

**PLEASE NOTE: This newsletter is completely
and totally unofficial/unauthorized by
CPMC or anyone on staff at the Center.**

**TX News Notes
2/14 2/14/07**



Think Green!

What's Here ~

Rules/NewsCalendar
Exercise – The Basics
MyMedSchedule.com
7HS Staff Appreciation Party

Thanks to Dave Ells
Thanks to Patti Maani
Thanks to Post TX Patients



**IMPORTANT: THE INFORMATION THAT YOU
FIND HERE IS FOR EDUCATIONAL AND
DISCUSSION PURPOSES ONLY AND IT IS NOT
INTENDED NOR IMPLIED 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.**

First the Rules:

I have heard that there is concern about the support group's **informal** [not connected with the transplant center] email list, and the newsletter that is disseminated via email:

1. There has been mention that information about your medical condition may be shared inappropriately. [You don't want to find details of your experience with procedures like bronchoscopies, etc. - spread all over the Internet.]

We've been doing this for a while, and during that time, we've gotten quite a bit of feedback. We have always been aware that some of you are eager to share every part of your transplant journey – but others are more reticent. You are pleased to share the highlights, but prefer to keep the details private. For that reason, we have not used any information without your permission to print. [If we have missed someone – someplace along the line, we are deeply sorry. Please contact us with details so we can be certain that it doesn't happen again!] If you have worked with us, you know that you have approved all photos [except for the ones taken in public at the Holiday Party] and the only info printed came to us from email from you – or one of your support people – or we talked by phone to work out details.

2. And Dr. Arcasoy assured those at the support group meeting that they are under no obligation to tell anyone about their condition, their procedures or their status – because some members of the support group have been intimidated to share such information when they want their privacy respected.

All 128 people who have been added to our email list asked to be added. We have tried to make certain that people had access to our email address – as well as our address and phone number! Over the years, a few people have asked to be removed – and we have promptly removed them from the list. But we are at a loss to understand how people have felt intimidated?? I'm just not that physically imposing! But seriously folks – if you want to be removed from the list – just email and “no questions asked!” [If you prefer to remain on the list – but have your email address screened, just let us know.]

In addition, when you share news, some of you have asked us to hold off telling the rest of the group for a few days, or until the end of the week – or even to not tell anyone at all. We have tried to respect your privacy and your confidences. As above, if we slipped up, it was never intentional and we would like an opportunity to apologize.

Now – if we need other rules, or to tighten down on procedures along the line, please email or call and let us know. The primary intent of the email list, and the news notes is support. If we educate a bit along the way, so be it. If we lighten the load and make a few friends as we go – so much the better!

Calendar: You can always call Phyllis to confirm ~ 212-305-6266

Wed.	2/21	1:30-3:30pm	Theresa M. Daly, FNP
Thurs.	2/22	4-6 pm	Caregivers Only 7HS, Room 7-213
Mon.	3/5	4-6 pm	Mathew Bartels, MD, MPH Rehabilitation Medicine
Thurs.	3/8	4-6 pm	Caregivers Only 7 Hudson South, Room 7-213
Tues.	3/13	4-6 pm	David Fedoronko, MD
Wed.	3/21	1:30-3:30 pm	
Thurs.	3/22	4-6 pm	Caregivers Only 7 Hudson South, Room 7-213
Thurs.	3/29	1:30-3:30 pm	Steven Kawut, MD, MS
Tues.	4/10	4-6 pm	Selim Arcasoy, MD, FCCP, FACP
Wed.	4/18	1-3 pm	
Thurs.	4/26	1-3 pm	Theresa Lukos, Pharm.D. Transplant Medications

News ~

Artificial lung saves transplant patient

Feb 14, 2007 by Helen Branswell



Transplant surgeons have successfully used an external artificial lung to keep a dying patient alive while they waited for donated lungs to become available, the Toronto surgical team announced Wednesday.

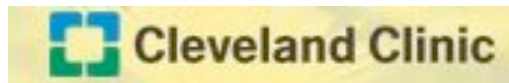
The device has proved to be a lifesaver in the U.S. battle hospitals of Iraq, but it's believed this is the first time it has been used in North America as a transplant bridge – a way to prolong the life of someone waiting for new lungs.

"This has taken lung transplantation and the number of patients we can save to a new height," said Dr. Shaf Keshavjee, director of the lung transplant program at Toronto General Hospital, one of three hospitals that make up the University Hospital Network.

The hospital is planning a clinical trial using the Novalung to help them – and others – determine the best uses for the device, which could serve both as a temporary lung replacement until transplantation and as a way to take the strain off disease-injured lungs until they have a chance to heal.

Use this link to read the full text: <http://www.thestar.com/News/article/181896>

How to Cope After Lung Transplant



Undergoing a lung transplant is a difficult experience for patients and their families. Facing the reality of a serious illness, fearing what is involved in lung transplantation, and dealing with complex, unfamiliar medical information can seem overwhelming and difficult to endure.

<http://www.clevelandclinic.org/health/health-info/docs/2700/2715.asp?index=4289>

And an update from Donna Z.:



I wake up every morning and am so grateful to my donor, my donor's family and the staff at CMPC. I've had a few reactions from the drugs, was hospitalized once

with severe cellulites and again last August for a hip replacement. Two major surgeries in one year....but well worth it. I finished PT for the hip last week and am doing very well.

Skip and I have just completed of fourth trip to Florida to see our one year old grandson. I received my transplant on Aug. 30, 2005 and Zane was born Dec. 28th of the same year. What a great year. I am keeping up with the exercising and Dr. Wilt said I am her poster girl for wearing those horrible support stockings as long as I did. Guess what? No more swelling in the ankles or legs! I still wear them occasionally when I think I need the. Like almost everyone else, I've gained about 23 pounds. They aren't so easy to lose at the ripe old age of 63.

I want you all to know that with each new transplant I hear about, the joy I feel is unexplainable. To all of us, I wish the best.....

From Mildred B.: The Last Word on Sponges and Your Microwave!

Microwaving Decontaminates Sponges, Scrubbing Pads

No doubt about it, sponges and scrubbers are common carriers of bugs that cause food-borne illnesses. Kitchen pathogens from uncooked eggs, meat and vegetables get from the foods onto countertops, utensils and cleaning tools and from there to the sponges and scrubbers used for cleaning. Now a new study has demonstrated that zapping your kitchen sponges and scrubbers in the microwave will kill any bacteria and viruses they may harbor. Researchers at the University of Florida soaked sponges and scrubbing pads in dirty water containing a disgusting mix of fecal bacteria, viruses, parasites and bacterial spores, including pathogens that can survive efforts to destroy them with radiation, heat and toxic chemicals. They then zapped the filthy, wet sponges in an ordinary microwave for various lengths of time. Results showed that two minutes at full power killed more than 99 percent of all the bad bugs (however, hard-to-kill *Bacillus cereus* spores needed four minutes). The researchers advised microwaving your sponges and scrubbers every other day. Make sure the sponges and scrubbers are completely wet before you zap them. *[The study was published in the December 2006 issue of the Journal of Environmental Health.]*



GOP's Norwood dies of lung disease, cancer

2/14/07 - By Christina Bellantoni

Rep. Charlie Norwood, who served in Congress a dozen years, died yesterday in his Augusta, Ga., home after a long battle with lung disease and cancer. He was 65.

The Georgia Republican, a dentist elected in the Republican wave in 1994, was known as a champion for health care during his tenure.

"This man never lost his zeal [and] his purpose for being here never diminished once," said Minority Leader John A. Boehner, Ohio Republican. "He was a great man who came here for the right reasons."

The House interrupted Iraq debate for a moment of silence in honor of Mr. Norwood, who fought idiopathic pulmonary fibrosis for eight years.

In 2004, he received a lung transplant, and later developed lung cancer, a common side effect of drugs prescribed for the transplant.

Shortly after he won re-election in November, Mr. Norwood learned the cancer had metastasized in his liver. His office announced last week he was declining treatment and would instead receive hospice care at home.

House Speaker Nancy Pelosi, California Democrat, praised him as a "plain-spoken and passionate public servant" who "faced the end of his life and his sickness with great bravery and dignity."

Mr. Norwood is survived by his wife, Gloria, two sons and four grandchildren. Services have not been scheduled.

<http://washingtontimes.com/national/20070213-111644-4558r.htm>

Exercise for Life

Improve Your Health by Staying Active



Even if you're older, you'll feel much better if you stay active and exercise regularly.

A small amount of exercise is better than none at all.

Why is exercise good for seniors?

While exercise is good for every-one, it's essential for older people. In fact, your physical and mental well-being depends on it.

- **It helps you take control of your life.** It's an effective way to help improve your everyday quality of life and be independent.
- **It helps you use oxygen more efficiently.** Exercise strengthens your breathing muscles as well as your arm and leg muscles.

- **It can help you maintain your independence.** The more you exercise regularly, the easier routine activities - like shopping, cooking and cleaning - become
- **Regulates your body's waste system:** Relieves constipation by increasing intestinal activity and curbs bloating by increasing perspiration.
- **Promotes strong and healthy bones:** Exercise increases circulation and flow of nutrients to the bones, reducing the risk of fractures and osteoporosis.
- **Better skin tone:** Helps keep skin more elastic.
- **Controls blood sugar:** Physical activity helps maintain the body's glucose levels, important especially for diabetics or those at risk for diabetes.
- **It keeps you from landing in the hospital.** Exercise can improve your general feeling of well-being while keeping you healthy - and living at home.
- **It helps you maintain your weight.** Excess fat - especially around the stomach - presses on the diaphragm, making it harder to breathe.
- **It can keep you from slipping into a downward spiral.** The less you do, the less you'll be able to do. Exercise stops this vicious cycle of inactivity, helping you live easier.
- **It can improve your mood.** Regular activity reduces symptoms of moderate depression and helps you feel more relaxed.
- **It can improve your sleep.** You fall asleep more quickly, sleep more soundly, and awake more refreshed, giving you more energy during the day.

Use it or lose it

What kind of exercise is good for seniors?

Stretching and breathing exercises, plus a daily walk, are a good start. Walking is one of the best forms of exercise around. It's simple, cheap, and can be done anywhere, any time of year. Try walking around your home, at the nearby mall, or a local park.

Over time, there are three kinds of exercise to incorporate into your regular routine. Try to exercise at least three times a week.

- **Stretching** - Stretching relaxes you and improves your flexibility and reduces back pain. It's also a good way to warm up before and cool down after exercising.
- **Aerobic exercise** - Aerobic exercise improves cardiovascular fitness, allowing your body to use oxygen more efficiently. Swimming, walking, climbing stairs, and dancing are all great aerobic exercises.
- **Resistance training** - When your muscles are stronger - especially in your upper body - your breathing muscles have an easier time. Working out with light weights is a good way to build strength.



Thanks to Dave Ells for providing the brochure that he prepared:

Exercise for Life.

We appreciate his permission to use it here.



What advice do you have?

Whether you're walking your dog around the block or swimming laps in a pool you should always keep the following in mind.

- ◇ **Pace yourself** - No matter what kind of exercise you're doing, never rush! Take your time. Rest if you ever feel dizzy.
- ◇ **Be patient** - Start off slow – with an exercise level that's suited to your fitness level and breathing ability. Over time, you can build up to your target fitness level. Remember that longer is better than faster and slower is better than harder.
- ◇ **Set goals** - Setting a fitness goal is the first step to achieving it. If you want to be able to walk for 10 minutes without becoming breathless, make that your goal.
- ◇ **Relax and think positive** - Relaxation and a positive outlook can help you get the most out of any exercising.
- ◇ **Watch pollution levels and weather** - Don't exercise outside if smog or pollution levels are high and avoid exercising outside on days that are too cold, too hot, or too humid.

Find exercises that are right for you. You're more likely to stick with an exercise program when it's something you enjoy. If you like to dance, sign-up for our ballroom dancing lessons. If you like to swim, check out the programs available locally. If you'd like to try yoga, Tai-Chi and resistance weight training many outlets offer classes. Ask at your local library, high school or rec center. Your doctor may be able to suggest other options for you.

We've looked at this before, but a couple of people asked for it earlier this week, so I assumed it was worth another look.

Dr. Patty Maani suggested that we take a look at this interesting website:



MedActionPlan.com announces the launch of My Med Schedule.com™. My Med Schedule.com™ is a free, secure website that allows consumers to create medication schedules that include images of the pills. Available on the web, the site lets consumers save schedules for themselves or family members. Registration is free at www.MyMedSchedule.com.

“My doctors love it when I bring my chart to each visit, so they can see everything taking at once.” says J.V. McPhillips, of Norfolk VA. The site targets people like McPhillips, who take a lot of medications or supplements, or who see multiple doctors. The printed chart helps both doctor and patient.



I am



Users simply click on medications and vitamins to add them to their own list. They can then print their schedule in a letter size that shows colored pictures of the pills. They can also print wallet-sized and large-type charts. Weekly or monthly checklists help people keep track of whether they have taken all their medications. My Med Schedule.com™ also allows patients to schedule refill reminders and map nearby pharmacies. Future plans include links to on-line pharmacies.



MedActionPlan.com, LLC was founded in 2004 by Tim Peters, President of Tim Peters and Company, Inc., a state-of-the-art multimedia group serving the healthcare industry for over 20 years. MedActionPlan.com offers a family of web-based applications to help patients and their healthcare providers improve medication adherence.



[I printed out a nifty copy of my list of meds – complete with an image of each pill! I take a LOT of stuff every day! Most of us are used to our meds, but if someone else had to help us – this would be a real help so they could identify each medication.]



Thanks, Patty! 😊

Did you smile at your support person today?? 😊

7HS Staff Appreciation Breakfast – January 2007

The post-transplant lung patients were pleased to have a chance to say thank you to all the staff on 7 Hudson South. We are grateful for everything they did to help us have a successful journey to a healthier life. [And thanks to all patients who contributed to make the event such a success!]



And a fine time was had by all - at the Staff Appreciation Breakfast for everyone on 7 Hudson South - sponsored by the Lung Transplant patients at NYP/Columbia University Medical Center - January 2007

For getting us endless cups of ice chips -
 We thank you.
 For waking us to take our vitals at 5 am -
 We thank you! :)
 For lifting our spirits as you sing
 while cleaning our rooms -
 We thank you.
 For keeping us company
 in the middle of the night -
 We thank you.
 For reassuring our very nervous support people -
 We thank you.
 For explaining our meds to us over and over -
 We thank you.

For running interference
 when visitors overstayed -
 We thank you.
 For calling the hairdresser for us!!! –
 We really thank you.
 For helping us to the bathroom –
 and back - and back again! -
 We thank you.
 For finding Cherrios to replace corn flakes
 for breakfast in the morning -
 We thank you.
 For your endless patience and good nature -
 We thank you.

