



Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

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

October/November 2010

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 1000 Elmwood Ave. Corner of South Ave. & Elmwood Ave. 7:00 to 9:00 pm

ENTER DOOR 5 FOLLOW TAO SIGNS



As a newcomer to the TAO board and its recently elected president, I would like to introduce myself to the TAO membership and tell you how privileged I am to be helping to

support the Rochester area transplant community which the organization serves. As you may know, I am a lung transplant recipient, having received my new lungs at the Cleveland Clinic in 2005. As someone who has been blessed with the "Gift of New Life", I well understand the challenges that all of us in the transplant community face, whether waiting for a transplant, as an organ recipient, or as an all-important caregiver. Emotional support and/or assistance in managing daily life are vital for all of us. For those individuals waiting for a transplant, first hand information from others who have gone through the same or similar experience is critical in helping to put the transplant surgery and life after transplant in better perspective, and in relieving anxiety. TAO's primary mission is to be there to provide whatever help it can to the transplant community. If it is to continue to do so, and to do it better with each passing year, **we need to have your input.** We need to know what we as an organization are doing well, and what we could do better. If you rarely attend our meetings, we need to know whether that's because the meeting location is inconvenient, because the meeting content isn't of particular interest to you, or perhaps for some other reason. Regardless, I encourage you to provide feedback to

A Message from the President

the board, and by all means feel free to e-mail me personally with suggestions or concerns. (GeoffF21@yahoo.com).

I look forward to meeting as many of you as possible in the coming year as we collectively share the blessings that the "Gift of New Life" can bring.

Geoff Foley

TAO Board Member Appointments

In May, Geoff Foley and Norm Breen were elected to the TAO Board. Geoff Foley assumes the duties of Board President, Debbie Yendrzeski, Vice President, Sally Stelljes, Secretary, and Dave Johnson, Treasurer. Norm Breen has been appointed Membership Chair.

Membership Meeting Guest Speakers / Topics

October 20, 2010

Donna Dixon, NKF and the Transplant Athletes - 2010 Transplant Games

November 17, 2010

Dr. Yousuf Khalifa - Corneal Transplants

In Memory . . . Sandy McNitt

On July 28, 2010 at age 44, at the Cleveland Clinic, six months post double-lung transplant from LAM, a rare lung disease Sandy McNitt lost her fight. Sandy fought courageously to live free of oxygen and had just achieved that goal only to be felled by yet another complication.

Survived by her parents David & Rose Mary McNitt; her brother Scott and his wife Diana; sister, Sharon Connors and her husband Andrew, and her younger sister, Susan McNitt. Sandy loved her several nieces & nephews; her cat Lilly; and her special loving friend, Mark Saresky.

Sandy was born October 14, 1965 and attended Rush Henrietta Schools where she ran track and cross country for four years, and made the all county team in cross country her freshman year. Upon graduation in 1983 she attended SUNY Geneseo, MCC and graduated from SUNY Buffalo in 1989. Sandy was an occupational therapist who formerly worked at Sunnyview Rehabilitation Hospital in Schenectady, NY. In 2003 she was forced to leave her job due to the increasing need for oxygen.

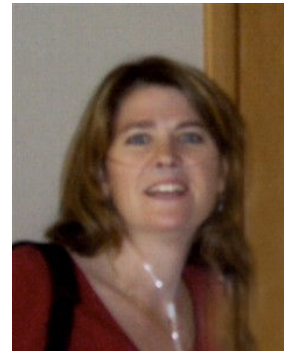
Sandy was diagnosed with LAM, or Lymphangiolo-myomatosis, when she was about 21 years old. LAM occurs in women of child-bearing age and is thought to be hormonally related. After multiple lung collapses she was diagnosed by open lung biopsy. No one in New York State had ever experienced LAM although Mayo Clinic and Cleveland Clinic had each seen one case. Sandy had been healthy prior to this and enjoyed skiing, running and swimming. Though this was difficult to face, Sandy has never let her condition

keep her down. She has touched the lives of so many through her work as an occupational therapist, her participation in Better Breathers, Transplant Awareness Organization, book groups and knit groups. "Every day she was at her computer communicating with other LAM patients" said her Mom, Rose Mary. Over the years, Sandy's doctors monitored her condition as she began to use more and more oxygen. She planned her activities around how long her various tanks would last.

This summer she was actively listed for transplant, and on January 28, 2010, Sandy received a double lung transplant at Cleveland Clinic. On January 27, she got the call. After 8-9 hours of surgery and many complications, she never gave up. She progressed to the Acute Rehab Unit and was walking with a cane. She was free from her oxygen tanks! "She was outside breathing fresh air", said her Dad, David.

Sandy was Vice-President of the Transplant Awareness Organization (TAO) & volunteered for the Finger Lakes Eye & Tissue Bank. In 2009 she was the recipient of the Bill Peterson Shining Example Award for the American Lung Association. Sandy was a parishioner of The Church of the Good Shepherd in Henrietta, NY where she was active in Visitation & Social Ministries. Sandy had an abiding faith in God and a wonderful caring way about her.

Sandy has been such a light in the life of all those who have known her. Sandy has moved on, but please carry the light of her cheer, her compassion, her friendship, and her kindness with you wherever you go, so that her light may truly move on.



United Network for Organ Sharing

Candidates listed as of 9/17/2010

86,167	Kidney
16,005	Liver
3,149	Heart
2,207	Kidney/Pancreas
1,807	Lung
1,431	Pancreas
254	Intestine
77	Heart/Lung

108522 **TOTAL**

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

www.unos.org

UNOS Launches New Corporate Web site

Richmond, Va. -- The United Network for Organ Sharing (UNOS) today launched a new corporate Web site, www.unos.org. Presenting a cleaner look, improved navigation and a host of added features, the new site provides visitors with a more user-friendly experience.

Key changes to the site include:

- An overhaul of the entire site's look/feel
- Streamlined content that promotes UNOS as a private, non-profit organization who is committed to advancing organ availability and transplantation
- "Quick Links" drop down available on every page with one click access to top content on our family of Web sites
- Simple navigation that helps you find what you need quickly and easily
- Expanded site search functionality
- Ability to share content with one click

UNOS launched its online presence in 1995. This is the first major redesign of the site in nine years.

New Better Breathers Club in Rochester

The American Lung Association invites you to join a new Better Breathers Club sponsored by VNS (Visiting Nurse Service) and Upstate HomeCare. This is an educational and support group for respiratory/pulmonary patients and their families. Meetings include guest speakers, group discussions and educational hand outs. There is no fee to join.

Meetings are held at:
Visiting Nurse Service Office
2180 Empire Blvd,
Webster
From 5pm - 6pm the first Wednesday of each month.

Contact Michelle Delzell at Upstate HomeCare for further info at 857-3187 or Julie Salo at the VNS at 787-8353

UPDATE; Electronic Signature Bill Signed by Gov. Patterson

In our last issue it was reported that Governor Patterson had yet to sign the *Electronic Signature Bill* for the NYS Donate Life Registry. Enacting this bill eliminates the need for individuals to download a form from the state Department of Health website, fill it in and then mail it back. We are pleased to report in this issue that the Governor signed the bill in July.

Karen Guarino
Rochester/Finger Lakes Eye & Tissue Bank

Introduce Your Place of Worship to National Donor Sabbath, November 12 - 14

National Donor Sabbath is part of an organ donation initiative launched by the United States Department of Health and Human Services in 1997. Observed on Friday through Sunday two weekends before Thanksgiving, the 3-day period seeks to include the days of worship of major religions practiced in the United States.

Donation and transplant professionals collaborate with faith communities to focus on the life-saving and enhancing gifts of organ, tissue and blood stem cell donation. Faith leaders and congregations participate in services and events to increase awareness of donation and transplantation. Donation helps to heal and strengthen not just recipients and their families, but donor families, friends, colleagues, and the larger community.

Faith leaders are often sought for help with life and death issues. Most religions in the United States support organ and tissue donation directly or support the individual choices of their members.

Donation is viewed by many religions as a compassionate and generous gift, and National Donor Sabbath is celebrated in many houses of worship, often with a transplant recipient sharing a story of what it is like to receive that precious gift of another chance at life.

Each year the Council for Donation of Organs and Tissues, of which TAO is an agency member, reaches out to the faith community by mail and asks faith leaders to observe National Donor Sabbath, bringing information on organ, eye and tissue donation to their members. You can help by personally delivering a Donor Sabbath packet of information and materials to your faith leader, offer to speak during worship services, or staff an informational table after each service. For a Donor Sabbath information packet please call Karen Guarino at (585) 272-7890 or email kguarino@rephpb.org

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.

Wishes of Wellness To...

Laurie Packard, former TAO Membership chair.



Join a Committee
Sunshine , Newsletter,
Membership, Awareness
Interested? Call **1.888.664.1463**

Is your garden bursting at the seams....

By: Elizabeth Keirstead RD, CNSD
Transplant Nutrition Specialist,
University of Rochester Medical Center.

Need a new, good idea for using a variety of home grown vegetables/fruits?



Have you ever considered using summer fruits and vegetables into salsas? Salsas can be made low in fat and calories, top a variety of dishes, adding a tremendous amount of flavor, texture and color.

For example:



- Dilute a favorite higher fat dressing making it lower in fat/calories or substituting it all together as a salad dressing alone.
 - Top or use complementing fish, chicken, steak, pork or with eggs, cheese, beans/legumes and tofu.
 - Use as a dip.
 - Individualized to diet restrictions. Use only vegetables/fruits that are low potassium if needing a low potassium food.
 - Omit ingredients containing sodium if following a sodium restricted diet.
 - Most vegetable salsas are low in carbohydrate.
 - Salsas can be canned or frozen to save all the wonderful abundance of this year's freshness to use in the winter and next year.
 - Grilling vegetables first creates roasted flavors.
 - Marinating vegetables can also add flavor but will add more moisture to the salsa.
 - Blenderizing will change the texture but increase flavor intensity.
 - Do not assume that salsas are spicy or hot, they can also be sweet, sour and most of all very complex.
- You can adjust the recipes to include the combination of flavors you enjoy or to lower fat by adding low fat or fat free versions!

By Linda Larsen, busycooks.about.com

Cucumber Salsa

Prep: 20 min chilling time: 1 hr

1 cup sour cream 1 cup plain low fat yogurt
1/4 cup chopped parsley 1/4 cup chopped cilantro
1 teaspoon ground cumin 1/2 teaspoon salt

3 cucumbers, cleaned, seeded and chopped.

Combine ingredients in medium bowl. Cover and chill 1 – 2 hours to blend flavors.

Serve as a topping for grilled fish or on bread/crackers as an appetizer.

Bobby Flay 1999, www.foodnetwork.com

Tri-Color Salsa

2 ripe tomatoes, diced 2 yellow tomatoes, diced
2 Tomatillos, dices 2 cloves garlic, finely chopped or minced
2 small Serrano Chile peppers, finely diced 2 tablespoons fresh lime juice
1 teaspoon honey 2 tablespoons chopped cilantro

Salt and freshly ground pepper

Combine all ingredients in a medium bowl. Let rest 30 minutes before serving.

Bobby Flay www.foodnetwork.com*Eggplant-Red Pepper Salsa*

8 servings

2 eggplants, cut vertically into 1/2 inch thick slices

2 yellow peppers, quartered and seeded

1/4 cup plus 2 Tablespoons olive oil

2 Tablespoons lemon juice

2 Tablespoons finely chopped oregano

2 red peppers, quartered and seeded

2 red onions, sliced 1/2 inch thick

2 cloves garlic, finely chopped/minced

4 ounces soft goat cheese, crumbled

Salt and freshly ground pepper

Preheat grill to medium high. Brush eggplant, peppers and onions on both sides with 1/4 cup of the oil and season with salt and pepper to taste (can omit or reduce salt if desired). Grill for 3 to 4 minutes on each side, until lightly golden brown and almost cooked through. Remove vegetables from grill and cut into 1/2 inch dice. Combine eggplant, peppers and onions in a medium bowl. Add remaining ingredients including the remaining 2 Tablespoons olive oil.

Deen Family www.foodnetwork.com*Pineapple-Cucumber Salsa*

4 servings

1 cup diced cucumber

3 Tablespoons freshly chopped cilantro

1 lime, juiced

*1 teaspoon finely chopped jalapeno pepper 1/4 teaspoon kosher salt

1/4 teaspoon hot sauce

** can substitute sweet peppers (orange, red or yellow) in for jalapeno**

1 cup diced no added sugar canned pineapple, drained

1 Tablespoon finely chopped red onion

2 1/2 teaspoons finely grated lime zest

freshly ground black pepper

Dave Munson, chef www.keystonefruit.com*Peach & Apple Salsa*

2 peaches, diced

1 sweet medium onion, diced

1/2 lime, juiced

1/4 teaspoon allspice

1 Tablespoon of honey OR apricot preserves OR orange marmalade

Salt & cracked black pepper to taste

Combine ingredients in bowl, set for flavors to meld.

1- 2 apples, diced (use your favorite)

1 jalapeno pepper, diced or sweet pepper or omit

3/4 cup cilantro chopped

1/2 teaspoon cinnamon

Don't Forget . . .

Flu Season is approaching.
Get vaccinated!

Out of the mouth of babes...

My granddaughter, Madeline, was saying her prayers:

"God Bless Grandma Mooney, God Bless her new kidney and please let us know if it's a boy or girl!!"

Two days later she called her grandmother and asked when she was bringing the baby home.

2010 U.S. Transplant Games

12 local athletes from the Rochester area, also known as Team Upstate New York, just returned from the 2010 U.S. Transplant Games sponsored by the National Kidney Foundation. This year, the Games were held in Madison, WI. They brought home an amazing 9 medals that represent hope, courage and proof transplantation works!

At the U.S. Transplant Games, people who have received solid organ or bone marrow transplants participate in competitive athletic events styled after the Olympics. Nearly 1,200 transplant recipient athletes participate to show transplantation works, an 84 living donor athletes laced up their sneakers to compete for the first time, and to show that living donation works too.

The Opening Ceremony was attended by more than 5000 transplant professionals, donor families, supporters and volunteers, and featured our own donor mom Holly Campbell, Horsehead, NY, singing a beautiful tribute to her son Jake and all those who gave the gift of life.

2010 Team Upstate NY: * = medalist

Donna Dixon, Team Manager
 Linda & Mike Maiellano, Donor family Liaison
 Gerald Bluff, Bernice Eblövi**, Karen Gledhill**, Bonnie Haefner,
 Dan Newhouse, Tim Parks*, Patience Prinzi**, Pat Ridge, Joanne Schum,
 Ben Smeenk*, Mike Swete, Eric Wright*

For more information on the next NKF's US Transplant Games and ongoing organ, eye, and tissue awareness programs, contact Donna P. Dixon, Education Director, 585-697-0874 ext 28 or donna.dixon@kidney.org, www.kidneynyup.org

Editor's note: Come meet members of the team at the next Tao meeting.



Team Upstate New York



Patience Prinzi (kidney) running for the gold



Jerry Bluff (lung) completes racewalk

TAO www.tao-rochester.org

G To act as a support group for transplant candidates, transplant recipients and their families.

O To provide education and information on transplantation issues that surround it.

A To promote organ and tissue donation awareness.

L All potential transplant recipients, candidates, family and friends are welcome. Meetings are held monthly and include programs of interest to the transplant community.

S

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 next issue. **THANK YOU.***

Ernst Baier

In memory of Kim Johnson:

International Brotherhood of Electrical Workers,
Local 139, Elmira, NY
Gene & Nancy Tunney
Ms. Barbara Hilton
Mr. & Mrs. Floyd Schutt
James & Carol Huff

In memory of Sandy McNitt:

Donald Sr. & Helen Dobesh
Sheila R. Cutler
Shawn Haarer
Janet L. Juneau
Scott & Deborah Strong
Friends of the Henrietta Public Library
James & Susan Selvek
Fred & Josephine Altrieth
Marian McHargue
Richard & Suzanne McNamara
Judy Rosenberg
Patricia Bernhard
Carolyn St. James
June & Bart Spratt
James & Julia Falzone
Lisa Faucz
Vincent & Rosanne Rosella
Janet McNally
William Jr. & Judith Embury
Linda M. Langer
Gary & Alan Schaeffer
Brian Emelson
Willaim Jr. & Adelaide Setek
Leonard & Delores Metzger
Lynn L. Neill
Michael & Cynthia Apostolakos
Heart Research Follow Up Program – University of
Rochester Medical Center
Michael & Marlene Goho
Jorge & Frances Ricaurte, MD
JoAnne Schum

In memory of Sandy McNitt. . .

Mark & Karen Coons
Linda Barnard
Dennis & Eileen Kovel
John & Katherine Zachman
Bonnie Haefner
Rob Kochik
Frank & Priscilla Imburgia
Tony & Karen Gledhill
Linda F. Daniele & The Shufflebarger Family
Michael & Diane Hammill

In Memory of Jim Fyfe:

Edward & Elaine Short
Bonnie Haefner
Rob Kochik
Linda Barnard
Elizabeth A. Schenk
John & Christine Treahy
Robert & Carol Bradshaw
Jeanne M. Charles
John & Jerilyn Heller
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Gertrude B. Brown
Tony & Karen Gledhill
Powder Mills Park Garden Club
David & Anne Greer
Duane & Barbara Czajka
Mr. & Mrs. Michael W. Kilroy
Mrs. Cynthia H. Gilman

In Memory of Robert Butts:

Bonnie Haefner

United Way Pledges:

Ms. Elouise Beardsley
Vincent J. Grillo
Ms. Sharon A Steacy

Our Sympathies To...

The Fyfe family on the passing of Jim Fyfe at Strong Memorial Hospital

The Imburgia family on the passing of long time TAO member Frank Imburgia.

The Goehle family on the passing of Ron Goehle

The Gledhill /Scott Family on the death of Karen's dad, "Scotty" - corneal recipient.

Festival of Softball

Tribute to Noah

100 Inning Game

The 3rd Annual Festival of Softball will be held on Saturday, October 2nd, 2010 at Cobbs Hill.

The game is a "Tribute to Noah Passero", an 8 year old youngster from Webster, who passed away April 13, 2008 while waiting for a heart transplant at Mt. Sinai Hospital in New York City, after a long battle with heart disease.

All proceeds will benefit the Golisano Children's Hospital Pediatric Cardiology Fund of the University of Rochester Medical Center at Strong Memorial Hospital.

Please consider supporting this event. Your sponsorship will be acknowledged at the event. Representatives from the Finger Lakes Donor Recovery Network will be on hand to provide information regarding Organ Donation and the importance of GIVING THE GIFT OF LIFE. Website for Donor Registration: www.nyhealth.gov/donatelife

100 INNING GAME SPONSORSHIPS

<u>NOAH'S ANGELS CLUB</u>		Players - \$10.00 each
Platinum -	\$1,000	Innings - \$25.00 per
Gold	- 500	
Silver	- 250	
Bronze	- 125	

Sponsor's Name _____

Address _____

Telephone (H) _____ (W) _____ (Cell) _____

Level of Sponsorship: Noah's Angels _____ # of innings: _____

Please check one: Cash _____ M/O _____ Check _____

Checks/MO payable to: Golisano Children's Hospital
Pediatric Cardiology Fund

Please mail check/MO to: Andy Yazwinski, 214 Filon Avenue, Rochester NY 14622



Save The Date . . .



Festival of Softball Saturday, October 2

In memory of Noah Passero - at Cobbs Hill Park baseball field. TAO and RETB are looking for players for an exhibition 3 to 5 innings starting at noon. (See flyer for more details) Fees are waived for the exhibition game. Donations are welcomed.

The Donor Family Network's Casino Night

**Friday October 8th from 6-10pm
Pucello's Restaurant at Foxfire Golf
Course in Baldwinsville NY.**

Advance sale tickets are \$20 and \$25 at the door.

Includes \$250 in playing chips, food, non alcoholic beverages (with cash bar) and dessert. We will have door prizes, raffle prizes and a 50/50 (the 50/50 will be the only monetary prize)

Please join us for a night of fun! We had a blast last year and want you all to join us for the fun this year.

For tickets , or if you would like to help sell some Tickets contact:

Michelle Lester (Donor Mom)
mle350@aol.com

Bring the whole family!

Gift Wrapping:

TAO does holiday gift wrapping at Barnes and Noble in December to raise awareness and as a fundraiser. We will need people to man shifts, if interested please contact Bev Shank at: shankbev@hotmail.com or 585 244-1536. The exact dates and locations will be determined. Stay tuned!!

Transplant Times

Submission Deadline

**For December / January 2011
issue: Monday, November 8, 2010**

Articles /ideas email to:
auggieday@aol.com or
kbliek333@gmail.com

or send by mail to:

TAO, PO Box 23552, Rochester,
NY 14692-3552

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Janice Odenbach

Bev Shank

Mike Stelljes

Thank You

The McNitt Family would like to extend their thanks for all the support from TAO members and for the meal TAO provided to them. "The food was delicious and well thought out." "We miss Sandy but are comforted that she is with God." Dave, RoseMary, Scott, Sharon and Sue McNitt

Transplant Anniversaries

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
DONNA CROSBY	LIVER	November	2003
PHILLIPS DANIEL	LIVER	November	2009
PETER DAVIS	LIVER	November	1996
DAN NEWHOUSE	KIDNEY	November	1995
DANIEL PHILLIPS	LIVER	November	2009
JERRY RUNION	KIDNEY/PANCREAS	November	1994
SCOTT SANFORD	LIVER	November	2009
ALICE SCEUSA	LIVER	November	2002
MICHAEL STELLJES	LIVER	November	2001
MIKE SWETE	LIVER	November	1995
ERNST BAIER*	KIDNEY	September	2000

*(INADVERTENTLY OMITTED FROM PRIOR NEWSLETTER)



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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)