

PLEASE NOTE:

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Great News:

From Mary Ann we hear terrific news: On Tuesday Oct 30, Rich N. had a double lung transplant. Still on respirator, but doing well. Will update next week



And, another post-tx update: Look who's out and around – and breathin' easy! It's Edwina P.!!

We haven't heard much news from anybody else, and are still waiting to hear who the other newly transplanted person might be??

Watch Jay's site for other news:

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

Support Group Schedule:

Tuesday Nov.13, 4-6pm (H)

Thursday Nov. 29, 1-3pm (H)

Tuesday, Dec. 4, 4-6 pm

Tuesday Dec. 11, 4-6pm (H)

Wednesday Dec.19, 4-6pm (H)

Thursday Dec.27, 1-3pm (H)

Brenda Klein, RD Transplant and Nutrition

Theresa Daly, NP Coordinator

Party!! 4th Flr. Faculty Club, P&S Bldg.

Dr. Steven Kawut, MD Post Transplant Testing

Dr. David Lederer, Research Studies for the
Lung Transplant Patient

Speaker to be announced

(H) = Harkness Pavilion, 8th floor Conference Room

Please see schedule for more detailed instructions and check back before coming, or call 212-305-6266, in case the meeting is moved to a different room.

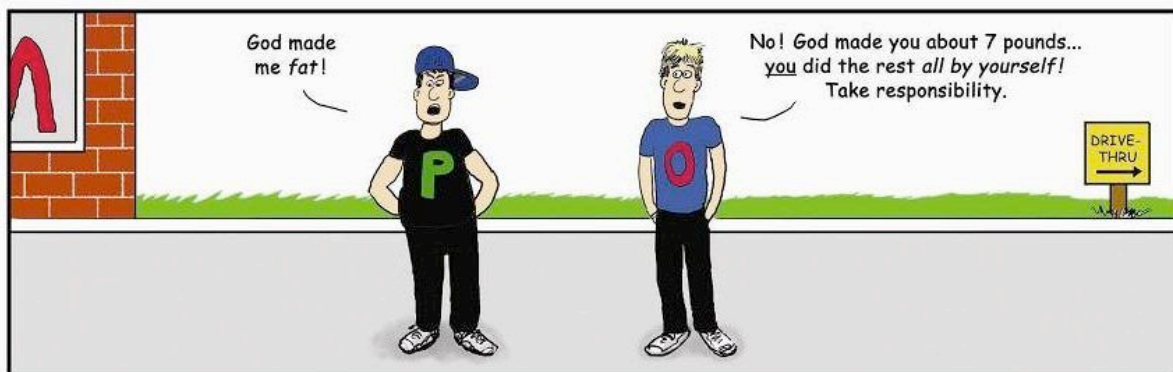
RSVP by Nov. 27th Support Group Holiday Party ~ Dec. 4th - 4pm-6pm
Faculty Club Columbia Presbyterian Med Center Presbyterian Bldg, 4th Flr.
Each patient can be accompanied by no more than 2 guests.
Call Barrett Gray: 212-305-6266 OR e-mail at adg9021@nyp.org

Rules for Holiday Season Weight Control – And Self Control

1. If you eat something and no one sees you eat it, it has no calories.
2. If you drink a diet soda with a candy bar, the calories in the candy bar are cancelled out by the diet soda.
3. When you eat with someone else, calories don't count if you don't eat more than they do.
4. Food used for medicinal purposes NEVER count, such as hot chocolate, brandy, toast and Sarah Lee Cheesecake.
5. If you fatten up everyone else around you, then you look thinner.
6. Movie related foods (Milk Duds, Buttered popcorn, Junior Mints, Red Hots, Tootsie Rolls, etc.) do not have additional calories because they are part of the entertainment package and no part of one's personal fuel.
7. Cookie pieces contain no calories--the process of breaking causes calorie leakage.
8. Things licked off knives and spoons have no calories if you are in the process of preparing something. Examples are: peanut butter on a knife making a sandwich and ice cream on a spoon making a sundae.
9. Foods that have the same color have the same number of calories. Examples are: Spinach and pistachio ice cream; mushrooms and white chocolate.

NOTE: Chocolate is a universal color and may be substituted for any other food color.
10. Foods that are frozen have no calories because calories are units of heat. Examples are ice cream, frozen pies and popsicles.

But Next Reality Should Set In:



Time for Attitude Adjustment? – Consider this ~



John is the kind of guy you love to hate. He is always in a good mood and always has something positive to say. When someone would ask him how he was doing, he would reply, 'If I were any better, I would be twins!' He was a natural motivator.

If an employee was having a bad day, John was there - telling the employee how to look on the positive side of the situation.

Seeing this style really made me curious, so one day I went up and asked him, 'I don't get it! You can't be a positive person all of the time. How do you do it?'

He replied, 'Each morning I wake up and say to myself, you have two choices today. You can choose to be in a good mood or ... you can choose to be in a bad mood I choose to be in a good mood.'

Each time something bad happens, I can choose to be a victim or...I can choose to learn from it. I choose to learn from it.

Every time someone comes to me complaining, I can choose to accept their complaining or... I can point out the positive side of life. I choose the positive side of life.

'Yeah, right, it's not that easy,' I protested.

'Yes, it is,' he said. 'Life is all about choices. When you cut away all the junk, every situation is a choice. You choose how you react to situations. You choose how people affect your mood.'

You choose to be in a good mood or bad mood. The bottom line: It's your choice how you live your life.'

I reflected on what he said. Soon thereafter, I left the Tower Industry to start my own business. We lost touch, but I often thought about him when I made a choice about life instead of reacting to it.

Several years later, I heard that he was involved in a serious accident, falling some 60 feet from a communications tower.

After 18 hours of surgery and weeks of intensive care, he was released from the hospital with rods placed in his back. I saw him about six months after the accident. When I asked him how he was, he replied, 'If I were any better, I'd be twins...Wanna see my scars?'

I declined to see his wounds, but I did ask him what had gone through his mind as the accident took place.

'The first thing that went through my mind was the well-being of my soon-to-be born daughter,' he replied. 'Then, as I lay on the ground, I remembered that I had two choices: I could choose to live or...I could choose to die. I chose to live.'

'Weren't you scared? Did you lose consciousness?' I asked.

He continued, 'The paramedics were great. They kept telling me I was going to be fine. But when they wheeled me into the ER and I saw the expressions on the faces of the doctors and nurses, I got really scared. In their eyes, I read 'He's dead man.' I knew I needed to take action.'

'What did you do?' I asked. 'Well, there was a big burly nurse shouting questions at me,' said John. 'She asked if I was allergic to anything.'

'Yes,' I replied. The doctors and nurses stopped working as they waited for my reply. I took a deep breath and yelled, 'Gravity.' Over their laughter, I told them, 'I am choosing to live. Operate on me as if I am alive, not dead.'

He lived, thanks to the skill of his doctors, but also because of his amazing attitude... I learned from him that every day we have the choice to live fully. Attitude, after all, is everything.

Therefore do not worry about tomorrow, for tomorrow will worry about itself. Each day has enough trouble of its own.' ~ Matthew 6:34.

After all today is the tomorrow you worried about yesterday.

Do what you can, with what you have, where you are.
- Theodore Roosevelt

Prescription Drug Assistance Programs: Many drug companies provide medications for patients who are financially needy. Call the following companies for more information:

Roche Patient Assistance Program (Cellcept) - (800) 772-5790

Novartis Patient Assistance Program (Cyclosporine) - (888) 455-6655

Novartis Transplant Reimbursement Info (Neoral) - (877) 952-1000

Prograf/Fujisawa Patient Assistance Program (Prograf) - (800) 477-6472

Abbott Patient Assistance Program (Gengraf) - (800) 633-9110

For a full directory of programs, including who is eligible and what drugs are covered, visit the Pharmaceutical Research and Manufacturers of America Web site.

And it never hurts to check: <http://www.needymeds.com/>

Let's talk support system and the time right after transplant:



As far as I'm concerned, my husband Stan should be recommended for sainthood. We've been married 42 years and the man is a treasure. If you think I have retained any dignity through this experience, well, my friends, just think again. [There were times the first few days post-tx that the man had to help pull up my underwear, ferheaven's sake!] Be prepared for that. And if you are shy, start working now to get over that! :)

Whatever your support, you will find him/her/them sitting holding their heads saying over and over, "Omigod! Omigod!" - at least once a day at first. They - and you will be overwhelmed - but it won't last because you simply do not have time to be overwhelmed. There's just too much to do.

When you leave the hospital, you are absolutely certain that you are hearing them say things like, ***"And your support person will only have to perform bypass surgery twice a day for the first week, and then after that they will just be doing your brain surgery every other day."***

Nothing you will have to do is anywhere near that scary, but it's all new, and it will just seem overwhelming. Meanwhile, it is going to surprise you AND your support team - when you just get up to get something for yourself when you want something - just because you CAN! You do not need people to fetch. You simply need them to help you keep everything straight, and remember to do things on schedule. If things seem absolutely positively overwhelming.

You need to get a notebook and write everything down. Every time somebody explains something to you - WRITE IT DOWN. You might remember, but probably not. There's just too much. You need to be sure, and you need to know for sure that you are getting it right, or you will make yourself crazy. WRITE IT DOWN. Put the time and the date down whenever you add anything to the notebook. Try to write down who is telling you. For example, Dr. Wilt called to tell me to lower my dose of Prograf from 3.5 mg to 3. mg. We wrote it down so we wouldn't forget or get confused.

I had some low blood pressure issues [This after 30 years of high blood pressure! Go Figure!!] - so we are taking it often and writing it down so we have a good record if it does anything weird.

Back to support: You are going to need somebody to double-check your pills. You will fill the week-long pillbox and check it yourself. Then you need to tell your support person what pills are in each compartment, and then your support person will double-check against your list of prescriptions. It's important enough to take the time to be very sure that you've got it right. Then you don't have to worry about meds for the week. Just be sure that you take them on time. We found that if you open all the compartments first, and put all the meds to one side - it helps. As you distribute each med into the compartments, then put the bottle to the other side. By the time you finish, your compartments will be full and all your bottles should be moved to the other side.



Your support person is also going to help you record your daily statistics: temperature, O2, peak

flows, heart rate, spirometry, blood pressure. You do them at least four times a day. You write it all down every time. It all goes into a very big 3-ring binder that they start you with at the hospital, and that you carry with you for every clinic visit. Genevieve and Dr. Wilt both check our homework.



Okay, now everybody remain calm. Stan also did IV meds for me once a day at the hotel. That sounds scary, but it is really just fine. They installed a picc line in my arm. It's a deeper vein IV - so it isn't close to the surface, and doesn't need to be changed. It just stayed right there as long as I needed it. Those of you with CF are probably familiar with picc lines. They were a whole new experience for us! :)

The line didn't hurt. I cut the top off a tube sock [as Dr. Wilt suggested] to cover the little tassel/plunger thingy on the end - just so I didn't snag it on shirtsleeves, blankets, etc. At the hospital, they showed Stan how to flush the line before starting the meds, how to hang the bag and feed the tube through the IV pump on the pole and how to start it into my arm. When the pump finished with the dose, he flushed again with saline and then with heparin [both premeasured in disposable syringes] so the line wouldn't clog, then close off the tubing et Voilà! Done. Every night, with *Jeopardy* – we IV'ed.

They showed him several times before we left the hospital. When we got to the hotel, the visiting nurse service came with all the gear. They showed Stan how to set it up again, and reviewed again to be sure that he could do it. They came back the next day - just to watch him do it again. No problem. They made sure I had enough premeasured bags of medicine, saline and heparin syringes, alcohol wipes, tubing, emergency phone numbers, etc. This is not complicated and not overwhelming. But when somebody says to you - "And of course, you will be taking care of the IV meds at home" - your support person will freak out. I needed the meds - gancyclovir - to address the CMV virus mismatch that I had with my donor. You may not need any IV. You may need what I needed. You may need something else. No big deal.

They also taught me to check my blood sugar while I was in the hospital. Mine wasn't an issue, so I haven't needed to continue to do that. You may have to monitor yours, and you may need to learn to administer insulin. Again, not a big deal. Lots of folks do it without any problems.

Take a minute now to sit and hold your head. All together now, "Omigod! Omigod!" Good to get that out of your system, eh? Let's remember that ALL of this is easier than what we HAVE been dealing with up to this point. And we can breathe while handling all of it. Kids can deal with this. Some people work all this out with minimal support systems. You can do this.

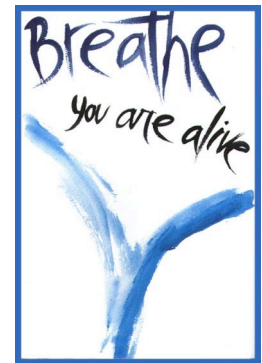


Mostly your support person is going to go to the store. You will want papaya juice, and Twizzlers and then bagels will sound really good, etc. And otherwise, it's going to be a lot like bringing a new baby home from the hospital. You spend all that time getting the baby fed, changed, cleaned up and by the time you've finished, it's time to start over again. And the baby SLEEPS most of the time!

The post-tx recovery felt about the same. You check temp, bp, peak flows, spirometry, you take meds, you get cleaned up, you work on removing SOME of the tape gunk that seems to be ALL over your ENTIRE body, you walk a little bit, you get something to eat - and then you start again

with temp, and bp, etc. And despite your best efforts, you're going to miss a few things. One night we got into bed, and we just about to go to sleep, when we realized that I hadn't taken my 10 pm meds. Omigod! Omigod!! Okay, easy to fix. It gets easier. :)

The other thing that your support person is going to do is sit and watch you breathe. They just can't believe that you can lie there and sleep and just BREATHE like that. It amazes them. I still wake up and find Stan sitting there grinning. [That's a little unnerving!]



Anybody want to share some support experience? We'll be glad to post questions and answers, and pass along any comments. [Watch the discussion board that Mike set up for the group to use: <http://lungtx.lostreception.com/>]

All you support people will also want to keep in mind that Dr. Federonko is available to us when we do need some backup. This process can be daunting, but should NOT really overwhelm. If it does overwhelm you, you need to have someone sort it out for you. And if your support person finds you insufferable - something is wrong! You will feel pretty good, tired, but otherwise just fine. You should NOT be difficult, unpleasant, etc. If you are - get a grip and get some help!

Talk to each other, folks -
This can be scary! Better to share!

Happiness is an attitude. We either make ourselves miserable, or happy and strong. The amount of work is the same. ~ Francesca Reigler

*That's all for now –
We're busy – out and around!
Upstairs at the quilt show –
And I never looked for the elevator!*

*Call or email with news!
~T, 11/4/07*

*Stan & Terry Lopata
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315-853-3342*



Did you smile at your
Support person today?

