

PLEASE NOTE:

This info is completely and totally
unofficial/unauthorized
by CPMC or anyone on staff at the Center.

Hi All –

We lived more than 100 years in New Hampshire. This week, we got an abrupt reminder of what happens when you violate a cardinal rule of rural living. During the summer growing season, you never go off and leave your house open. [“We should know better!” she said disgustedly.]

We came back home the other day to find two very large zucchini squash had been left for us! That's a whole lot of zucchini for just two people. We were able to fob one off on an unsuspecting friend. [“Don't be silly. Your wife will know what to do with it. We'll still have plenty. You'll just love it.”] Moral of this story: Lock your doors!!

We had been out of town for a few days. We made our annual trip up to Vermont to the Amateur Telescope-Makers Convention at Stellafane - in Springfield, VT - official home of the Simpsons [though we don't care much about that!]. We got to see old friends, enjoy wonderful weather, and look at the stars. [*And YES, we are strange folks!*] Here are some photos [or just skip ahead if you are bored!]:



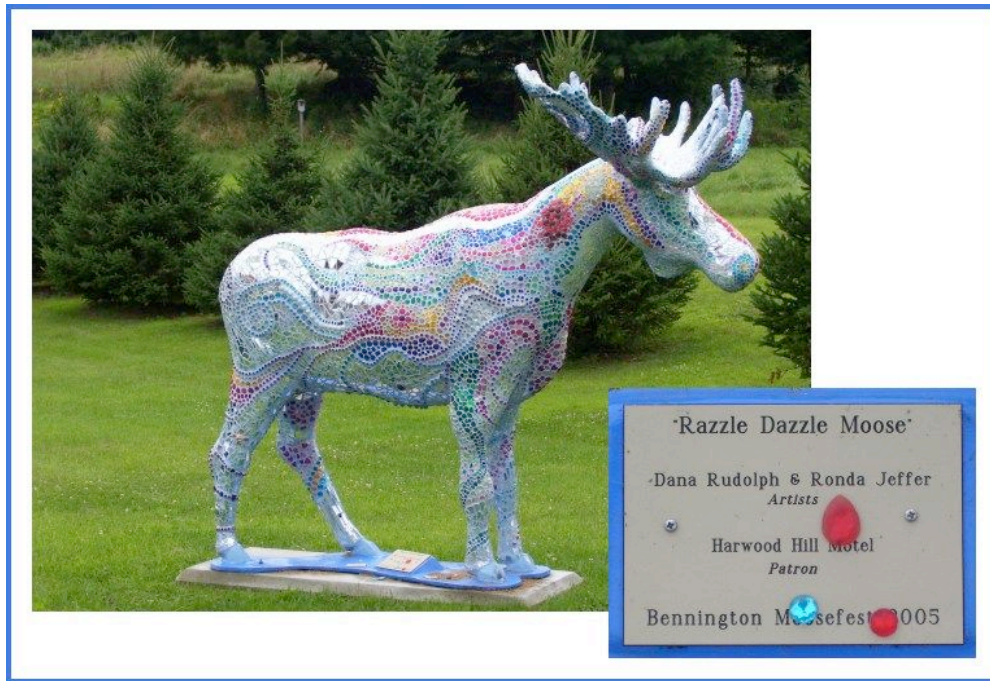
So many styles ...
So many materials!!



Yes!! Those are Legos!!



And a fine time was had by all!



And the photo finish! It is Vermont, after all.
It's not Vermont without at least one MOOSE!

We've had a few random thoughts [actually, with all the meds, we've had more than a few] but ...

1. When you call Velita to make your arrangements to stay at the Crowne Plaza, that's just STEP 1. You need to follow through with STEP 2 - which is to call the Crowne Plaza to double check that they actually entered your reservation in the computer, and GET YOUR CONFIRMATION NUMBER. Velita assures that it will save you a whole lot of time and trouble in the long run!

Speaking of the Crowne Plaza, they are trying to get all the transplant rooms re-settled on the 2nd floor - hoping that it may be quieter and more convenient for everyone. That is the newly designated non-smoking floor, and recently, all the rooms had a very thorough top-to-bottom cleaning.

2. We are still trying to get info on this year's TRANSPLANT PICNIC at Tallman State Park. We will send out an email with details and directions as soon as possible.

3. If you are post-tx, you should be wearing a Medic-Alert bracelet to indicate that you are immune-suppressed. Mine has my name, the words TX RECIPIENT - IMMUNE-SUPPRESSED, and on the back it says, "Please call Columbia Presbyterian Lung TX Center - 212-305-7771." You can order yours online at this website:

<http://www.americanmedical-id.com/>

If you are still pre-tx, it doesn't hurt to plan ahead.

4. About Support Group: A few of you have emailed to say how much you enjoyed Anne Lawlor's presentation, and also how informative you found Dr. D'Ovidio. With his talk, several remarked how easy he was to understand! He gave all the important medical information using everyday language and down-to-earth terms that made everything very clear. [You can usually find an overview of recent support group presentations at Jay's website: <http://www.lackritz.com>]

Here are the next few sessions according to Jay's website:

Wed., Aug 22, 1-3pm	Dr. Jessie Wilt	Bronchoscopy & Post-TX Infections
Thur., Aug 30, 1-3pm	Sophia Brown	Financial Coord. - SS Disability
Tues., Sept. 11, 4-6pm	Dr. Joshua Sonett	Lung Transplantation Surgery
Wed., Sept. 19, 4-6 pm	David Zimmel	PT Exercise Pre/Post TX

It is always a good idea to give Phyllis a call to check on location/time/etc.: 212-305-6266.

Please remember that we need help with information to share with others on the email list who may not be able to attend. Just email your perspective on topics that are presented at support group sessions with a summary of the information, or your questions, or your ideas.

We were very grateful to **John L.** who sent along this review of Dr. Bartels' talk this week:

Once more, Dr. Bartels served as a wealth of information regarding exercise and pulmonary physiology. He started with a combination of an explanation of some of the CPET and PFT measurements they take and how exercise can affect/improve them. Then, he moved to a question and answer format. I thought you might like to hear about one of the questions that I asked him, "Revatio seems to be the greatest thing since sliced bread for treating pulmonary hypertension. I found out that the drug Revatio is the same as Viagra but has to be taken 3 times a day. So, if a guy takes Viagra 3 times a day, does this lead to a 24 hour erection?"

Of course there were chuckles from the crowd. Dr. Bartels first acknowledged that Revatio is the drug Sildenafil which is also prescribed as Viagra for erectile dysfunction. Then he answered, "No, taking Revatio/Viagra 3 times a day will not lead to a 24-hour erection. Viagra does not cause erections; it only helps what would take place normally. For men with ED who cannot get enough blood in to maintain an erection, Viagra helps by increasing the needed blood flow when an erection would normally take place."

Well, that was a relief. My doctor had been talking about switching me to Revatio and I started wondering about that. I mean if you had a 24-hour erection how could you do simple things like have company over?

Just imagine greeting them at the door, "Hi, I'm glad you were able to come over today." The logical response would have to be, "Yes, I can see that!"

6. We pass along this information from David Soohoo, Director of Programs & Operations, Cystic Fibrosis Research, Inc.: www.cfri.org

The fall school year is right around the corner.

We, at CFRI, are pleased to announce that Cystic Fibrosis in the Classroom is now available to our CF community. We hope this will be an important resource all who have children that are attending school, teachers, nurses and school administrators.

Thanks to Digestive Care, Inc., hardcopies have arrived "hot off the press". Our thanks extend to the contributing writers, patient advocates and parent mentors who made this possible. (Attached is the copy of the cover.) If you wish a hardcopy and not in our mailing list, please email us with your mailing address and contact information at cfri@cfri.org OR fax it to 650.404.9981.

Cystic Fibrosis Website Guide, 3rd Edition is also available as a hardcopy. The sixteen page booklet is now filled with updated websites and meaningful and informative resources for our CF community. If you have patients or caregivers who may be interested, please call us at 650.404.9975, email your request at cfri@cfri.org or just drop by our office in Mountain View for a copy.

Next we are pleased to have an update on some folks:

Carl [and Karynell] S.: Carl was discharged on August 5th and he's been doing pretty well. We had our first visit with the doctors' on Monday, August 13th and everything looked good. His new lungs are already operating at 70%.

Heard from **Sandy** that **Angel** continues to get stronger. Certainly good news!

We have an **Edwina P.** spotting from **Susan N.:** We saw Edwina today. My, oh my, what a wonderful picture of health and happiness she is. Edwina was the breath of fresh air we needed. She is doing well and is excited that she will celebrate her one year anniversary on October.

We've heard from **Donna Z., Susan J., DeeDee B., Walter M., Dave E., Dave S.** – and all are doing well. We were very pleased to hear that **Angela C.** is feeling pretty much pain-free after her recent disc surgery. **Karen K.** is getting stronger after dealing with some anemia. We've heard that **Natasha K.** [almost 4 years post-tx!] will be traveling to Italy soon. Enjoy, Tash! ☺

We were especially relieved to get a call from **Joseph V.** to report that his mother – our very good friend **Elaine** is getting stronger and has been moved to the 4th floor medical ICU. She is working hard at getting well and a change of scene can always brighten anyone's attitude. Only "healthy" PRE-TX folks are allowed to visit. The POST-TX folks are immune-suppressed and she has the kind of pneumonia that IMMUNE SUPPRESSED patients can pick up. She is fighting her way through it. It's very slow going. Please keep thinking good thoughts for her!



*And look how healthy **Barb D.** is - more than two years post-tx back at work after her recent trip to Italy.*

A special thank you to **Lois H.** for sharing this thought: I know you're not allowed to garden post-transplant, but I think you can still be active in this type of gardening.

How To Plant Your Garden

*First, you Come to the garden alone,
While the dew is still on the roses....*

PLANT THREE ROWS OF PEAS:

- 1. Peace of mind*
- 2. Peace of heart*
- 3. Peace of soul*



PLANT FOUR ROWS OF SQUASH:

- 1. Squash gossip*
- 2. Squash indifference*
- 3. Squash grumbling*
- 4. Squash selfishness*



PLANT FOUR ROWS OF LETTUCE:

- 1. Lettuce be faithful*
- 2. Lettuce be kind*
- 3. Lettuce be patient*
- 4. Lettuce really love one another*



NO GARDEN IS WITHOUT TURNIPS:

- 1. Turnip for meetings*
- 2. Turnip for service*
- 3. Turnip to help one another*



TO CONCLUDE OUR GARDEN WE MUST HAVE THYME:



- 1. Thyme for each other*
- 2. Thyme for family*
- 3. Thyme for friends*

*Water freely with patience and cultivate
with love. There is much fruit in your
garden because you reap what you sow.*

Not bad, huh?!