

TRANSPLANT NEWS NOTES

JANUARY, 2007

When you can't breathe..... nothing else matters!

Record Breaking News—Just in!

Columbia Does 51 Lung Transplants In 2006!

Sheila rings out the year at #51! Information Sources

Congratulations to Sheila – recovering at Milstein after her double lung transplant on 12/29. Sheila's surgery brings the CUMC lung transplant total for 2006 to 51.

Also out of Milstein - and at home - Walter is recovering after triple by-pass surgery. Walter had his double lung transplant last spring, and needed cardiac surgery to clear some blockages that had developed. As one of our post-transplantees commented, "I have heard that getting any surgery done after transplant is like getting your teeth cleaned. So Walt can rest easy; the hard part was over a long time ago."

A couple of nice folks have had calls, but the lungs were not able to be used. No surgery, but reassuring that they are getting closer!

<http://www.newlungs.com/>

This is Roger W. Stevens rather irreverent look at the entire Lung Transplant process. This is not affiliated with any specific transplant center, but is pretty typical of what happens everywhere. Just be aware that things will be a bit different at CUMC!

<http://users.adelphia.net/~terryl2952/Resources.pdf>

Now available on the 14th floor is an excellent Community Resources document that our social worker, Phyllis Sachs created for all transplant patients. You can download it here – and on Jay's website – which also has other resources: <http://www.lackritz.net/>

<http://users.adelphia.net/~terryl2952/NeedToKnow.pdf>

"What Every Patient Needs to Know" - Information about organ transplantation, financial strategies and more – from the Transplant Living website sponsored by UNOS.

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2007 Support Group Meeting Schedule

Tues, Jan 9, 4-6 pm

Jessie Wilt, MD
Advance Directives
Clark Conf Rm. 1 & 2

Wed, Jan. 17, 1-3 pm

Theresa M. Daly, FNP
Clark Conf Rm. 3

Thurs, Jan 25, 1-3 pm

Charlotte Cabello, DNP
Clark Conf Rm. 3

Mon, Feb 5, 4-6 pm

Jessie Wilt, MD
Bronchoscopy & Post-TX
Infections

Clark Conf Rm. 1 & 2

Tues, Feb 13, 4-6 pm

Selim Arcasoy, MD
Clark Conf Rm 1 & 2

Wed, Feb 21, 1-3 pm

Theresa M Daly, FNP
Clark Conf Rm 3

Full schedule can be found at

<http://www.Lackritz.net>

A Post-TX Report - by Donna H

News from me is that my course of recovery has been nothing but upbeat. No infection, no rejection. I am putting on weight from 89 to 109 lbs since March, 06. Surgery was December 12, 2005, so I am over 1 year.

Cheeks are rosy, energy is astounding, I work out 3-4 times per week and my hair got curly! Whoopee!

My husband and I go every-where: dinners, movies, museums, theatres, strolling in NYC, apple picking—you name it.

My voice is much stronger and people tell me I look great. The only downer is itching from a drug or two but controlled with Aveeno products. Of course, immediately post op there was some difficulty, but only the usual stuff recouping with surgical

insult to the old bod, I am 66, after all. I was discharged after one month and permitted to drive and travel by air after three months.

I had PT at home and then outpatient in first five months and I think that is totally ESSENTIAL AND THEN TO KEEP ON working out in the same mode.

Getting up and going is so good for morale, and stress relief. It's a no brainer: Put on the walking shoes and get out of the house. Do the things that you like and the heck with the rest!

Hope this helps - sounds like I'm tooting my horn but it's important to let folks know that bad times can turn over. Nothing needs no work - All the best, Donna H



IMPORTANT THE INFORMATION THAT YOU FIND HERE IS FOR EDUCATIONAL AND DISCUSSION PURPOSES ONLY. IT IS NOT INTENDED TO BE A SUBSTITUTE FOR PROFESSIONAL MEDICAL ADVICE. ALWAYS CONSULT YOUR OWN PHYSICIAN OR HEALTHCARE PROVIDER WITH ANY QUESTIONS YOU MAY HAVE REGARDING A MEDICAL CONDITION.

Let's go winter walking!!

Don't let winter stop you from fitness walking or starting a walking program. Every minute counts towards improving your health whether it's a three mile walk around the neighborhood or a ten-minute walk at the mall. You'll see an improvement in your energy level and feel better about yourself.

Finding a walking group to join (or create one), meeting up with a friend or making a commitment to walk with the family can help keep you motivated through the winter months.

Here's a 6-week schedule that will start you out with a new and motivating walking program.

•Before you start:

- Consider Yaktrax or Icers to help you stick to slippery snow and ice-covered surfaces.
- These are wonderful gadgets that can be pulled over your shoes and have metal that grips the ice and snow.
- Layers of technical fabric clothing wicks sweat away from your body and helps keep you warm.
- Vaseline on exposed skin will minimize the chance of frostbite.
- Choose routes that are sheltered from the wind and if not, walk into the wind first.
- Make sure routes are as clear of snow and/or ice as possible.

- Warm-up your muscles by marching in place for three to five minutes followed by a series of stretches.

Remember.....BREATHE!

Shin stretch: Sit in a chair with your knees at a 90-degree angle and drag your right leg back so your toe is on the floor. Press down on your foot until you feel a stretch on the front of your leg. Try three 10-second stretches per shin. After your walk, try these shin stretches again.

Thigh stretch: Placing your left hand against a wall for balance (or a wall), grab your right ankle with your right hand and gently pull your heel toward your buttocks and hold for 10 to 30 seconds. Stand tall and try not to arch your back. Switch sides and repeat

Remember.....HYDRATE!



EXERCISE, LIKE YOUR LIFE

DEPENDS ON IT!

IT DOES!!

Calf stretch: Stand 2 to 3 feet from a wall, with feet perpendicular to wall then lean against the wall for 10 to 30 seconds. Keep knees slightly bent. Make sure your rear heels stays on the floor. Switch legs and repeat.

Back stretch: Lying on your back, clasp one hand under each knee. Gently pull both knees toward your chest, keeping your lower back on the floor. Hold for 10 to 30 seconds, relax, then repeat.

Hamstring stretch: Lie on your back with both knees bent. Grasp behind the right thigh with both hands and pull toward your chest. Slowly straighten your leg, keeping your foot relaxed. Hold for 10 to 30 seconds, then lower leg, switch legs and repeat.

Mix up your routine. Change the music you listen to while you walk – try slower music, such as jazz, for a slower, more leisurely pace and tune into up tempo music for a faster stride. Try a different route every time you head out to give yourself a change of scenery.

Walk to Better Health In 6 Weeks!

Remember: Always check with your physician before beginning any exercise program

Goal

Set a personal goal to walk a particular distance or period of time. You can also set a goal to make a charity walk of 5 or 10 km in the Spring. Goals help keep you focused. Doesn't all this sound fun and we haven't even started walking?

Weeks One and Two

Tuesday and Thursday, easy walks, 30 minutes, arms by your side.

Weeks Three and Four

Mondays and Wednesday, 30 minutes, arms by your side.

Thursday and Saturday, 45 minutes total workout: arms by your sides for first 15 minutes, then bring the arms

up to walk fast for 20 minutes, arms down for last 10 minutes.

Weeks Five and Six

Monday and Wednesday, 35 minutes total workout: arms hanging by your side for first 10 minutes, arms up for brisk walk for 20 minutes, arms down for 5 minute cool-down.

Thursday, 45 minutes total workout: arms by your side for first 10 minutes, then bring arms up to walk fast for 25 minutes, cool down for 10 minutes with arms down.

Saturday, 60 minutes total workout: arms by your side for first 10 minutes to warm up, bring arms up for fast walking for 20 minutes.

Continued on back page— Walk

Those Moldies, But Goodies, Remind Me of Spores

Toxic Mold Related Diseases

Mold, in your home, can be a very ugly sight and can ruin upholstery, clothing, and furniture. There are certain types of mold that produce toxins, which are known as toxic mold. The toxins produced by toxic mold can cause a lot of diseases, in animals and in humans. These illnesses can range from something as slight as a common cold, but in some cases, could even result in death. Here are some of the illnesses which are related to toxic mold, and which people can suffer from if exposed to toxic mold.

◆ **Allergic Reactions:** Most types of mold are known to cause allergies in humans, so also toxic mold. People who have weaker immune systems, or those who are prone to allergies because of their genetic makeup, can suffer badly from exposure to toxic mold. Allergies could result in hay fever, runny nose, breathing problems, and also sinusitis. Some people could develop skin diseases and skin rashes as an allergic reaction to toxic mold. The symptoms can range from mild and infrequent, to severe and chronic. Statistics show that a large percentage of Americans suffer from allergy related rhinitis, sinusitis, asthma, skin problems, and other allergic diseases, most of which can be caused by toxic mold.

◆ **Pathogenic Infections:** Some types of toxic mold are pathogenic in nature and contain illness producing pathogens. Toxic mold types such as aspergillus, fumigatus, histoplasma, etc are known pathogens in toxic mold, which can cause severe infections in people who are vulnerable to such pathogens. Although such toxic mold usually grows in plants and soil, it does find its way into homes due to animals or via open doors and windows, and thus can infect people.

◆ **Mold Smell Illnesses:** Mold has a very musty and distinctive odor. Some people can recognize the smell of mold more easily than others. The odor of toxic mold is not only unpleasant, but can also cause illnesses such as headaches, vomiting, nausea, blocked noses, and asthmatic symptoms in people exposed to toxic mold odors.

◆ **Toxic Illnesses:** Toxic mold produces mycotoxins, which are poisonous substances that can affect the entire body of humans. Mycotoxins can be inhaled by people through the air, ingested through food, and can also come in contact with skin, resulting in many illnesses. Different molds produce different mycotoxins, which also depends on what kind of material the toxic mold is growing on. The most common illnesses that are caused due to exposure to mycotoxins are respiratory illnesses. Mycotoxins in toxic mold can affect the lungs and result in a host of respiratory problems. These include difficulty in breathing, stuffy noses, and are even known to cause bleeding in the lungs, which can lead to death.

Hello, You've Got Mold - Now What?

WHAT WORKS?

- ◆ Stop the source. Most mold problems are created by some type of roofing, waterproofing, plumbing or mechanical problem. Mold needs water to proliferate. Repair the source of the water infiltration.
- ◆ Remove and replace rotted wood, carpeting, wallboard or other rotted organic building materials.
- ◆ Provide for adequate ventilation.
- ◆ Clean the area with a solution of bleach and water (one part bleach to 10 parts water).
- ◆ Keep humidity below 50%. Use a humidity gauge to monitor. Air conditioning will remove humidity. If this is not sufficient, use a dehumidifier.
- ◆ Use high quality air conditioning filters (MERV 11). This type of filter will capture most airborne mold spores.
- ◆ Use a HEPA air purifier. Stand alone and whole house HEPA systems are very effective at reducing mold counts. Mold spores are light and stay in the air for extended periods of time. Properly sized, efficient air purifiers can reduce mold counts by 90%.

WHAT DOESN'T WORK?

- ◆ **Ionizers** Despite manufacturers claims ionizers are not very effective at reducing mold counts. A MERV 11 air conditioning filter is 2 to 3 times more effective than an ionizer at removing small particles from the air. HEPA air purifiers are 10 to 20 times more effective.
- ◆ **UV lights** UV light will destroy mold. However, one must have two things — UV light intensity (which decreases rapidly with distance from the bulb) and dwell time - which is the time that the mold spore is actually exposed to the UV light. The amount of exposure time required to destroy the mold varies greatly for the different types of mold. Some molds are destroyed after a few seconds — others require 8,000 seconds or more. The air traveling in an air duct is moving at a minimum of 100 feet per minute. What are the chances that a mold spore in the duct will be exposed to the UV light for a sufficient length of time? Pretty slim. UV lights have been shown to reduce mold when exposed continuously to the coils of the HVAC system. Cleaning the coils periodically would accomplish the same result.
- ◆ **Ozone generators** Ozone is a highly reactive, toxic gas. Extensive tests have shown that low levels of ozone will not significantly reduce mold spores in the air. However, adding ozone to indoor air alters the chemical make-up of the air — often with unexpected and potentially damaging results. Tests have shown that ozone producing machines can actually increase the amount of small particles and potential carcinogens such as formaldehyde. Machines that generate ozone should never be used around people with asthma, COPD or other respiratory diseases.

Walk

-Continued from page 3-

Now pick up the pace: twenty minutes go as fast you can for about 100 yards then take a short 50 yard break walking slowly, repeat for 20 minutes, 5 minutes arms up fast walking, 10 minutes arms down to cool down.

Naturally, adjust your speed for your condition and do not walk outside on extremely cold days. Remember to breathe, rhythmically, through the diaphragm, in through your nose and out through your mouth. Every day that you walk, you are meeting part of your goal. Better to go slow, long distances than fast for short distances.

"Life may not be the party we hoped for...

but while we are here we might as well dance!"

~ Author Unknown

That's it for now

Email with news:

TerryL2952@AOL.com

Or Phone: 315-853-3342

Lighter Side

A patient is overweight, so the doctor suggests a diet. He says, "I want you to eat regularly for two days, then skip a day and repeat the procedure for two weeks. The next time I see you, you'll have lost at least five pounds."

When the patient returns, there was a loss of nearly 20 pounds. "Why, that's amazing!" says the doctor. "Did you follow my instructions?"

The patient nods and answers, "I'll tell you, though, I thought I was going to drop dead that third day."

"From hunger, you mean?" asks the doctor.

"No", came the reply, "from skipping!"

Have you hugged your support person today?

Discount and Valet Parking

Discount Parking

All transplant patients and candidates are eligible for REDUCED price parking passes, good for up to 24 hours. Phyllis, social worker, will give you a signed patient discount parking form, to be taken to the parking garage at 165th Street and Washington Avenue to purchase advance reduced parking tickets. The office is just inside the parking garage. Passes are only \$13.00 each, but you must first buy 5 passes and leave a \$10.00 refundable security deposit. Later purchases can be for 1 or more passes with no additional deposit. Major credit cards are accepted. You MUST go to the garage office to get the passes. You can use the reduced price tickets for valet parking.

Valet parking

Valet parking is available for all lung transplant patients, families and visitors from 5:45 am to 10:00 pm, Monday through Friday, at the front of the Milstein entrance at Ft. Washington and 166th Street. For all other times, use the 165th Street and Fort Washington parking garage. Parking is free on the day of discharge. Call 212-305-4903 for more information.

Challenges are what makes life interesting;

Overcoming them is what makes life meaningful.

-Joshua J. Marine

See what Jay has done!

<http://www.lackritz.net/>

IN OTHER NEWS ~ Terry L Milstein, (roving reporter, learned mistress extraordinaire of all she surveys and writer of this publication)

Hey, I heard from Edwena who didn't hang around for support group last time because she finished up around noon, and just didn't want to sit around the hospital! She said, "There were are few people there that felt the same way. Maybe next time, we could do a lunch-time thing for those who have to come to clinic. Whatcha think?"

This is a terrific idea! I am due back in for a regular clinic appointment on Jan. 9. You and I may not overlap that day, but we will someday! I just left myself a note to suggest "brunch" in the Garden Cafe on the first floor of Presby for ALL clinic patients who might be around late morning / noon-ish. And if you are tied up in x-ray or blood-letting - send a support person on down to let us know how you are doing!

From Danielle: A friend of mine, sent me this link after doing some research. I was telling him I don't understand why we can't eat soft cheeses, since they're still pasteurized. He's in med school, so of course he had to find out, and here's what he came up with. I'm probably not the only one who misses brie and gorgonzola and feta and (!) fresh mozzarella!

<http://www.medic8.com/healthguide/articles/listeria.html>

And if you happened to miss Dr. Wilt's talk on rejection, thanks to Jay - it's almost like being there!! Also included - as a bonus - is Phyllis' recent presentation on The Social Worker and the Transplant Team - along with several other handy links at: <http://www.lackritz.net/>