

T S O TRANSPLANT SUPPORT ORGANIZATION



Serving Westchester, Putnam, Dutchess, Bronx Counties and Southern Connecticut
VOL. 18, ISSUE 1 JANUARY/FEBRUARY 2013

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Meeting Dates

- 1/16/2013
- 2/20/2013
- 3/20/2013
- 4/17/2013
- 5/15/2013
- 6/19/2013

And the Beat Goes On

2012 Holiday Party and Celebration of Life

On December 10th ninety TSO participants, family members and friends came together at the Doubletree Hilton in Tarrytown to celebrate the Holidays. Good food, wonderful service, and a festive atmosphere made the evening enjoyable and very special. TSO was joined by donors and their families who were accompanied by Alicia Algeo from NYODN and our presenter at the November monthly meeting. NYODN had an important presence at this event; they donated to our silent auction and scholarship seating for attendees. Jennifer Schwerin, NYODN's volunteer manager was on hand to offer her support and gratitude to our volunteers and Helen Irving, CEO of NYODN, made a special presentation to Patricia Tomsulo and Anthony Bonelli in recognition of their years of community outreach and volunteerism, naming them among the many unsung heroes who work tirelessly to promote organ donation. TSO also presented the annual leadership award to 2 board members, Ira Copperman and Glenda Daggert. Ira and Glenda have been very active leaders within TSO; Ira is currently Co-Vice President and chairperson of the fund raising committee as well as the main organizer of the silent auction. Glenda has been very active on the board and now heads the Programs Committee which is

responsible for bringing TSO the wonderful speakers for our monthly meetings. Please join TSO in offering our heartfelt congratulations and gratitude to all of the award recipients who give so much of themselves for TSO and for organ donation. TSO also wants to thank Noel Mick and Carmela DeLuca from the NY Eye Bank for their continued support and their important presence in TSO. We are also grateful to Mike Mancini for the very enjoyable Holiday music.

This celebration is an important marker for TSO and it affords participants an opportunity to enjoy each other's company and to celebrate the accomplishments of the year. Renewing acquaintances and connecting with new friends gives special meaning to the spirit of this season.

Continued on page 3

Transplant Support Organization meetings are held at 7 p.m. on the third Wednesday of the month (with some exceptions) at Westchester Medical Center, Taylor Building, Valhalla, NY.

**Schedule for monthly meetings
hosted by Westchester Medical Center**

7:00 PM — Social Time 7:30 PM-9:00 — Meeting and program for evening

January 16th - "What's New in Transplant Programs" - **Dr. Milan Kinkhabwala**, Chief of Transplantation, Dept. of Surgery, Montefiore Medical Center, and Professor of Surgery, Albert Einstein College of Medicine, will be our guest speaker. Dr. Kinkhabwala will discuss how new programs support the transplant community.

January 19th - Training Session, 10 a.m. to 2 p.m. at Westchester Medical Center's Taylor Pavilion Media room on the 1st floor. Lunch will be provided. RSVP to Janet Ocasio — **GKJP@aol.com**

Future Meeting Agendas

February 20th - "Tissue Transplantation" - **Elizabeth McNamara**, Regional Director of the Musculo-Skeletal Tissue Transplantation will be our guest speaker.

For directions to our meeting, donor registration form, and further information, please check our website: **www.transplantsupport.org**

To contact us by mail please write to:

TSO, 1154 Webster Avenue, New Rochelle, NY 10804

We are also on facebook. Check us out for information and updates.

You do not have to be a facebook member the access this account.

To all recipients of this newsletter.
Please send your email address so we may notify you of any last minute changes to our meetings. If you have changed your address recently please let us know so we can update our records.

Please send all correspondence to:

Janet Ocasio - GKJP@aol.com

The UNOS National Patient Waiting List

Candidates as of 12/21/2012

95,053 patients waiting for a kidney transplant.
15,966 patients waiting for a liver transplant.
1,198 patients waiting for a pancreas transplant.
2,125 patients waiting for a kidney-pancreas transplant.
254 patients waiting for an intestine transplant.
3,427 patients waiting for a heart transplant.
49 patients waiting for a heart-lung transplant.
1,635 patients waiting for a lung transplant.
117,147 TOTAL PATIENTS

Every 12 minutes a new name is added to the waiting list.

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And the Beat . . . (continued from page 1)

On behalf of TSO, I want to express my warmest gratitude and wishes that you and your family have a wonderful Holiday and I invite you, in advance, to join us at next year's Celebration of Life.

Janet M. Ocasio, Co-President of TSO

Fund Raising at TSO

So how did we do in 2012? Very well, thanks to the efforts of all the people who support TSO, not just with their membership dues, but with their time and effort. And the highlight of our year was the silent auction and raffle at our Holiday Party on December 10, 2012. More than 50 items came from your efforts, overflowing the 5 tables we set up at the party. There were sporting event tickets, fine jewelry, Broadway theatre tickets, original art from our members, and electronic devices. What a display!!!

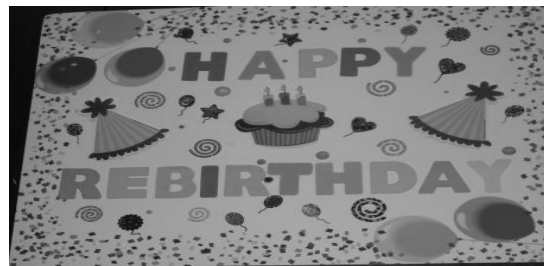
By the end of the evening, we had raised more than \$3,000 to help TSO with its outreach activities. Your efforts will help sustain us throughout the year.

There are so many people to thank for all the time and effort that was put in to help us make our activities and our holiday party such an outstanding success. We thank all of you very much!

Happy Rebirthday to You

Warren Agatston	Kidney	January, 1991
Monique Eveillard	Kidney	February, 1993
Helen Bellhouse	Liver	January, 1995
Stephen Arnold	Kidney	February, 1996
Gerard Bushel	Kidney	January, 1997
John Talbutt	Liver	January, 1998
Richard Marasco	Kidney	January, 1998
Bill Williams	Cornea	February, 1998
Sherinah Lugo	Kidney	January, 1999
Ana Rosado	Kidney	February, 1999
Vicky Rebatta	Kidney	February, 2000
Betty Bottinelli	Liver	January, 2001
Jack Powers	Liver	January, 2001
Ruth Konefal	Lung	January, 2003
Rudy Masry	Kidney	January, 2003
Theresa Mallon	Liver	January, 2004
Meredith Laubin	Kidney	January, 2004

Charles Brown	Liver	January, 2004
Irene Sherman	Kidney	February, 2004
Kathryn Kerpchar	Liver	January, 2005
William Seery	Liver	February, 2005
Louis Hamway	Kidney	January, 2006
Donald Simons	Liver	February, 2006
Judith Sokol	Liver	January, 2008
Angelo Stekardis	Lung	February, 2008
Robert Mavian	Kidney	January, 2009
Peter Sinnott	Heart	January, 2010



Our best wishes to all for many more happy and healthy years to come!

How Will You Play Your Hand at Life?

By: Mary H. Wu

As 2012 draws to a close and the new 2013 year will begin, I reflect on thirty years of my life thus far. Because my health complications and journey began at seven months old from a diagnosis of renal agenesis, I believe that my health has been and still is my arranged marital partner. I did not have a choice and sometimes we do not have a choice with the unpredictable cards of life that are dealt to us, but I and all of us have a choice of how we play out our hand.

After nearly thirty years of marriage to my health, I realized that I play my hand by enjoying life to the fullest, treasuring the people I love and care for the most, and that I honor both my organ donor families when I participate in activities and speak out vocally about the miracle and gift of organ donation and transplantation. In 2010, I attended the Transplant Games hosted by the National Kidney Foundation in Madison, Wisconsin as a spectator. The experience of seeing transplant recipients competing to showcase the power of organ donation and transplantation and honoring organ donor families completely transformed my life. From that one experience, I wrote about the Transplant Games for "The Journal News" that was published as a community view. This then led to a series of astounding and extraordinary experiences. Some highlights include public speaking engagements, active participation and advocacy work on my own and with transplant organizations (Transplant Support Organization, New York Organ Donor Network, TRIO, and Renal Support Network), my published opinion editorial articles about organ donation and transplantation, other individuals who wrote articles about my advocacy work, an unexpected reunion with my childhood nurses that cared for me throughout my first kidney transplant, arthritis advocacy work, a Donate Life float rider experience at the 123rd Rose Bowl Parade in California, athletic swimming competitor at the 2012 Transplant Games of America and winning of three medals (two bronzes and one silver), and the final completion of my personal autobiography "Confessions of a Kidney Transplant" that will be published as a hard copy book in Spring 2013.

The greatest gifts that were bestowed to me were my two chances at life with my first kidney transplant when I was five years old and then second kidney transplant when I was twelve years old. These priceless and selfless gifts allow me to play my hand of loving and living life and paying all that was given to me forward. In the process of playing, I have experienced the extraordinary and met the most inspirational people within and outside of the transplant community. I live by my own personal motto in life: "Learn from the Past, Live for Now, Create Your Future"

I am forever grateful to Transplant Support Organization for welcoming me and always supporting my organ donation and transplant advocacy work and personal projects and for all they do in the transplant community and beyond. While I greatly encourage you to play your hand by paying forward, I ask each and every one of you personally: How will you play your hand at life?

Whilst answering and acting to that question, I wish everyone a most happy, healthy, prosperous, and safe holiday and 2013 New Year!

Beating the Winter Blues

Submitted by Mimi Greenman, LCSW, MPH

During this time of year when the weather is cold and the days are short many of us may experience a sense of malaise. You may experience a decrease in your activity level; once you're at home you just don't want to go outdoors again. You may not see friends who you spend time with during the warmer, summer and spring months. You may experience a tendency to over sleep, over eat and become couch potatoes. This, in turn, can lead to feeling sad, depressed, or cut off from people or things that give you a sense of enjoyment or fulfillment. When these feelings are carried to the extreme, some may suffer from a condition called "Seasonal Affective Disorder".

It's important to remember that we need to keep our bodies and our minds active at all times of the year. Below are some suggestions to help beat those winter blues.

1. Light does help. Believe it or not, improving the lighting in your home, opening blinds during the day, or even doing a room make over using lighter colors can brighten your outlook as well.
2. Buy a Wii. Go skiing or play tennis in your living room. A virtual work out on a Wii is fun and will keep you in shape too.
3. Learn simple yoga and meditation. Yoga does not have to be strenuous. There are many yoga positions that are easy on you joints and your muscles and will help keep you focused too.
4. Take a virtual vacation. So you always wanted to visit Italy. Go to the library and use the internet to "visit" and learn about the museums and the towns you always wanted to see.
5. Educate yourself. Choose a topic you always wanted to know more about from ancient Greece to antiques to becoming computer proficient. Learn, explore and have fun.
6. Become creative. Is there a hidden part of you that you never had time to develop? Paint, knit, learn bead work, creative writing or become a master chef.
7. Choose a hobby. Scrapbooking, puzzles, collecting can help you develop fun goals.
8. Get involved. There's a lot of charity work that can be done right from home. Organizations including TSO are always seeking people who can donate their time for a wonderful course.
9. Thinking about a friend you haven't seen in a long time, or lost touch with? Reach out.
10. Communicate. Talk to friends and family about how you are feeling. If the blues persist talk to your social worker or a health care professional.

LETTER FROM THE PRESIDENTS

Dear TSO participants and friends of TSO,

As we enter a new year it is always important to reflect on the past year, the accomplishments, where we met our goals and where we fell short of meeting them. 2012 was a very busy year for us as we encouraged participants to join committees and to become actively involved. The school program reached out to over 10,000 students and the Community Volunteers registered over 2000 new organ donors. TSO won first place in the first Campaign 4 Life contest and second place in the second one. The relationship with NYODN has been a solid one and has resulted in Summit meetings led by Jennifer Schwerin, Volunteer Manager, where leaders from the different regions were asked to attend and to share experiences and activities and to generate ideas for future programs and initiatives. Now as we begin a new year, TSO looks to continuing and expanding these activities. TSO is very grateful to the Westchester Medical Center for hosting our monthly meetings, they have been very helpful in many ways and their support of TSO has been very important.

We recognize and salute all of our wonderful volunteers who give so much of themselves to insure that TSO remains vibrant and current. Our volunteers are individuals who are extremely dedicated to the cause of organ donation and insuring that the gift of life remains in the forefront of public awareness. Thank you for all of your hard work, TSO would not exist without you and the important work that you all do. Whether you are a transplant recipient, waiting for a transplant, a family member, a donor, or just someone who cares about this issue, you are what make TSO work! You are all invaluable contributors and we encourage you become more involved, offer your suggestions and your feedback, and accompany us on another year.

Thank you and may this new year bring you and your loved ones health and happiness!

Janet M. Ocasio & Jeff Graham

Co-Presidents of TSO

Thank You... Thank You... Thank You

Thank You to the following for
making our Silent Auction a success

Doubletree by Hilton – Tarrytown
Amore Pizzeria & Pasta - Armonk
An American Bistro – Tuckahoe
The Cookery Restaurant – Dobbs Ferry
Red Hat Restaurant - Irvington
Rosa's La Scarbitta Ristorante - Mamaroneck
Ruth's Chris Steak House – Tarrytown
Tuscan Grill Restaurant – Briarcliff
Culleton & Marinaccio, Attorneys at Law
The Law Offices of Brian D. Perskin & Assoc.
Hudson Adventure Tours
Ivan Pharmacy
Madison Handbags – Denise Bard
New York Organ Donor Network
Our Artists – Helen Andrew, Carole Graham,
Danielle Wahren, Tony Ziegler

Rose & Arthur Aglieco, Ike Copperman & Glenda Daggert,
Meryl Didio, Cathy Duke & Paul Kaye,
Carole & Jeff Graham, Carol & George Johnson,
Ted & Trina Lawson, Madeline & Gerard Marinaccio,
Lauren Mitchell & Michael David,
Janet Ocasio, Suzanne Perucci, Hailey Puleo,
Pat & Anthony Tomasulo, Danielle & Barry Wahren

He's Got Heart

By David Levine, Westchester Health & Life
December, 2012

At 6-feet, 1-inch tall and more than 300 pounds, Miles Banks looked every inch the star football player he was at Peekskill High School. Banks also played lacrosse and was on the track team, and he was in the physical prime of his life. So when he caught a cold his senior year of high school, he thought nothing of it. But the cold lingered and then worsened. He grew weak, short of breath and lethargic. He couldn't work out. He had severe coughing fits.

In January 2011, one of those fits sent him to the Hudson Valley Hospital Center emergency room, where doctors found the last thing you'd expect in such a big, strong young man: His heart was failing. Banks is the fifth of the six children (all boys) of Linda, a case manager at a homeless shelter, and Darryl, a security officer. There is no history of heart trouble in his family, so when he went to the ER he was shocked to learn he had an enlarged heart and was being transferred to Maria Fareri Children's Hospital at Westchester Medical Center.

He was first seen by Joseph Giamelli, M.D., a pediatric cardiologist, who diagnosed dilated cardiomyopathy, an enlargement and weakening of the heart muscle. "That can be caused by a host of things, but the most common cause is a virus," Dr. Giamelli says. Banks spent 10 days in the hospital and was put on medication, which helped stabilize him for a while. But his heart didn't heal. "Only one-third of patients get better on their own," Dr. Giamelli says. "One-third need medication all their life but stabilize. And one-third die or need a transplant." Banks, unfortunately, was in the last group. His heart deteriorated, and on April 1, he fainted at school. He re-entered the hospital and was admitted to the Intensive Care Unit. His heart was so damaged that Dr. Giamelli put him on another, more potent medication that helped it pump.

"Miles was in heart failure, and once you need those meds, the next step is to get a transplant," says the doctor. "It took me three to four days to come to grips with it," Banks says. "But then I focused on football, and my prom and graduation. I started looking forward to all that and put the bad stuff out of my mind. My parents were freaking out, of course." Dr. Giamelli consulted with Alan Gass, M.D., Medical Director of Heart Failure, Heart Transplantation and Mechanical Circulatory Support at Westchester Medical Center. "Miles was really sick," Dr. Gass says.

While Banks waited for an organ match, he was kept alive with a rare combination of two advanced technologies: a balloon pump that increased his cardiac output, and an extracorporeal membrane oxygenation (ECMO) system. His condition grew worse, though, and by his 18th birthday, April 28, he was in mortal danger. On May 10 he was scheduled to meet with the Make a Wish Foundation. That same day, he learned a match had been found. "He might not have lasted another 24 to 48 hours," Dr. Giamelli says.

The transplant was performed by David Spielvogel, M.D., Program Director, Heart Transplantation, and Ramin Malekan, M.D., cardiothoracic surgeon. And it was completely successful. "Miles was the perfect type of candidate," says Dr. Gass. "He is very motivated and calm and has supportive family and friends. He's a very mellow guy, takes everything in stride and is always looking forward." That meant looking ahead to his prom and graduation.

He wasn't well enough to attend the prom, so the nurses at the Medical Center held one for him in the hospital. "They gave me a dress shirt, my friends came over, they sat me up in a chair, brought some punch and cupcakes, it was really cool," he says. But he was able to graduate with his class. "I came secretly, and when my father pushed me out in a wheelchair, everything stopped," he says.

"Everyone yelled my name, and then my big brother Marquise pushed me up the ramp and I got a standing ovation." He returned to the hospital to finish his rehab and was released on August 4. By December, he was feeling better, and in January he started classes at Westchester Community College. He's playing basketball and working out again, and his weight has risen from 225 to 290 pounds.

His ordeal has brought some exciting opportunities—he was named an "honorary captain" at an Army football game and went onto the field for the coin toss, and the Make a Wish Foundation is sending him to the 2013 Super Bowl in New Orleans. For now, though, Banks is back at Maria Fareri Children's Hospital, this time by choice. He has taken the fall semester off from his college schedule to volunteer. "I help with washing clothes, talking to children, reading books to them," he says. "My mom suggested it because I really appreciate what they did for me, and this is a way to give back."

DIRECTIONS TO WESTCHESTER MEDICAL CENTER TAYLOR BUILDING

*****See note at bottom of page for Taylor Building*****

Taconic Parkway SOUTH

to Sprain Brook Parkway to Medical Center exit (just past New York State Police Headquarters). Make right at top of exit onto Route 100 (south). Follow to entrance to Medical Center grounds on right.

Route 684 SOUTH

to Saw Mill River Parkway to Sprain Brook Parkway to Medical Center exit (just past New York State Police Headquarters). Make right at top of exit onto Route 100 (south). Follow to entrance to Medical Center grounds on right.

Saw Mill River Parkway SOUTH

to Sprain Brook Parkway to Medical Center exit (just past New York State Police Headquarters). Make right at top of exit onto Route 100 (south). Follow to entrance to Medical Center grounds on right.

Saw Mill River Parkway NORTH

to 1-287 east to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

I-87 (New York State Thruway) SOUTH

to Tappan Zee Bridge. I-287 east to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

I-87 (New York State Thruway) NORTH

to 1-287 east to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

Sprain Brook Parkway NORTH

to Medical Center exit. Make left onto Medical Center grounds.

I-95 (New England Thruway) NORTH or SOUTH

to 1-287 west (Cross Westchester Expressway). To Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

Hutchinson River Parkway NORTH

to 1-287 west (Cross Westchester Expressway). To Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

Meritt Parkway SOUTH

to Hutchinson River Parkway to 1-287 west (Cross Westchester Expressway). To Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

Bronx River Parkway NORTH or SOUTH

to Virginia Road exit. West on Virginia Road to Route 100 (Grasslands Road). Make right, and follow to stop light at junction of routes 100 and 100C. Make right onto Route 100 north. 1 mile to entrance to Medical Center grounds on left.

I-287 (Cross Westchester Expressway) EAST

to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

I-287 (Cross Westchester Expressway) WEST

to Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

*****Taylor Building*****. After entering Medical Center Grounds (left at Wood Road), turn right onto Westview Drive. Wind around about 1/10 mile until you see sign for Taylor building on right. Park in front and go to A/V room.



TSO Transplant Support Organization

Participant Application: New Renewal

Please fill out this form and mail it with your tax-deductible contribution to:
TSO, 1154 Webster Ave., New Rochelle, NY 10804

NAME(s) _____

Mailing Address: _____

Phone #: Daytime: _____ Evening: _____ Cell: _____

Email: _____

PERSONAL INFORMATION (optional)

Birthdate: _____ Sex: _____ Marital Status: _____

Occupation: _____

CANDIDATE / RECIPIENT INFORMATION — Please check appropriate description

Transplant Recipient _____ Transplant Candidate _____ Family Member _____

Donor Family Member _____ Interested Individual _____ Professional _____

Have you already had a transplant? Yes _____ No _____

Type of Transplant(s) _____

Date of Transplant _____ Time waited (or waiting) _____

Where did you (will you) have your transplant? _____

PARTICIPANT CATEGORIES & SUGGESTED CONTRIBUTIONS

Regular (Transplant recipient, transplant candidate, family member, donor family)

Individual Participant \$25.00

Family Participant (2 members, same address) \$35.00

Additional participants at same address \$10.00 each

Professional (Surgeon, Physician, Clinical Coordinator, Nurse, Social Worker, etc.) \$25.00

Additional optional voluntary contribution (at your discretion) \$ _____

I would like to take an active role within TSO (please check all areas of interest):

Speaker _____ Membership Drive _____ Fund Raiser _____

Clerical _____ Contributor _____ Patient & Family Support _____

Newsletter _____ Date Processing _____ Other _____

Help Promote Donor Awareness License Plate Frames For Sale

\$ 10.00 each 2 for \$ 18.00 3 for \$ 25.00



LPF 1 Top: Make a Miracle
Bottom: Be an Organ Donor

LPF 7 Top: Transplantation Works
Bottom: Lung Recipient

LPF 2 Top: Miracle Maker
Bottom: Kidney Donor

LPF 8 Top: Transplantation Works
Bottom: Liver Recipient

LPF 4 Top: Organ / Tissue
Bottom: Donor Family

LPF 9 Top: Transplantation Works
Bottom: Heart Recipient

LPF 10 Top: Transplantation Works
Bottom: Kidney Recipient

Name _____
Address _____
City, State, Zip _____
Phone _____
Frame(s) desired _____

(add \$2.00 for postage and handling)

Send order with payment to: TSO, 1154 Webster Ave. New Rochelle, NY 10804

Save the Date

On Saturday, January 19th from 10 a.m. to 2 p.m.

TSO will be joined by the NYODN and the New York Blood Center to offer you a unique training experience

If you are a volunteer for organ donation, if you want to be a volunteer, or you just want to learn more about the organ donation and community outreach, please plan to attend.

The training session will be held in the Westchester Medical Center's Taylor Pavilion, Media Room on the 1st floor.

Lunch will be provided

So mark you calendars for this important opportunity to learn amongst friends and enjoy a warm and educational experience together.

All are welcome

RSVP to Janet Ocasio via email at gkjp@aol.com

TSO
Transplant Support Organization
1154 Webster Ave.
New Rochelle, NY 10804

NEXT MEETING: January 16, 2013

Transplant Support Organization's Mission

To help save lives by:

- *Providing education relating to organ donation and transplantation;*
- *Promoting organ and tissue donation as an important social responsibility;*
- *Giving support to transplant candidates, recipients, their families and donor families;*
- *Effectively communicating to government bodies and the general public, the concerns and needs that affect the welfare of those individuals impacted by the transplant process.*