



Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

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

September / October 2011

www.tao-rochester.org

1.888.664.1463

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Membership Meeting Guest Speakers / Topics

September 19, 2011

Elizabeth Kierstead
Transplant Nutrition Specialist

October 17, 2011

Susan Hartfield
*Pharmacist
Generic Medications*

TAO Meets

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

A Message from the President



It's hard to believe that Fall will soon be upon us and with it the new season for TAO membership meetings. For each of you, I hope the summer sunshine has brought with it time spent with family and friends, and plenty of good memories to take into the Fall and Winter.

Our line up of speakers for the Fall membership meetings is still being finalized as this newsletter goes to press. We are working on bringing to you a number of interesting topics. I recommend that you check our website <http://www.tao-rochester.org> periodically for updates on upcoming talks. At the same time, I will make sure that in the week before each of our meetings we send out meeting reminders to those members for whom we have an email address with information on the speakers. Meetings will continue on the same schedule with which we began the year, namely the third Monday of the month at 7:00 pm at Christ Episcopal Church in the village of Pittsford. If you haven't attended a meeting there previously, more information is available on the website.

As a transplant recipient myself, I have found that one of the most valuable benefits of participating in TAO is having an opportunity to talk to other recipients. In my case, the ability to discuss common experiences with other recipients, and to understand how those individuals have successfully dealt with challenges similar to my own has been very helpful. The membership meetings, with a relaxed atmosphere in which to socialize with others, play a very useful role in this regard. So, whether you are a recipient already, hoping to become a

candidate for a transplant, or a caregiver, I encourage you to come to one of our membership meetings to meet with others who may be sources of valuable help and encouragement. The old saying "Walk a mile in my shoes" applies very well to the transplant experience. It is very difficult for those who have not been through the reality, either of waiting for a transplant, or ultimately becoming a recipient, to truly understand the challenges one faces. TAO meetings provide an excellent venue to meet people who have already "walked that mile".

If you are already a regular at our meetings, we look forward to seeing you again at our first meeting of the season on September 20. If you have never attended a TAO meeting before, I invite you to join us and see if TAO has something to offer that would be helpful to you.

Finally, I want to share the results of the May board elections with you. I am pleased to report that Bonnie Haefner and Debbie Yendzkeski, who held the two expiring seats on the board, were reelected. In addition, the two open board seats which resulted from resignations earlier in 2010, have been filled by Kathy Wesline and Matt Felo.

Continued on page 2

A Message from the President (continued)

Both Kathy and Matt are lung transplant recipients and will be great additions to our board, bringing a variety of skills and volunteer experience with them. My sincere thanks goes to the board for volunteering their time and talent to enable TAO to continue the good work that the organization does in our transplant community.

I look forward to seeing you on September 19.

Geoff Foley

Estate gifts will benefit Nonprofits

(Reprint from Democrat and Chronicle June 9, 2011)

The Rochester region has a reputation for being one of the most giving in the country, but that could change in coming years as baby boomers and younger people move away.

A study commissioned by the Rochester Area Community Foundation shows that an estimated 42 percent of the area's wealth will be passed down in future years. The estimated wealth of the nine-county region is an eye-popping \$80 billion, and foundation leaders are rightly worried that much of that could leave with the heirs, never benefitting the communities in which it was earned.

Foundation leaders fortunately are urging citizens to think about setting aside a small portion of their estates for the causes and charities they love now and want to make sure live on in perpetuity. This isn't about millionaires with large portfolios, either. People with much more modest assets have many options, such as donating a life insurance policy, stocks or a home. Such gifts are also a great way to honor a loved one. For example, Bertha Simpkins of Irondequoit and her mother have made plans to help children and education in honor of Simpkins' father, a deceased minister.

Undoubtedly there are many others with the potential to emulate the Simpkinses. Nonprofits, especially struggling ones, need to think beyond the short term. The numbers offer a compelling reason. Just a 5 percent transfer of wealth to charities could generate \$1.7 billion by 2030. That's no small chunk of change. Nonprofits should seize this message and reach out to current patrons, educating them about the options.

Such conversations today can lead to a more secure tomorrow.

Proceeds from July 9 Z Car Show Benefits TAO

By Rob Kochik

Question: What does a Mini Cooper Convertible and more than 125 other import cars have in common?

Answer: They all participated in the 4th Annual Jonathan Krenzer Memorial All Import Car Show Weekend that was held on July 8 -10 at the Webster-Fairport Elks Lodge sponsored by the Z Car Club of Rochester!



On Saturday, July 9 I had the pleasure of entering my new Mini Cooper Convertible in the All Import Car Show. This was first time I ever entered a car show and I wasn't sure what to expect, but since I knew that some of the proceeds of this event would benefit TAO and give us another opportunity to show the benefits of organ, eye and tissue donation. I was more than happy to attend!

During the show, we all had the pleasure of seeing all different types of import cars and trucks – some old, and some brand new! I also had the opportunity to talk with some organ transplant recipients and at least one gentleman who will likely need a liver transplant sometime in the future.

Kathy Wesline and Bev Shank helped provide information at the donor awareness table. Geoff Foley, TAO President, happily accepted a check in the amount of \$2500 that Mike Noonan presented that was donated to TAO.

On Sunday, July 10, more than 40 import car enthusiasts took a scenic drive to Watkins Glen and then drove three laps on the famous race track. Talk about a thrill! I look forward to participating again next year!

Board of Directors & Officers

President

Geoff Foley

GeoffF21@yahoo.com

Vice President

Debbie Yendrzkeski

Treasurer

Kathy Wesline

Secretary

Bev Shank

Linda Barnard

Norman Breen

Matt Felo

Karen Guarino

Bonnie Haefner

Rob Kochik

Janice Odenbach

Karen Porterfield

Jerry Runion

Kathy Wesline

Maplewood Rose Garden Revitalized: Honors Organ & Tissue Donors, their families and recipients

The rose garden bed that was originally planted and dedicated to honor all donors, their families and transplant recipients in 1998 by TRIO, Rochester Chapter (now TAO) is being revitalized. Over the years the original rose plantings died or were removed. Upon learning of this, TAO board members moved to reinstate the garden as it was originally intended - a place for reflection and remembrance.

VanPutte Gardens donated three rose bushes to TAO and are now planted in the new memorial bed in Maplewood Park. The Rochester Gynecologic and Obstetric Associates, PC donated monies to TAO for the purchase of five rose bushes. We're happy to see the bed flowering once again. The City of Rochester is providing signage and will be transplanting other rose bushes. The location of the new garden is left of the gazebo and is in the shape of a boomerang. A ribbon cutting ceremony is being planned for the future, so stay tuned for more information on this event.



Garden Center • Landscaping • (585) 225-7770
136 North Ave., Rochester, NY 14626



United Network for Organ Sharing

Candidates listed as of 8/16/2011

89,421	Kidney
16,121	Liver
3,185	Heart
2,137	Kidney/Pancreas
1,732	Lung
1,355	Pancreas
252	Intestine
69	Heart/Lung

111,804 **TOTAL**

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

www.unos.org

Transplant Anniversaries

John Odell	Liver	July, 2010
Lisa Faucz	Kidney	August, 2008
Tom Fuoco	Heart	August, 2008
Moira Miller	Liver	August, 2005
Rebecca Snyder	Heart	August, 1998
David Spiro	Liver	August, 1997
Lisa Abbey	Heart	September, 2008
Tom Arcara	Heart	September, 2005
Marianne Benvenuti	Liver	September, 2006
Phillip Ronzo	Liver	September, 2007
Joanne Schum	Double lung	September, 1997
Ivan Tzoontchev	Kidney	September, 2000
Debbie Vernam	Kidney	September, 2004
Novalie Nguyen	Heart	September, 2010
Susan Bennett	Kidney	October, 1998
Bernard Blocchi	Liver	October, 1996
Bob Legge	Kidney	October, 2009
Claudia Ciresi	Liver	October, 1994
Ronald Goehle	Liver	October, 2001
Michelle Halloran	Kidney	October, 1997
Jim Hey	Kidney	October, 2001
Dave Johnson	Liver	October, 2000
Dennis Kovel	Kidney	October, 2001
Suzanne McNamara	Heart	October, 1993
Thomas Murphy	Liver	October, 2009
Keith Oliver	Liver	October, 2002
Carrie Rodriguez	Kidney/Pancreas	October, 2005
Mary Stein	Liver	October, 2005
Carol Weinlander	Kidney	October, 2001

Transplant Times

Submission Deadline

For November/ December 2011
issue:

Monday, October 3, 2011

Articles /ideas email to:

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

The WISE Shopper



*Elizabeth Keirstead RD, CNSD
Transplant Nutrition Specialist
University of Rochester Medical Center*

You may have noticed some new products in the nutritional supplement aisle of your local store. Abbott Nutrition® has expanded their Ensure® product line.

I would like to take a moment and point out the differences, since some could impact transplant recipients or people with reduced kidney function.

Two of the new products called Ensure Muscle Health® and Ensure Clinical Strength® contain Revigor ®(CaHMB, calcium β-hydroxy-β-methylbutyrate) a protein claimed to maintain and rebuild lean body mass, (although more research studies are needed to confirm). There are two other important concerns. First, anyone taking Rapamune (Sirolimus)®, an immunosuppressant medication, there is a concern for a potential food-drug interaction. Secondly, due to Potassium needed for preservation increases the Potassium content to 840 mg per 8 oz. serving = to 2 bananas. Ensure Bone Health® also contains a higher amount of Potassium and Sodium. The following table lists some of the nutritional information for you to compare. I always urge consumers to pay attention to food labels and understand your dietary restrictions. Please contact your physician or Registered Dietitian for questions/concerns.

Product	Calories	Protein grams	Carb. grams	Sodium mg	Potassium mg	Phosphorus mg
Ensure®	250	9	40	200	370	250
Ensure® Immune Health	250	9	42	200	370	250
Ensure® Muscle Health	250	13	32	240	840	350
Ensure® Clinical Strength	350	13	51	240	840	350
Ensure® Bone Health	220	10	31	290	500	250
Ensure® Plus	350	13	51	220	420	300

TAO Membership dues
are now due for the upcoming year.
Your membership dues are used for funding
support initiatives and social activities of TAO.

END OF YEAR PICNIC : GOOD FOOD, GOOD WEATHER, GOOD TURNOUT

Our end of the year picnic was loads of fun. WhatchaGot Cookin' catered the event under sunny skies. Marcia & Dave Johnson's Texas Caviar was a hit and they have shared the recipe with us. The sweets table was astounding! Rob & Carole Kochik's fudge was gobbled up! Transplant recipient members and their families, the TAO board and their families enjoyed a lovely evening at the Carmen Lodge in Brighton. It was a "sweet" ending to the year and a nice start to summer. If you couldn't join us this year please save the date for next June.

Texas Caviar

1 14-16 oz. can black eyed peas
 1 14-16 oz. can black beans
 1 14-16oz. can shoepeg corn
 1 jar pimentos
 1 jar chopped jalapeno peppers
 1 chopped red onion
 2 stalks celery, chopped
 ½ cup vegetable oil
 ¼ cup cider vinegar
 ¼ cup sugar
 Adobo seasoning to taste (start with 1 tbsp)
 Pour all cans/jars into a colander, rinse and drain. Add onions and celery. Heat oil, vinegar and sugar until sugar dissolves. Pour mixture over beans and marinate overnight. Drain and serve with chips. (scoops work great!)

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.

United Way Reminder:

TAO is recognized as a "donor designation eligible agency for the United Way campaign" Our agency number is 2493.



United Way
of Greater Rochester



2010 Annual Report

Charge: TAO is a group of transplant recipients, candidates, their families and professionals which provides support, education and awareness regarding organ and tissue transplantation.

Board Member Names:

Jerry Runion
Sandy McNitt
Linda Barnard
Norm Breen
Geoff Foley

Jim Fyfe
Karen Guarino
Bonnie Haefner
Linda Hicks
Dave Johnson

Rob Kochik
Kate Norway
Janice Odenbach
Bev Shank
Mike Stelljes

Sally Stelljes
Dennis Stenshorn
Debbie Yendrzeski

Membership:

TAO Membership consists of 200 families, recipients, professionals, caregivers and friends throughout the United States. Membership meetings and Organ specific groups provide avenues of support to the community.

Financials

TAO is financially supported by membership dues, donations, memorials and fundraising. This enables TAO to provide support to needs as they arise. A complete financial report is available upon request.

Accomplishments:

New format for newsletter, increased distribution of newsletter, Strategic Planning Workshop

Social Events:

Holiday Recognition Dinner, Picnic

Fundraising, Contributions and Memorials:

- 3 DVD Players donated to 7-3400 Cardiac Transplant Floor in memory of Jim Fyfe
- River Run
- Harbor House
- Transplant Games
- Gift Wrapping
- Sales of scarfs, shirts and bracelets
- Tops cards
- Pop tabs

Financial Donations and Remembrances

Fred & Josephine Altrieth
Catherine B. Anderson
Michael & Cynthia Apostolakos
Ernst Baier
Linda Barnard
Ms. Elouise Beardsley
Patricia Bernhard
Patricia & Leo Bianchi & Family
Robert & Carol Bradshaw
Norm & Phyllis Breen
Gertrude B. Brown
Jeanne M. Charles
Mark & Karen Coons
Helen & David Cox
Sheila R. Cutler
Duane & Barbara Czajka
Linda F. Daniele
Diane Davidson
Peter Davis
Donald Sr. & Helen Dobesh
Bonnie Edelstein
William Jr. & Judith Embury
Brian Emelson

James & Julia Falzone
Lisa Faucz
Ann Finger
Geoff Foley
Friends of the Henrietta Public Library
Kenneth S. Fyfe
The GAP
Alma Gilman
Mrs. Cynthia H. Gilman
Tony & Karen Gledhill
Michael & Marlene Goho
James Graczyk
David & Anne Greer
Vincent J. Grillo
Shawn Haarer
Bonnie Haefner
Michael & Diane Hammill
Heart Research Follow Up Program- URM
John & Jerilyn Heller
Ms. Barbara Hilton
James & Carol Huff

IBEW, Local 139, Elmira, NY
Frank & Priscilla Imburgia
Janet L. Juneau
Rick Juskiewicz
Mr. & Mrs. Michael W. Kilroy
Rob Kochik
Dennis & Eileen Kovel
Linda M. Langer
Louis A. Latorre
Patricia Legge
Charles M. Lundeen
Louis J. Mascaro
William J. Mather, Sr.
Kathleen McCaffery
Marian McHargue
Janet McNally
Richard & Suzanne McNamara
Dave & Rosemary McNitt
Leonard & Delores Metzger
Lynn L. Neill
Joseph A. Nolan
Janice Odenbach
The Estate of Chester Palozzi

Thomas O. Pandick
Powder Mills Park Garden Club
Robert & Shirley Rheinwald
Jorge & Frances Ricaurte, MD
Vincent & Rosanne Rosella
Judy Rosenberg
Joanne Rourke
Jerry Runion
Gary & Alan Schaeffer
Elizabeth A. Schenk
John Schroth Jr.
JoAnne Schum
Mr. & Mrs. Floyd Schutt
James & Susan Selvek
William Jr. & Adelaide Setek
Edward & Elaine Short
The Shufflebarger Family
David Spiro
June & Bart Spratt
Carolyn St. James
Ms. Sharon A. Steacy
Mary Stein
Marilyn L. Stottile (*continued*)

2010 Annual Report Donations (continued from page 6)

Scott & Deborah Strong
 Mike Swete
 Mrs. Priscilla J. Swing
 John & Christine Treahy
 Shirley Tuites
 Gene & Nancy Tunney
 Ultra Electronics
 Dennis & Carol Wittman
 John & Katherine Zachman

Loan Cupboard

Are you in need of a pulseometer or oxygen pull carriers? The McNitts have graciously donated their daughter's (Sandy) gently used equipment to TAO. We are starting a "loan cupboard", if you have items to donate or are in need of certain items contact TAO @ 1-800-664-1463

Looking for a way to help families of people waiting for transplants?

7-3400, the cardiac unit for transplant patients is looking for a subscription to Highlights Magazine for the children of candidates when they visit their parent. This donation would be greatly appreciated.

Wishes of Wellness To...

Our healing thoughts and prayers go out to Jerry Runion, Diane Bluff, Bernice Eblovi, MaryAnne Scroger, Linda Barnard, Geoff Foley and Kathy and Jack Wesline



Our Sympathies To...

Richard Perez on the passing of his mother.
 Jerry Runion on the passing of his mother.

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.***

Rochester Gynecologic and Obstetric Associates, PC

In Kind:

Van Putte Gardens
 Matt Felo
 Debbie and Mike Yendrzkeski

Save The Date . . .

TAO Organ Specific Support Groups

"OPEN AIRWAYS" - Lung Gathering

Monday, August 22 - NOON - Aladdin's Pittsford - 8 Schoen Place (indoor or outdoor dining, walk the cute village of Pittsford, check out some historic homes)

Wednesday, September 14 - NOON - Aladdin's Pittsford - 8 Schoen Place (indoor or outdoor dining).

Wednesday, October 5 - NOON - Aladdin's Pittsford - 8 Schoen Place (indoor or outdoor dining, Lots of history and places to walk in the village!)

Call or email Joanne if interested: 671-7635
 twoluckylungs@juno.com

The Liver Lunch Bunch

For the Liver Lunch Bunch times and dates, contact Bernice Eblovi at (585) 421-0531.

Mark Your Calendar

Attention all organ, eye, tissue and bone marrow transplant recipients

You are invited to participate in the first ever *Virginia Transplant Games!* The games, presented by Donate Life Virginia, will be held on **October 1, 2011** in Richmond, VA.

Transplant recipients from all over the state will be competing for gold in events such as 3 on 3 basketball, softball throw, discus, various swimming and running events...and much more! If you are not a recipient, but want to participate, join us for the 5K run which is open to everyone!

Registration for all events is currently open at www.VirginiaTransplantGames.org. While there, don't forget to sign up for free tickets to cheer on Virginia's transplant recipients!

You can also stay up to date on the Virginia Transplant Games and connect with other participants on Facebook at: www.facebook.com/VATransplantGames

For more information, contact:
info@virginiatransplantgames.org or 804-521-1921.

Thank You

TAO wishes to thank Dave Johnson for his nine years of dedication to the TAO Board as Vice President, President and Treasurer. Dave has decided to step down so he can enjoy more time in Florida in his new condo. We wish him well, thank him for all he's done and hope to see him at future meetings.



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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)