

Transplant Times

NEWSLETTER OF THE TRANSPLANT AWARENESS ORGANIZATION OF GREATER ROCHESTER



May/June/July/August 2008

www.tao-rochester.org

1-888-664-1463

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Transplant Times Co-Editors:

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Shelley Whitney: whitney618@aol.com

Newsletter Deadline August 20th 2008 for the September/October newsletter

- MEMBERSHIP MEETINGS -

Meetings are on the 3rd Wednesday of the month from 7:00 - 9:00 p.m.

Pinnacle Lutheran Church, located at 250 Pinnacle Road corner of Stone Rd.

Go south on Winton Rd. from Jefferson. Winton becomes Pinnacle. Take Pinnacle to the light at Stone Road, turn left, the parking lot is behind the church. Use the Office entrance.

Upcoming Meeting Topics

May 21

Dr. Richard Demme, Ethical Issues in Transplantation. Dr. Demme is Associate Professor of Medicine and Humanities at the University of Rochester Medical Center. He is chair of the Strong Health Ethics Committee, sits on the Transplant Quality Council and is a member of the Independent Donor Advocate Team for the Living Donor Liver Transplant Program. Dr. Demme is a nephrologist who works with dialysis as well as kidney transplant patients.

We would like to hear from you. Our speaker for May would like to focus their presentation on our questions and concerns. Please contact Dennis, TAO president at dstensh1@rochester.rr.com or 585-323-1392. We want these meetings to give you the information you need. Hope to see you there.

June 18

End of the year party!!! Location will be at Bonnie Haefner's home - 20 Wood Acre Drive, Pittsford, New York 14534 334-7034 More information and directions will be available at the May 21st membership meeting. Any questions, contact any of the board members. Thank you Bonnie for opening your home to us.

ELECTIONS – MAY 21, 2008

There is three officer positions available – president, vice president and secretary. Also a board member position. If you are interested in learning more about these positions you can ask any of the present board members or the committee volunteers.

Slate of candidates running: Jerry Runion, Linda Barnard, Kate Norway, Karen McCissock, Shelley Whitney & Dennis Stenshorn.

Short description of the positions:

***President** – preside and conduct all meetings of the board and membership meetings.

***Vice President** – perform the duties of the president when the president is absent.

***Secretary** – act as secretary at all board & membership meetings, and type up the minutes of all the meetings.

The board and membership meetings meet every 3rd Wednesday of the month – September through June. If interested contact: Shelley Whitney(whitney618@aol.com 334-8267) or Dennis Stenshorn (dstensh1@rochester.rr.com 323-1392)

TRANSPLANT ANNIVERSARIES – May, June, July & August

Richard Orczyk – 05-23-91 Heart
Nancy Thompson – 05-18-93 Liver
Joseph Yahn – 08-27-94 Heart
Roger Duryea – 05-01-95 Kidney
Shelley Stone – 06-05-95 Lung
Phillip Ronzo – 07-19-96 Liver
David Spiro -- 08-01-97 Liver
Donna Christy – 08-05-00 Liver
Otto Schuster – 06-23-01 Liver
Patricia Bianchi – 05-16-02 Liver
James Blake – 07-24-04 Liver
Kevin McCorry – 06-11-04 Bone Marrow
Phil Sinaguglia – 05-04-04 Kidney
Barbara Robida – 05-18-02 Liver
Patricia Terra – 05-20-02 Liver

Mike Yendrzkeski – 05-25-02 & 06-09-02 Liver
Moira Miller – 08-17-05 Liver
Bernice Eblövi – 06-27-02 Liver
Shelley Whitney – 05-09-03 Lung
Joseph Logalbo – 06-07-03 Kidney
James Fyfe – 06-12-06 Heart
Karen Lee Sommer – 06-27-06 Liver
Joanne Tucker – 07-01-06 Liver
Ralph Toscano – 03-01-89 & 06-01-90 Cornea
David Watts – 08-30-90 Kidney
Bonnie Patten – 05-21-95 Liver
Giulio Verde – 07-30-98 Heart
Ethel Jean Schrader – 06-15-02 Liver

**Congratulations! Did we miss yours? Get your date wrong? If so, please let the editor know!
(Note: This list is members only)**

GIFT IDEAS

A contribution to TAO in honor of or in memory of a loved one, a special person or a relative is always a thoughtful gift idea. It is a gift of caring that you can give on any occasion - a birthday, an anniversary or a special holiday. Send your check, made out to TAO, Transplant Awareness Organization of Greater Rochester, PO Box 23552, Rochester, NY 14692-3552

DONATIONS

Donations were received from: Kate Norway
Dennis & Carol Wittman in memory of Adolph "Jack" Chmielowiec

Keeping in Touch

New Members: Karen McKissock

TOPS NEVER STOPS.....Helping TAO Raise Money - The Tops Gift Card Program allows our non-profit organization to earn a 5% return by selling Tops Cards. The more we sell, the more we earn. The cards are available in denominations of \$25, \$50 and \$100. Cards are available at membership meetings or you can contact Karen Gledhill (kgledhill@rochester.rr.com).

Transplant & Organ/tissue donation events

And the beat goes on heart transplant fundraiser will be held on Saturday, June 14, at the Double Tree Hotel on Jefferson Road. The event begins at 6:00 PM with a large raffle and silent auction. There will be a sit down dinner (as opposed to the buffet the past 2 years) and there will be two live bands for dancing. There will also be speakers including doctors from SMH. The tickets are \$35 each. This year's theme is "100 heart transplants and still going strong". For more information you can call Susan Sullivan at Friends of Strong number 585-275-2420 or Christine Arcara 349-0686.

The Seventh Annual Rochester River Run/Walk 5K fundraiser will be held on Saturday, August 16 at Genesee Valley Park. Pre-registration is \$15 and \$20 the day of the event. Prizes will be offered to runners in various age groups and to the top 2 pledge collectors. All proceed benefit the transplant program.

For more information contact the Friends of Strong at 585-275-2420 or FOS@urmc.rochester.edu.

THE LONG WAIT FOR A KIDNEY

74,489 People nationally wait for a kidney; locally the number is 277

For the second time in their life, Jerry Runion and Laura Packard have reached a difficult conclusion in order to live, somebody else has to die.

Runion and Packard are both awaiting a second kidney transplant.

“They tell me that it would be my best bet to get a living donor. As of right now, I don’t have a living donor to donate to me,” said Packard, 41, of Macedon. “I know it sounds mean, but obviously somebody has to die for me to get a donor kidney from a cadaver.”

“I’ve always thought about, and so when the holidays come around, New Year’s, Christmas, Easter and Fourth of July, and unfortunately, accidents happen, this might be the time. It’s not a very nice thought, but unfortunately, if you ask a lot of transplant patients or people that are waiting and you will hear the same response.

Packard, who is diabetic, received her first kidney transplant in 1991 after experiencing kidney failure during the birth of her first son, Brandon. That kidney lasted for nine years before failing. She has been on the waiting list for eight years.

Runion also has diabetes. He got a transplant in 1994. That kidney worked for him until six months ago. He was approved for the waiting list three months ago.

“Most people that get donor transplants have gotten from people that have passed away. The families that approved their bodies for use are called donor families and they are revered like gods within the transplant community. “Because they are true heroes” said Runion of Farmington. “A lot of people don’t think too much about it, but both times I’ve been on the list now, I get an overwhelming sadness that for be to get better, someone has to die unless someone comes up to donate a kidney to me.”

“That happens more frequently now than in the past, but not enough to make a dent in that number.”

The number to which Runion refers to is 74,489, the number of people on national waiting list as of Feb. 8, according to the Organ Procurement and Transplant Network.

The list at Strong Memorial Hospital in Rochester, the only hospital in the region to perform kidney transplant, has reached 277 patients.

Runion waited 13 months for his first transplant. Packard waited only two weeks for her first transplant, but did not decide to get on the list the first time until getting dialysis treatment for a year.

“I came back home on the day before Easter and life was just what I considered normal,” Packard said of her first transplant “I wasn’t tired, I could be-a mom and not have to worry about doing dialysis on a daily basis. I could do whatever I wanted to do.”

Packard became a mom again after her transplant, giving birth to a daughter, Amanda. She continues to work at Preferred Care.

Runion became a father after his transplant, witnessing the birth of his son, Mason, now 7. He worked 50 hours at Kodak, but is now on disability after his second kidney failure.

“Kidney disease took a lot away from me, but on the flipside, I got a lot of gifts,” said Runion. “15 year old is graduating from high school and I got to see him get his master’s degree and give me three beautiful grandchildren, I wouldn’t have got to see that if it weren’t for dialysis and the transplant. My second wife, (Melanie) and I were finally able to have a baby. We have a little boy with Down’s Syndrome and he is God’s gift to us.”

Packard and Runion both go through dialysis, but with different methods. Packard has a machine at home the she uses once a day and also filters her blood while she sleeps. Runion is treated three days a week at the Finger Lakes Dialysis Center in Farmington.

“One thing I can say is that when I talk to new kidney patients and people on the transplant list, is that at least with kidney disease there is a bridge treatment,” said Runion about dialysis.

Runion keeps going through his second stretch of dialysis treatments by educating people about kidney disease and organ transplants. He is a board member of the Transplant Awareness Organization and speaks at schools and businesses about organ donation. Runion also helps raise funds for the Finger Lakes Organ Recovery Network and the Rochester Eye and Human Tissue Bank.

“It’s my way of paying back. I have no idea whether I’m on the plus or minus side of the ledger sheet,” said Runion. “My guess is I’ve helped a lot of people and I am not going to stop.” Runion credits his wife for her support.

Packard has a husband named Doug, whom she relies on for support. She hopes that other families can take time to talk about organ donation.

“I know people have been told to sign the back of their driver license to be an organ donor. My thought to that is go ahead, but the best thing to do is sit down and talk to your family,” said Packard. “When there is a car accident or whatever happens, they don’t go looking for a license, they are going to ask your family and if your family doesn’t know your wishes they won’t know what to say, but if they know, they will go by what the family says.

“Sit down with your family and have a conversation about it.”

March 2008 Article In Good Health – Rochester/Genesee Valley Healthcare Newspaper

LILAC FESTIVAL PARADE

Saturday, May 10 is the annual Lilac Festival Parade and C-DOT will be participating.

Those transplant recipients and donor families who wish to ride in this year's parade, please let me know before May 6.

Total time commitment is 9:30 am to 12 noon.

I do not have final parking details or parade location, but will let you know as soon as I do.

At this time, we need to know who will want to ride on the float, the type of transplant you had and the year you had it.

**Thanks,
Karen Guarino
585-272-7890**

TAO–Rochester Board of Directors 2007/2008

Name	Phone	Email	Office	Term Exp.
Karen Gledhill	586-9252	kgledhill@rochester.rr.com	Vice President	2008
Karen Guarino	272-7890	kguarino@rehpb.org	Rep. Rochester Eye and Tissue Bank	
Bonnie Haefner	334-7034		Board Member	2009
Linda Hicks	275-8306	linda_hicks@urmc.rochester.edu	Rep. Dept. of Transplantation, SMH	
David Johnson	889-1346	davejohn@rochester.rr.com	Treasurer	2009
Sandy McNitt	359-8015	sdmcnittot@aol.com	Board Member	2009
Janice Odenbach	216-9856	janiceodenbach@aol.com	Board Member	2009
Rob Kochik	272-4930	rob_kochik@urmc.rochester.edu	CEO Finger Lake Donor Recovery Network	
Jerry Runion	733-3422	jgrunion@rochester.rr.com	Board Member	2008
Joanne Schum	671-7635	twoluckylungs@juno.com	Board Member (Times Editor)	2009
Sally Stelljes	245-9579	salstell@rochester.rr.com	Board Member	2009
Dennis Stenshorn	323-1392	dstensh1@rochester.rr.com	President	2008
Shelley Whitney	334-8267	whitney618@aol.com	Secretary (Times Editor)	2008
Debbie Yendrzkeski	377-6028	auggieday@aol.com	Board Member	2009
OTHERS NOT ON THE BOARD:				
Laurie Packard	425-8034	kidtr0311@aol.com	Membership chair	
James Grossman	295-4416		TAO attorney	

TAO GOALS

1. To act as a support group for transplant candidates, transplant recipients and their families.
2. To provide education and information on transplantation and the issues that surround it.
3. 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.

TAO/ROCHESTER MEMBERSHIP APPLICATION

No one is denied membership because of financial considerations.

- New Member Renewal unable to make due payments at this time
 \$10 Family \$10 Institutional 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_____ PHONE_____

Spouse or companion_____

ADDRESS_____ E-Mail_____

CITY/STATE _____ ZIP_____

- CANDIDATE RECIPIENT FAMILY MEMBER
 HEALTH PROFESSIONAL FRIEND DONOR FAMILY

Candidate/Recipient Information

Number of Transplants_____

Organ(s)_____

Dates(s)_____

Where_____



Transplantation Works! Ask Us

Transplant Times
TAO/Rochester
1104 Bay Road
Webster, NY 14580

