Crying on My Coffin Sheets

February 3, 2009 By Richard Ferri, PhD, ANP

It happened last night. I could no longer live in my comfort zone of denial. I was having classic symptoms of “hypersensitivity reaction” to Abacavir. It had been about 3 weeks since I started the drug (this time frame for which these symptoms to generally appear), and I felt like shit. Dying was too good for me at this point.

I looked at the “Warning Card” about Abacavir hypersensitivity reaction and I ruefully smiled to myself like the jerk heard big pharma whore I used to be. The warning card said that if a patient had TWO or more of the FIVE listed symptoms the patient (hey, that is me btw) should stop taking Abacavir immediately and call thier doctor. It also gently remind me (the stupid patient) that if I were to stop taking Abacavir for these symptoms, and accidently ever started to take the drug again (or the two other HIV Abacavir containing meds) I would likely die of severe low pressure, and a heart attack. Sweet.

This shit was not supposed to happen. I did all the right things. I had the required prescreening genetic test for HLA-B*5701 gene performed at the fucking Mayo Clinic which came back negative! Plus these reactions only happen to about 5 percent of the population who attempts the drug (well, someone has to make up that 5 percent so why not me?) Well it did happen. It is happening as I write.

I am sitting here naked watching a blizzard blanket Cape Cod checking my temp, slugging down throat numbing medicine mashed in with Oxycontin and ibuprofen feeling like hell, and just waiting for the fifth and only missing symptom to appear - rash.

But the one who I am really made at is me. Once again during my fame and glory days I went on road to introduce Abacavir for the drug’s manufacturer. I am trying not to remember how glib I was about this “so-called” POSSIBLE hypersensitivity reaction. “After all,” I can hear my words boomeranging in my head, “it is a good drug with only a 5% potential for serious reaction which is a hell out of a lot better than most any other drugs out there. And the warning signs are very clear and spelled out….and on and on and on…..”

The fact of the matter is that Abacavir is a good drug for most patients and does indeed have very clear warning signs spelled out, and now even has a genetic marker to predict the possibility of the hypersensitivity reaction from happening. Swell.

What it doesn’t have is the ability to jump out of the bottle and walk across the room and slap someone, like me, in fact and say: “Stop taking the fucking drug asshole. You are killing yourself!” Ah, only if it did.

I always come to the reality party a little later than most people. After all when I was an active drunk and user you think reality had any real influence over my actions? You begin to fully understand this when you realized that you had been downing your daily chemo for years with vodka just to steady your hands

to set up some slams, and it never occurred to me that maybe this was wrong. Not for one minute.

So last night after my temp went over 101, I could no longer talk, was in severe pain, and my guts were screaming “Mambo!” like the Sharks and Jets at the gym I decided it was time to dump the fucking pills, have a good cry, make sure my “Do Not Resuscitate” paperwork was clearly by my bed and go to sleep. It was totally out of my hands. It was up to God, as all things are.

However, as I pulled back my bed covers a chill ran up my spine as I wondered was I pulling back the covers to my own coffin. Just staaring at the nice clean sheets I felt some tears form. Honestly, only some of those tears were for me. The majority were for all the other people who had been down this road with this drug, and if I wondered if I had anything to do with it? I cannot imagine I got off scot-free here. But I also realized I am not to blame. I was reporting the on the science and while I may have given off a sense of “fuck it” I also spoke the clinical truth. It just happened that the truth I spoke years ago was not going to apply to me.

So here it goes again medical science and clinical reality do not always hold hands in “happily ever after” land. I guess that is where I have a chance of coming in as the HIV medical clinician that is also living with AIDS. Let?s hope I do a little better of job next time.

Anyway, as one of my favorite novelists famously said in his bestselling novel The Confessions of a Male Nurse - “Some days chicken; some days feathers.”

Today it is all fucking feathers if you ask me.

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