Turvy

In yet another turn of fate, the game board has been flung skyward.

I spent the first part of the week at the hospital getting tested for my fitness to endure an autologous stem cell transplant. The good news is that I am a picture of health, passed all my tests with flying colors.

The bad news is that I am experiencing an aggressive recurrence of the lymphoma. All bets are off.

This is not quite all the way back to square one, but close. There will not be a transplant unless we can get to remission. In the mean time, I will undergo yet another “salvage” regimen in hopes that we can get the cancer under control. There are two primary options to choose from once results from my bone marrow and neck biopsy come back.

The likeliest is a drug called Romidepsin. Unlike my prior therapies, this one will be done locally, one day a week for 4-5 hours. There will be two cycles of this, each cycle consisting of three weeks on and one week off.

The good news is that this therapy is supposed to be very mild on the side effects and is far less toxic than standard chemotherapy. (This is a newer generation of drug.) It has a good track record in general, though again, the rarity of AITL means that there is insufficient research to indicate whether my cancer will respond.

It is something of (another) leap of faith. The good news is that it will give me about two months to clear the previous chemo sludge out of my system. If I am not in remission after the two cycles of Romi – or if the biopsies come back with something unexpected – we will move to another chemo cocktail or perhaps a clinical trial of some sort. None of this is good news, though at least I still have some options for treatment.

Our transplant doctor was blunt: “You have a very aggressive form of cancer, and no good options.”

Thanks, doc. On the other hand, our oncologist is not quite so fatalistic, you should excuse the expression.

The odd thing is that I feel pretty good aside from some ongoing fatigue issues and a sore spot in my hip where they removed some stem cells and bone for the biopsy. (Not as bad as it sounds, but almost.)

So the saga continues. Thanks again for the music and books and cards and emails and such. I appreciate you all. I owe a couple dozen thank you notes and return phone calls and such. Damn, y’all are good friends.

I’ll post again when I have more news. Until then…

LOVE EACH OTHER, MOTHERFUCKERS!

Ask Not For Whom…

Life since the last update has been fairly routine, if by routine one means a seemingly endless succession of inpatient chemo sessions punctuated by deep exhaustion, malaise, and occasional mild bouts of tummy tumult.

The last round of standard chemo left me pretty well flattened, a piece of unidentifiable road kill sprawled on the sofa, incapable of following a thought for more than a few seconds at a time. It was as though I were looking at a huge, jostling crowd from above, everyone wearing big, yellow hats with nothing to distinguish one from another. Then, one person would take off their hat and I would try to follow that person/thought. But no matter how hard I would try to concentrate, the damned thought would put the yellow hat back on and start trying to hide. Then another would take off the yellow cap for a few seconds before hiding. Ad infinitum.

Then, everybody’s hat would turn red, and I would try to figure out what had changed, but there was no hope of ever remembering what that change could have been. Then I would forget anything had changed at all.

Rinse. Repeat.

Gah.

This lasted a solid week. Since then I have enjoyed a rare stretch of clarity and (slightly) elevated energy. Reading is again enjoyable, the words alive on the page and taking lively shape in my mind.

Alas, all good things must end.

My PT Scan came back with terrific results and I have been off all meds, feeling pretty darn good. The scan showed that the chemo did its job. That means I am eligible for stem cell transplant. That process begins next Monday. Once more, unto the breach.

I am filled with hope and dread. Hope that the SCT will work as planned. Dread because the chemo I will receive for this will make the previous chemo look like child’s play. And dread because following a few rounds of outpatient testing and treatment, I will likely spend the bulk of August and September in confinement.

An essential part of the transplant process is application of chemo in doses sufficient to destroy pretty much everything I’ve got in the way of bone marrow, white cells, platelets, etc. The whole immune system has got to go, basically, and cell division – which is the basic characteristic of any living organism – will be nothing but a memory. Shorter: They want to get as close to killing me as they can without me actually dying.

The original begin date for this was July 23, and boy was I looking forward to the next couple of weeks. But somebody canceled their treatment, so I was moved up by 8 days. On the one hand, this is good. We get started on my treatment sooner and deny the AITL an opportunity to return.

On the other hand: Well, fuck.

Fun Fact: Because the transplant process will take my immune system down to zero, I will have to get all my childhood immunizations again.

Greatest thanks to all who have sent messages, books, food, music, &c. I have a universe full of amazing friends. Can’t wait until I can see you all and can give you a giant hug. This elbow tapping is a poor substitute for a heartfelt neck squeezing.

Locals: Hoping to set up an outing to one of our local drink spots before I once again disappear into the gaping maw of the medical-industrial complex. Likely Friday or Saturday. Stay tuned via FB/Twitter.

Also too: