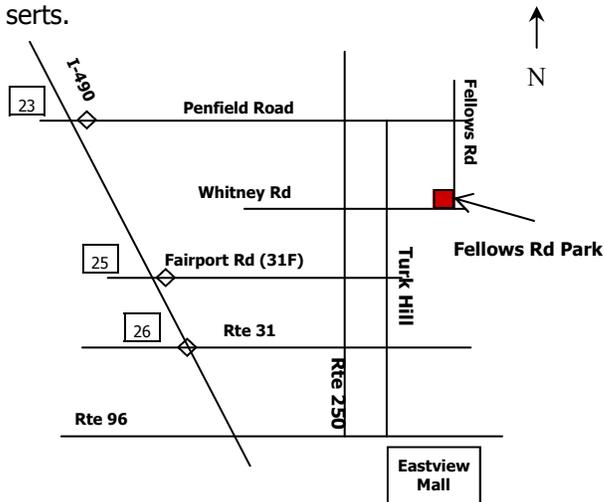


The annual TAO Picnic will be held on **Wednesday June 17** at **Fellows Road Park**, Fairport, NY (enclosed shelter)

Donation of \$5 per person with children under 8 free.

Make your reservations by June 10 by sending a check to TAO, PO Box ,Rochester, NY 14692-3552 or by emailing auggieday@aol.com, subject: picnic.

TAO will supply the drinks (soda/water) and desserts.



Casino Trip



Come join us on **Saturday June 27** for a day of fun & excitement at the Seneca Casino in Niagara Falls, NY. We will be departing at 8:00 AM from the Bushnell's Basin Park and Ride. At 4:00 PM we will depart Seneca Casino and return around 6:00 PM. \$45 includes transportation, bus driver's tip, \$20 in casino dollars, and a \$5 food voucher. Hurry and make your reservation by May 15 with check payable to TAO at: P.O. Box 23552, Rochester, NY 14692-3552

We can accommodate 40-50 people. Tell your friends and families too!

Coming soon!

TAO lapel pins! Shirts! Awareness bracelets! We will have TAO merchandise available at upcoming meetings. Currently we have t-shirts. The pins are in the works. Donations are accepted.

TAO Wish List

- Folders with the 2 pockets (any color)
- Pens
- Pads of paper that will fit in 2 pocket folder
- STAPLES gift cards to buy labels, etc.
- Fleece - 1 yd. quantities, plain & patterned to match
- Joann Fabric gift cards
- LCD Projector
- Get well, sympathy, thinking of you greeting cards for Sunshine Club

United Way

TAO has received an acknowledgement from the United Way approving TAO as a "donor designation eligible agency for the United Way campaign". This will go into effect with the upcoming fall United Way campaign.

The organization name is Transplant Awareness Organization and our agency number is **2493**.

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

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

Financial:

Linda Hicks
Alman Gilman
Louis & Rita Mascaro
John Wood

In Kind:

Greg Post
Kathleen McCaffery

WELCOME New Member

A warm TAO welcome to Geraldine Mondri. Geri awaits a liver transplant; she is not listed at the moment but knows it's in her future. After her initial visit to URM where she picked up a copy of the Transplant Times and met Richard Perez in clinic, she sent her application in. Geri and her husband Anthony reside in Niagara Falls, NY, where they've raised two children during their 39 year marriage. Their daughter Christina currently resides in Tampa, FL, with her husband and two sons. Austin 11 and Jared 6. They are the apple of their grandma's eye. Geri works at the City Hall of Niagara Falls as the administrative assistant to the City Council, while Anthony is the manger of security at the Seneca Casino. We may put him to the test if TAO sponsors a trip there! Geri is the oldest of 10 children and she and Anthony reside in her childhood home. The 100 year old house keeps them busy with renovations. Geri is now the "matriarch" of the family the home is still the core for the family. Geri also serves as the secretary to the Tourism Board of Niagara Falls, which has roaming meetings in order to promote the local spots. With working full time, family being number one and renovating the house, Geri still finds time to garden. She joined TAO to alleviate her fear of transplant. Please welcome Geri and Anthony and offer support for their long journey ahead.

Transplant Anniversaries

| | | | |
|------------------|--------|--------|------|
| Ernst Baier | Kidney | May | 2000 |
| Patricia Bianchi | Liver | May | 2002 |
| Norman Breen | Heart | May | 2007 |
| Amber Castle | Kidney | May | 1999 |
| Roger Duryea | Kidney | May | 1995 |
| Bonnie Patten | Liver | May | 1995 |
| Barbara Robida | Liver | May | 2002 |
| Phil Sinaguglia | Kidney | May | 2004 |
| Nancy Thompson | Liver | May | 1993 |
| Robert Alves | Liver | June | 2004 |
| Bernice Eblovi | Liver | June | 2002 |
| James Fyfe | Heart | June | 2006 |
| Karen Lee Sommer | Liver | June | 2006 |
| Mike Yendzieski | Liver | June | 2002 |
| Rick Clark | Kidney | July | 2004 |
| Cindy Deshane | Liver | July | 2005 |
| Bonnie Gottorff | Kidney | July | 2005 |
| Richard Perez | Liver | July | 2003 |
| Joanne Tucker | Liver | July | 2006 |
| Giulio Verde | Heart | July | 1998 |
| Lisa Faucz | Kidney | August | 2008 |
| Moirra Miller | Liver | August | 2005 |
| Rebecca Snyder | Heart | August | 1998 |
| David Spiro | Liver | August | 1997 |

A special celebration of life and love

- By Denise M. Champagne Fairport-East Rochester Post (*edited*)

Louis Mascaro of Perinton and his son each have one functioning kidney. They're both Marc's.

Marc was 19 when he donated a kidney to his ailing father, whose health was deteriorating from a progressive renal disease he'd inherited from his father, Nate.

That was 30 years ago, and Marc, who works for a software company in South Carolina, returned home recently so the family could celebrate the anniversary together. That included dinner at Rocky's in Rochester, one of their favorite restaurants, with Marc's mother, Rita, brother Anthony and his wife and son of Irondequoit, and uncle Lee and aunt Rosemary Austin of Addison, Steuben County.

"A number of times over the weekend, we were commenting on how 30 years is really amazing for a transplant and just what a special time it was that we were able to share together," Marc said. It's a milestone worth celebrating. "Organ transplantation saves lives," said Marc. "I think those miracles happen every day when surgeons transplant organs into people that need them."

Wishes of Wellness To...

"Our healing thoughts go out to Jerry Runion, our president, feel better soon!"

Let us all keep those listed in our thoughts as each continues to recuperate and offer support as needed.

Our Condolences ...

Our sympathies go out to Larry & Joanne Tucker on the death of Larry's mother.

Our sympathies go out to Ray Lyman on the passing of his son, Scot.

If you are aware of members that we should list in *Wishes of Wellness*, or to express our condolences to, please call TAO and leave a message at 1-888-664-1463.

Guest Speakers



Steven Wittlin M.D., Endocrinologist, spoke at the February 18 meeting about diabetes and the transplant patient.



Susan Hartfield, Pharmacologist, spoke at the March 18 meeting about outpatient pharmacology program for the transplant patient.

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

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.

POP TABS: Yes we are still collecting aluminum can tabs. At the present time we are giving the money to Harbor House in an effort to help a gentleman attain his goal of saving a "ton of tabs" for the house. If you have any tabs bring them to the meetings or call Linda Barnard at 585-227-2887 to make arrangements for her to collect them. Thank you in advance.

Transplant Times

Deadline

For:
September/ October
issue:

Monday, August 3

Submit

Articles /ideas email to:
auggieday@aol.com or
kblied333@gmail.com
or send by mail to:

TAO
PO Box 23552
Rochester, NY
14692-3552

Board of Directors & Officers

President

Jerry Runion
jgruion@rochester.rr.com
(585) 733-3422

Vice President

Sandy McNitt
sdmcnittot@aol.com
(585) 359-8015

Treasurer

Dave Johnson

Secretary

(to be elected)

Board Members:

| | |
|------------------|-------------------|
| Linda Barnard | Janice Odenbach |
| Karen Guarino | Rob Kochik |
| Bonnie Haefner | Joanne Schum |
| Linda Hicks | Sally Stelljes |
| Karen McCissock | Dennis Stenshorn |
| Katherine Norway | Debbie Yendrzeski |

TAO www.tao-rochester.org

**G
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S**

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.



Return service requested

PO Box 23552
Rochester, NY
14692-3552

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or you would like to be removed
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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

- checkbox New Member checkbox Renewal checkbox \$10 Family checkbox \$10 Institutional
checkbox unable to make dues payment at this time Date _____

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 _____

- checkbox Candidate checkbox Recipient checkbox Family Member checkbox Donor Family checkbox Friend checkbox Professional

Candidate/Recipient information: # of Transplants _____ Hospital _____

Date(s) _____ Organ(s)/Tissue(s) _____