

September / October 2009

www.tao-rochester.org

1.888.664.1463

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TAO Membership dues are now due for the upcoming year. Your membership dues are used for continuing the activities of TAO including: funding the Holiday party, the yearly summer picnic, and room rental for meetings.

TAO Meets

3rd Wednesday of the Month at the Al Sigl Center Cafeteria (Unless otherwise noted) 1000 Elmwood Ave. Corner of South Ave. & Elmwood Ave. 7:00 to 9:00 pm

ENTER DOOR 5 FOLLOW TAO SIGNS

2 New Surgeons Join Division of Solid Organ Transplantation

The University of Rochester Medical Center's Department of Surgery welcomes two new surgeons to its Division of Solid Organ Transplantation: Christopher Taylor Barry, M.D., Ph.D., and Carlos E. Marroquin, M.D. Both begin August 3.

"I am proud to welcome these two impressive surgeons to our growing faculty," said Jeffrey H. Peters, M.D., Seymour I. Schwartz Professor and chair of the URM



Christopher T. Barry, M.D., Ph.D

Department of Surgery. "As surgical specialists and researchers, they fit perfectly into the vision of the Medical Center's Strategic Plan."

Barry and Marroquin join veteran surgeon Mark S. Orloff, M.D., professor of Surgery, chief of the Division of Solid Organ Transplantation and director of Live Donor Liver Transplant, and Randeep S. Kashyap, M.D., assistant professor of Surgery.

"The addition of Chris and Carlos to our transplant team, with their clinical and research expertise in the areas of renal and liver transplant, will further enable us to provide the very best care for our patients," Orloff said.

Barry specializes in liver, kidney and pancreas transplantation, as well as laparoscopic removal of kidneys from healthy living donors. He performs traditional and laparoscopic resections and laparoscopic radiofrequency ablation of liver tumors. He has

research interests in liver cancer and employs genomic analysis (the study of the entire genome to determine which genes are on and which are off) to better understand the prognosis and best treatment options for an individual patient's liver tumor.



Carlos E. Marroquin, M.D.

Barry is a Rochester native who graduated from Brighton High School. He earned a bachelor's degree in music from the University of Wisconsin-Madison and went on to earn both his M.D. and Ph.D. in immunology from Tufts University School of Medicine. He did post-doctoral training at Stanford

(Continued on page 2)

Membership Meeting Guest Speakers / Topics

September 16

Come meet one of our new Transplant Surgeons: Carlos E. Marroquin, M.D.

October 21

Organ Donation: Demystifying Community Myths and Misconceptions

Rob Kochik Executive Director of Finger Lakes Donor Recovery Network Academy of Medicine 1441 East Avenue

(Surgeons, continued from page 1)

University School of Medicine and also transplant surgery fellowship at the University of California San Francisco, where he also served as a clinical instructor, Barry was most recently appointed assistant professor in residence in the Department of General Surgery/Section of Transplantation at UC-San Diego.

Marroquin specializes in abdominal solid organ transplantation and hepatobiliary surgery, with a special interest in laparoscopy both for kidney retrieval and applications to the management of hepatocellular carcinoma (HCC). In addition to developing new algorithms for the treatment of HCC, his research interests include the evolution of tolerance and innovative strategies to transplanting sensitized patients. He will be the surgical director of kidney and pancreas transplantation and bring a number of these strategies to an expanded effort in the treatment of renal failure.

Marroquin earned his bachelor's degree from the University of Maryland and completed his pre-medical studies in bio-chemistry at from California State University, Northridge. He was a post-sophomore pathology fellow at the University of California Los Angeles School of Medicine, and earned his M.D. from UCLA/DREW School of Medicine. At Georgetown University he did a general surgery internship and a general surgery residency, followed by an immunotherapy fellowship and a surgical oncology fellowship at the National Cancer Institute, National Institutes of Health. He subsequently served as the general surgery chief resident at Georgetown University before being accepted as a solid organ transplantation fellow at Duke University Medical Center. He most recently was named assistant professor in Duke's Department of Surgery.

United Network for Organ Sharing

Candidates listed as of 8/21/2009

80,888	Kidney
15,915	Liver
2,860	Heart
2,229	Kidney/Pancreas
1,899	Lung
1,499	Pancreas
240	Intestine
85	Heart/Lung

103,147

TOTAL

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

www.unos.org

Harbor House

An open house and Ribbon Cutting was hosted by Harbor House of Rochester on July 28.

The neighborhood, supporting members and hospital staff received a tour of the house. The house at 89 Rossiter Road, built in 1948, has undergone extensive renovations over the past several months.

With its 4 bedrooms; each equipped with cable TV and a private bath, 2 kitchens, laundry, dining and common gathering areas, Harbor House of Rochester will serve as a home-away-from-home for patients and families who travel from across New York State and northern Pennsylvania to receive care at the Program in Heart Failure and Transplantation and other critical care programs at the University of Rochester Medical Center.

For many patients receiving heart failure and transplant care at the University of Rochester Medical Center, hospital stays can result from an emergency situation and may last for months. More than 60 percent of the families live outside the Rochester area and must travel many hours to receive care, finding themselves in an unfamiliar city with no support system, unsure of when they will be going home.

Harbor House is scheduled to open mid to late September, pending appointment of a new director.

Plans for the future of Harbor House call for additional houses to further meet the needs of patients and their families.



Harbor House Board Members

WELCOME New Member

Welcome to new member Carol Comfort and her husband James! Although they spend half their time in Florida, Carol enjoys the information she receives from the *Transplant Times*. Carol has had two kidney transplants, one in Buffalo, New York and the latest one in Tampa, Florida in 2003 and is doing well. She stays busy with golf, gardening, boating and fishing and is able to spend a lot of time on the water in Florida. A native of Medina, NY, Carol worked and owned her own practice as a Certified Public Accountant. Jim worked as a produce manager, buying and selling apples mainly for baby food to businesses such as Beech-Nut. Distance affects Carol's participation in meetings and events but she is interested in staffing health fairs in the future in her area.

The TAO community hopes to meet Carol & Jim in person and hope they send some warm air our way this winter!

Common Nutrition Questions & Answers...



While brainstorming what my next topic for the TAO newsletter should be, I thought maybe a Nutrition FAQ "Frequently Asked Questions" in a question & answer format, might be helpful. The following are questions I am frequently presented with by patients. Please keep in mind any food or nutrition

topic you would like to hear more about and....just let us know!

Q: How can I get more vegetables into my diet?

A: To start, make a list of vegetables you like.

- It doesn't matter if vegetables are cooked or raw. Then, design a weekly schedule to work them in. Schedules ensure that you get variety, good nutrition and prevent burnout from eating the same things all the time.
- It can be fun to place attractive, tasteful vegetable choices that compliment the rest of your meal.

Remember it is difficult to over-consume vegetables as most of us don't eat enough. They are great fillers to prevent and avoid over-eating higher calorie/fat entrees and sides. They can also be mixed with foods in the starch family to extend and keep the portion of starch in check.

Q: What is considered a portion of starch?

A: There are a couple ways to answer this question:

One serving of starch is defined as **15 grams carbohydrate**. This can assist with reading food labels. Start by looking at the top of the food label for serving size or servings in the package.

Next, scroll down to the number of carbohydrate in "grams", and then you can determine how many portions used of purchased products. For example, if the serving size is 1 cup and there are 30 grams of carbohydrate then 1/2 cup is one serving.

If you use 1 cup of the food product you are eating 2 servings.

Usually we figure **within the starch family alone** (breads, rice, pasta, corn, peas, potatoes), a person can have 1 – 2 servings with each meal (15 – 30 grams carbohydrate per meal)/(3 – 6 total per day). Of course, the total amounts per meal and per day are based on your body size and activity level.

Second, If numbers make you nervous, some picture/size references are;

1/2 cup = small fist or inside of you hand cupped.

Small hamburger bun or English muffin are 2 servings (each half = one portion)

Q: Are starches the only carbohydrates I am allowed with each meal? "Two servings doesn't seem like very much to eat."

A: No. In order to have a well balanced diet you should

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

include **ALL** food groups. Fruit and Milk are two other food groups containing carbohydrate. These other food groups, in combination, with starch will make up the 50-60% of carbohydrates at a meal.

For good blood sugar and weight loss strategy it is important to use higher fiber carbohydrates. For example reading the food label and looking for breads, cereal, chips, rice, crackers, pasta that contain >2 grams fiber per serving. Eating your fruit is better than drinking it as a juice. By consuming the pulp and skin of fruits you can add 2 – 4 grams of fiber to your diet.

Q: How much fiber should someone have per day?

A: In the United States the dietary guidelines are 25-30 grams of fiber per day. In Europe they tend to get > 40 grams of fiber per day.

- If you haven't thought about fiber in your diet, you will notice on food labels that many of your foods have < 2 grams fiber/day. If you don't eat many fruits or vegetables, you probably aren't coming close to the 25-30 grams of recommended intake.
- Don't just go crazy with adding fiber to your diet. It is important to gradually add fiber since you can get gas pains, cramps and bowel movement changes.
- All of these symptoms will lessen the more you stick with these new changes, drink plenty of water and get daily exercise.

The flavor and texture of foods containing fiber is also something you will get used to. Try different companies they all have different recipes.

Q: How can I keep my sodium to 2000mg or less per day?

A: Ideally it is important to become familiar where sodium occurs within YOUR diet.

- Everyone has different high sodium foods they like. Obvious sources are canned, brined/pickled/cured or processed foods. You can simplify by using fresh, low sodium or no added sodium, frozen foods.
- Keeping 3 meals to 500-700mg each without snacks one way to stay within 2000mg/d.
- When looking at recipes that contain nutritional breakdown, I suggest main entrées to be <300-500mg and sides <100mg.
- You rarely have to worry about the natural sodium in foods such as plain milk, eggs, fresh meats, fruits, fresh vegetables.

Sometimes you can rearrange/substitute foods in combination in order to meet the guideline. For example: Ham, scalloped potatoes are two very high sodium foods. If you have a homemade recipe for lowering scalloped potatoes and you then pair it with pork tenderloin instead of ham. This is a good substitution for an old time favorite.

Lung Transplant Support Website

By Joanne Schum

Hello Again,

I am sorry to anyone who attempted to use the Bravenet site I set up for LUNG TRANSPLANT information and chat, and you could not access. Bravenet no longer works.

I have found another site where we can talk about LUNG TRANSPLANT/LUNG ILLNESS issues.

The site formally began on Wednesday, JULY 1. Please visit the site and leave a message.

<http://health.groups.yahoo.com/group/LungTransplantSupportForPatients/>

E-Mail is:

LungTransplantSupportForPatients@yahoogroups.com

I am hoping many people with various lung illness and their friends and family will check it out and begin emailing. Presently it does not have a chat room, but I am researching this.

A bit of history on me: I am 45 years old and live in upstate New York. I had a double lung transplant, due to Cystic Fibrosis. The transplant was performed September 12, 1997 at University of North Carolina Hospitals - Chapel Hill - Dr. Thomas Egan was my surgeon.

I also wrote a book: *Taking Flight- Inspirational Stories of Lung Transplantation* in 2002. transplant was performed at University of North Carolina Hospitals - Chapel Hill - Dr. Thomas Egan was my surgeon.

If you have questions about the site, ideas for the site, questions regarding transplant or if you know a good chat room site, please don't hesitate to email me: twoluckylungs@juno.com or luckylungsforjo@aol.com

Thanks for your patience - this was a long time in the making!

Joanne Schum

National Donor Sabbath

November 13, 14 and 15

Donation and transplant professionals join faith communities and focus on the life-affirming gifts that can be passed to others through organ, tissue and blood stem cell donation. Faith leaders participate in services and programs to increase awareness of donation and transplantation and the critical need for donors.

Nearly every religion in the United States officially supports organ and tissue donation or supports the individual choices of its members. Donation is viewed by most religions as an act of compassion and generosity. Temples, churches, mosques, and other places of worship observe the National Donor Sabbath in their own ways.

Each year the Council for Donation of Organs and Tissues (C-DOT) sends packets of information to places of worship in the Rochester and Syracuse areas.

Donor Sabbath information packets will be available at the September meeting for TAO members who wish to deliver a packet in person to their place of worship.

For those who would like a packet sent to them, please contact Karen Guarino at kguarino@rehpb.org or by phone, (585) 272-7890.

Contributions

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.***

In memory of Chester Palozzi:

The Oaks (Mr. Justin Guetti)

Mr. & Mrs. Soldi

Mr. & Mrs. Stephen C. Trombley, Jr.

F. Robert & Frances O'Loughlin

Stephen C. and Sandra Trombley

Mary Ann Cassotta

Daniel J. & Elaine Cavuoto

Walter J. Licata

Barbara & Donald Grendaw

Thomas & Loretta Zambuto

Mr. & Mrs. Gennaro Reale

Mr. & Mrs. Richard A. Borrelli

Barbara & David Trombley

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Mrs. Rose Koonmen

Mr. Dominic S. Bianchi

M&T Bank, Sara A. Cardillo

Marilyn Solimano & Family

Mr. & Mrs. Angelo Gersonia

Lisa & Steve Capizzi

Transplant Anniversaries

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
Susan Bennett	Kidney	October	1998
Bernard Blocchi	Liver	October	1996
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
Keith Oliver	Liver	October	2002
Carrie Rodriguez	Kidney/Pancreas	October	2005
Mary Stein	Liver	October	2005
Carol Weinlander	Kidney	October	2001

Wishes of Wellness To...

"Our healing thoughts go out to Jerry Runion, our president, and to Ray Lyman, 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 deepest sympathies go out to the families of Chester Palozzi and Dave Messmer on the loss of their loved ones.

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.

Save The Dates . . .



Rochester River Run 5K

Date: September 26, 2009
Location: Genesee Valley Park

On Saturday, September 26, 2009 Friends of Strong and the Transplant Unit will host its Eighth Annual Rochester River Run/Walk 5k at Genesee Valley Park. In addition to great refreshments provided by local businesses, prizes will be awarded to both runners and walkers in various categories. Last year's event raised over over \$12,000 for transplant patients and their families. Funds raised will be used to ease financial hardship for patients as it impacts on their transplant experience.

To Register: Call Friends of Strong @ 275-2420 or email: susan_sullivan@urmc.rochester.edu **register**

NKF of Upstate, NY Kidney Walk

Date: September 26, 2009
Location: Seneca Park Zoo
Contact: Michelle Castrogiovanni
Email: michelle.castrogiovanni@kidney.org
Phone: 585-697-0874 ext. 30

Calling all transplant recipients!

Join the Team Upstate New York and participate in the US Transplant Games in Madison, WI in July/August 2010.

Recruitment breakfast meeting: Saturday October 3, 9 AM- Noon, at the Hammocks Club House in Fairport. Call Donna Dixon for directions, 697-0874, ext 28. Come and learn the details, meet the other team members and enjoy some good food!

Transplant Times

Submission Deadline

**For November/ December issue:
Monday, October 12**

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

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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

New Member

Renewal

\$10 Family

\$10 Institutional

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 _____

Candidate Recipient Family Member Donor Family Friend Professional

Candidate/Recipient information: # of Transplants _____ Hospital _____

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