Paging Dr. Larry Kramer

August 14, 2008 By Shawn Decker

Am trying to catch up on everything that happened at the International AIDS Conference last week while staying on top of Olympic badminton... man, those guys are *fast*.

In regard to HIV/AIDS, I noticed an article written by Tim Horn, which addresses why a lot of positoids are afraid to start meds. A chief concern? The fear of side effects.

Reading Tim’s article took me back. A few years before I started on HIV meds in 1999, I felt the same way. The HIV-related fatigue I could deal with, I’d lived with it for so long and managed to enjoy life with subpar energy levels. When I got really sick, however, there was no longer a choice in the matter, and the medications saved my ass by raising my t-cells from 30 back up to over 200 and knocking my viral load from 800,000 to under 100 copies.

However once I was on the pills my fear of side effects merely *increased.*

It must be noted that one of my starter drugs was Viracept, which is known to be harsh. When I switched to Sustiva, I enjoyed a honeymoon period until I realized the side effects had not gone away, they'd merely switched from physical to mental. And speaking of going mental, shortly after starting HIV meds, I saw Larry Kramer speak at my friend Stephen's memorial service in New York… HIV meds may have saved my ass, but Larry railed that they had taken his away.

Literally.

"I have to wear overalls because I have no ass now!" He was upset and was going off- not off of his meds, but going off on the pharmaceautical companies. He suggested that positoids should stick it to them by taking our meds half the time. "Half the profits!" Larry yelled.

He was angry. But I was thankful. Thankful to be alive, in large part because I got sick when HIV medications were in existence and available to me as a middle class American.

As I left the memorial service, I couldn't believe that someone would advocate such a risky move in regard to HIV treatment. A couple of years later, and a few more hundreds of pills down the hatch, however, my perspective began to change. After reading an article on Structured Treatment Interruptions, and acknowledging my own growing fears of long-term side effects (particularly with my liver), I spoke with my doctor about giving it a go. If lab results suggested that my HIV levels were on the rise, I'd just go back to taking my pills all the time.

That was in 2002, and it was among the best decisions of my positoid life.

I haven't written about a central part of my positoid life- my life on HIV meds- in some time, and felt the need to put it out there. I'm not so bold as to suggest that this would be right for everyone, but I'm not naive in thinking that I've simply lucked out.

Here's an article on where the medical community stands on Structured Treatment Interruptions. There's a brief mention of week on/week off near the end, how one small study was promising but conflicted with a similar study's results in Thailand. Here's a whole list of information on treatment interruptions.

In the beginning, there was the hope that these interruptions would teach the body to manage HIV on its own. When that hope wasn't realized, and studies came back with mixed results, the scientific community moved on faster than those Olympic badminton fellows.

Still, as HIV medications get better, I hope that the theory that less-could-be-more can be revisited. Because, whether someone is newly diagnosed or a longterm survivor, quality of life issues should not be ignored. And as wonderful as these drugs have been, the side effects can be as unbearable for the longterm survivor as the thought of beginning treatment is for the newly diagnosed.

Positively Yours,
Shawn