

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

**Mike's new discussion board** is up and running - but not seeing much action yet! How about taking a look, getting yourself registered and starting a discussion of whatever is on your mind. A lot of you are dealing with some diabetes and disbetes like issues. Need tips on management? Good places to order supplies? How to manage side effects? NO medical advice here, but some practical support might be a real help.

<http://lungtx.lostreception.com/>

**Or what about diet?** A lot of us are working with extra pounds. I can't imagine where they came from, but there they are. I'm pretty sure that it isn't all the extra calories - or is it?? We can talk about it on Mike's board: ways to get a lot of flavor with NO salt; ways to get so much taste that you just don't need to eat as much; the really good [filling and satisfying] low-cal, low-fat, no-salt snacks.

**Practically speaking - if you need** more log sheets for your daily post-tx stat's, you should check Jay's website for the link as he writes:

I have scanned in a copy of the Log Sheet that must be filled out and brought to clinic for Post-TX folks. Here is a copy as an Adobe PDF or as a JPG picture file. If you have created your own sheets and would like to share them, please send me a copy.

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

And while you are there, don't forget to check out Dr. Lederer's presentation for the support group. Jay has made it available in both PowerPoint and Adobe formats.

**Interesting news note from Ofelia:**

By Jane Elliott  
BBC News health reporter

Emily Thackray: Emily needs oxygen and regular medication  
Emily Thackray needs a double lung transplant,  
but knows her chances of dying on the waiting list are 50/50.

There are too few organs available for transplantation and, although 90% of the population has said they support organ donation, less than a quarter of these are on the register.

There are currently over 6,500 people waiting for organ transplants, but less than 3,000 are carried out each year. Last year alone over 400 people died while on the waiting list.

## [Their Campaign](#)

Emily, aged 22, and Emma Harris, 32, who both have cystic fibrosis, have launched a campaign to raise awareness of the national organ transplant shortages and to encourage people to register.

They are also selling T-shirts with the logos 'I'd give you one...' and 'Live life then give life', to encourage people to show their support for organ donation.

### **LET'S WORK HARDER TO RAISE AWARENESS!!**

**Great t-shirts:** So many of us go to regular rehab, and need t-shirts! And I find that sometimes, a really good t-shirt will answer some of the unasked questions, and actually start a dialogue. I have two terrific shirts from Cafe Press:

*Ask Me about My Lung Transplant ...* and  
*A Lung Transplant Save My Life*

You can order online [and NO! I do not get a commission!]

Another great place to get t-shirts: <http://transplantawareness.org/productcatalog.html>

But maybe you will be given an opportunity to speak to a local group or class about organ transplants and organ donation? Your first reaction will likely be - "I can't do THAT! I don't know what to say. I don't know enough to talk to other people about this! I wouldn't know what to say or where to start!"

Go for it! This can help: <http://pbcers.org/ODA.htm>

### **Local Support Groups:**

Some of us here in Upstate NY are looking to start a regional "get-together" for lung patients - both pre- and post-tx, and their caregivers. David suggests either a breakfast meeting [and we will entertain suggestions for location!], or an early evening "coffee" time. What do you think?? Do you want to keep it informal, or do you want to try to schedule a specific topic for an actual "meeting?" Email, or use the new message board to talk it over. Do any of you belong to a local support group?? Do any of you get together informally to just keep in touch? Please let us know how things are going, and what works for you! :)

**Update on Mildred:** Mildred is determined to do this the hard way. The latest in a series of difficulties is blood clots! From Susan we hear: Mildred made a trip back to 7 Hudson North this weekend (Friday night). She is experiencing clotting in the lungs. So Dr. Wilt (lovely lady) put Mildred on blood thinner medication for the weekend. Today (about 3 pm) Mildred will have a 3 hour procedure where they go into through the groin and insert a filter (like an umbrella) to block any clots from passing through.

[Ed. note to Mildred: You hang in there, girl. We are all with you on this one!!]

**And:** We have heard from Joseph that Elaine continues to fight off the infection that has plagued her since her transplant. She continues to gain strength as they take good care of her in ICU - where she will remain for the next few weeks at least.

Let's remember Elaine [and Joseph!] in our thoughts and prayers.  
We'll let you know when she can have visitors.

*Remember to watch Jay's site for an updated schedule for support group sessions. Phyllis will email one to him this week – and he will it post for us. It is always good form to give Phyllis a call to check on location/time/etc.: 212-305-6266*

That's about it from here -  
We've heard informally that a couple more TX's have been done -  
No direct contact - so no real news yet -  
Email what you would like to share!!  
Keep in touch -  
~T, 7/10/07

“Mitakuye Oyasin!” (We are all related) .... Lakota Sioux

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