

PLEASE NOTE:

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Hey All –

Not a whole lot of news for update. We do know that they are up to #33 as of Wednesday morning. Anybody know who?

Carl S. is the last tx we know, and according to wife Karynell – he's doing just fine. They are dealing with all the common post-tx anxieties, so please keep them in your thoughts. We're going to take advantage of this opportunity to reassure that this is normal, and encourage both pre- and post-tx caregivers to consider attending the Caregiver's Forum which will be meeting in Milstein on 7HS in the Reemtsma Conference Room for the rest of the summer. The group meets every other Thursday from 4:00-5:30. It is a valuable support session that is meant only for caregivers. Come one, come all. The dates are: July 26, Aug. 9, Aug. 23, Sept. 13, and Sept. 27. Please visit Jay's website to get more info and to check out the scheduled discussion topics:

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



[Ed. note: Now, let's talk to each other, and see what we can find out about recent surgeries and near misses – with dry runs: who to congratulate; who needs our prayers; what we can do to help. Please be sure to get permission from the folks actually involved before you email us to spread the word. Thanks!]

We have heard from Mildred B. that she is getting stronger. We saw her [and sister Doreen] at pfts on Monday and the air is going in – and the air is going out. Just like it is supposed to!

We saw other folk, too. Susan J. [and Andy] are doing fine – looking strong and healthy.

We saw Sheila K. – who had her transplant at New Year's – and Willie. They played 18 holes in a golf tournament last week. See! This whole thing really does work.

We also saw Frederica W., who is three years post-tx. And we ran into Craig Y. again. We saw Patti and Bobby D., and Karen K with sister Maureen. We were pleased to meet a relatively new tx friend: Phyllis P., along with sister Pat, and a CF patient who was tx'ed last August, Jake R. and wife Lisa. Everyone is under control and getting on with life – though we all kept getting strange looks at pfts, while waiting for the lab, and in the bronchoscopy suite when we tended to get a bit rowdy exchanging stories and accounts of recent experiences. We all have very in-ter-est-ing tales to tell!

MONEY!! Lots of concern lately about the cost of medications necessary – especially post-tx. Go to Jay's website: <http://www.lackritz.net/> for info, and also check Joann's site – the links along the left side that will detail help for all:

<http://groups.msn.com/TransplantSupportLungHeartLungHeart>

From Jim, we get: *What do you know about West Nile Virus ??????*

I just caught a report on the radio the other day that said in part that persons with weak immune systems have a big problem with West Nile. Being most of us out of Columbia live in areas where mosquitoes frequent I think it might be important for us to know. What do you think ?????



From Jay, we get this response:

For what it's worth, there have been no reported (human) cases in the tri-state area in 2007. However, the season usually peaks in late August and runs through November, and is made worse by heat waves.

So.... They recommend use of repellent, eliminating breeding sites (standing water), fixing your screens, etc. As for repellents, the CDC recommends they should contain one of these active ingredients:

- DEET (N,N-diethyl-m-toluamide)
- Picaridin (KBR 3023)

Picaridin is relatively new, and is supposed to be much more pleasant to use than DEET:

<http://www.epa.gov/opprd001/factsheets/picaridin.pdf>

Cutter uses Picaridin: <http://tinyurl.com/2nz2g9>

- A product containing 23.8% DEET provided an average of 5 hours of protection from mosquito bites.
- A product containing 20% DEET provided almost 4 hours of protection
- A product with 6.65% DEET provided almost 2 hours of protection
- Products with 4.75% DEET were both able to provide roughly 1 and a half hour of protection.

Here's an article from the NEJM from 2002 which includes brand names of DEET repellents:

<http://content.nejm.org/cgi/reprint/347/1/13.pdf>

And, yes... not only people with weak immune systems, but anyone over 50, especially those with high blood pressure or diabetes (more side effects of tx) are at high risk if bitten.

Here's an interesting article from China (yes, China) that says it will be our worst season ever:

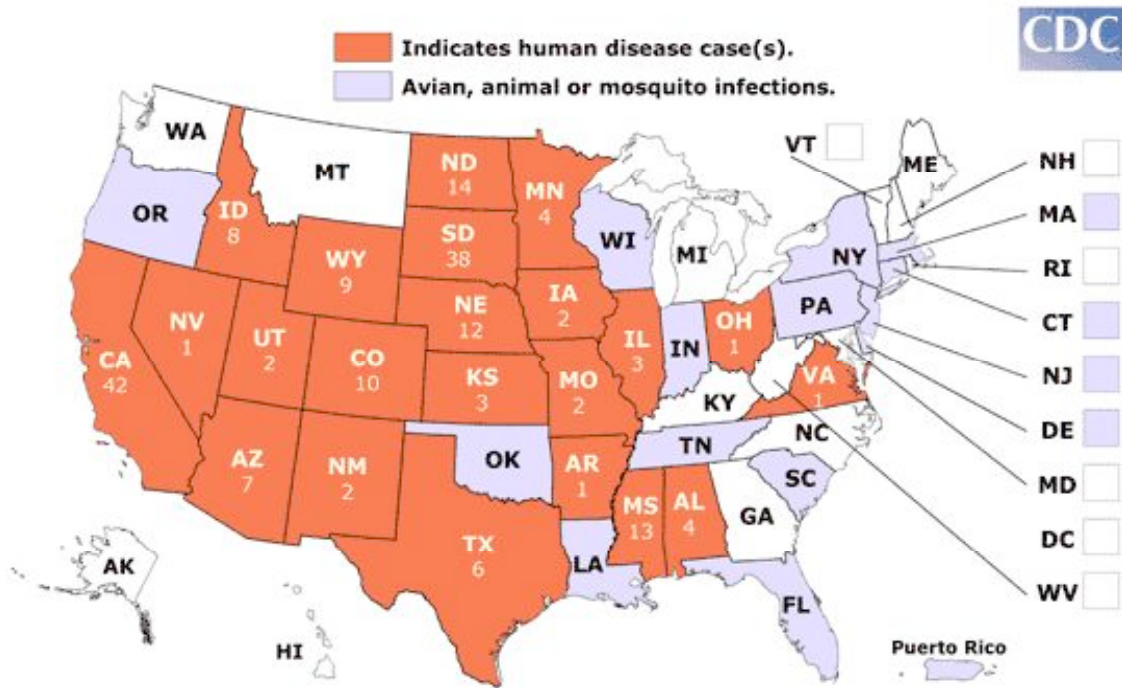
http://news.xinhuanet.com/english/2007-07/31/content_6457285.htm

They may be speaking of California, where four people have died this year from WNV

<http://www.latimes.com/news/printedition/california/la-me-westnile1aug01,1,4911016.story?coll=la-headlines-pe-california>

Here's a map of the U.S. with reported cases in 2007 from the CDC:

Ref: <http://www.cdc.gov/ncidod/dvbid/westnile/index.htm>



And there you have it! More than you ever wanted to know about West Nile Disease – but exactly what you need. So listen up and use your DEET!! 😊 ***But - talk about timely: Read this next item!!***

Party Time!



It's getting to be time for the Heart Transplant Program's annual picnic – usually in mid-September. They graciously extend the invitation to those of us in the lung transplant program, too. Last fall, some of our folks accepted the invitation, and attended the festivities in Tallman State Park. Everybody had a great time. It's a wonderful place to have such a group event, and very convenient for everyone in the tri-state area. We are waiting for info about this year's picnic, and will send out an email as soon as we have details. [Ed. note: Use your DEET, when you go!]

Immunizations

Pretty soon, school will be starting again. It's not unusual for children of various ages – ***including teen-agers and those heading off to college*** – to need immunization shots. If you are post-tx, you need to be very careful around all children [including your grandchildren] – who may be having inoculations! Ask your doctor what you need to know, and what to do.



[Here's a good perspective on exercise from Kathleen S.](#) [who is still pre-tx – but this is equally valid for everyone who is post-tx!]: Today as I was shopping at a small boutique, I met the owner and it turns out that her husband just had a liver transplant at CPMC. He did great with the surgery since he kept himself in good shape prior to the surgery, working out to keep strong. So, let everyone know that it really helps after the surgery. Yes, all of the doctors tell us that and we say, “O.K., O.K.,” but we may not have it high on our list of daily priorities, especially if we don’t have a formal setting (gym). I now look at exercise as basic to my health, like brushing your teeth and flossing and using the WaterPik. If there is a facility around your neighborhood, that’s terrific. If not, you can drive a distance. I am sure you will find one. It’s that important.

Strictly Me – Off on a Tangent!



After transplant, sometimes it feels like we spend a lot of time getting lab work, getting x-rays, having various “procedures” – and tests. We sure seem to need a whole lot of tests! This week I had a barium swallow, routine lab work, a sleep study [not nice!], a bronchoscopy, pfts, an x-ray and two [count ‘em 2!] consultations. All pretty standard stuff based on my stats/symptoms/indicators. This week was NOT typical – but it has been busy! Many of the others have also “enjoyed” these, and other interesting doings!

The doctors and transplant coordinators do a good job getting us ready for all these tests. We know why we need the test, what to expect, where and when, and what will happen when we get there. They make it as easy and convenient as possible. If you need a test or procedure, and if you are concerned, have questions, or want to talk about it – you should ask your doctor or coordinator for more information.

We won’t do medical advice, but you might also want to chat with the group via email to me, or check Jay’s website for a link to provide more background information: <http://www.lackritz.net/> - or post your question on the discussion board that Mike set up for us: <http://lungtx.lostreception.com/>

Sometimes, you can get **practical** advice that is invaluable. For example, I sure wish someone had suggested that I take a hat for use after the sleep study! I had several hundred thousand things glued to my hair with some substance about the consistency of toothpaste. After the study, they scraped most of it out, but ...

Anyway – don’t sit and worry about all the tests. Ask your questions. Worry out loud and we can talk. But remember that the time doing tests, is time well spent because it keeps you healthy. And the air continues to go in, and out! What more could you ask?

~T, 8/4/07

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Email with news –
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