



# Green Week Challenge to Big Pharma

November 8, 2007 By [Shawn Decker](#)

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So this week is Green Week, right? Well, I think my week-on/week-off meds schedule makes me green enough. That's half the electricity and whatever else used to maintain my health through meds.

I know, that pat on the back isn't fair if some readers take meds all the time, which most do who have access to treatment. I'm just dicking around, as usual. I went week on/week off years ago because the general thinking was that longterm side-effects of HIV meds were considered a serious threat. By 2002, when I first did it, I'd had friends who'd tried everything and still died, friends who'd lost vision, developed diabetes, all kinds of things associated with side-effects of HIV meds. With my hepatitis C co-infection, I thought my liver would appreciate a, "vacation's all I ever wanted, vacation had to get away". So, in a way, hepatitis C may have led me to a healthy decision for myself. (Note: In 2005, it was discovered that my hepatitis C virus was, in fact, non-threatening to my longterm health. I was in the "Lucky 15", 15% of hepatitis C non-progressors.)

So for a year and a half I've been doing week on/week off with my HIV meds, and I've been happy with the results. Which is why I was surprised when I heard the new word on treatment is the old word. An article in Poz said, basically, that the general thinking now is that those old side-effect worries were nothing more than HIV progression. *What?* After roughly 15 years of watching and studying HIV progression before combination therapy (the multi-pill approach) doctors and HIV/AIDS researchers had no grasp of HIV progression? Or that they genuinely couldn't figure out what was a side-effect and what was the virus once meds were introduced into the equation?

I knew my health decline in 1999 was a result of HIV progression. Fatigue led to more fatigue and loss of appetite: my body was shutting down. It needed help against the virus. I know for a fact that my first ten months on meds, I had diarrhea. When I switched meds, that stopped. I don't think my virus was causing that, or the nausea that stopped as well. For two years after that, I took another set of drugs. Then realized I felt crazier than usual. Side effects switched from physical to mental, which was a relief until I realized what was happening. Went on week on/week off for two years, and felt less crazy.

So, I had a brilliant idea which festered from my good health. That was to cease meds for a few months so I could really clear my head and finish my book. A side effect of that decision? My virus actually progressed, out-of-control, causing my immune system to freak out, making me have the worst nosebleed of my life.

That sucked.

That's why I don't take meds lightly. But I won't let side effects of the drugs off the hook as easily as the

HIV/AIDS establishment. They are real. Don't tell us that it's all the virus, don't insult our intelligence. We can handle a world of grey, where the effects of the virus and side effects co-exist. Now I've been on my second round of week on/week off for a year and a half. I'm good at remembering when I restart, and when I stop, and my t-cells and viral load have remained stable. I'm not saying this would work for everyone- other factors come in such as a healthy living environment and I don't abuse substances outside of the quarterly letting-down-of-the-hair.

But I am saying that this should be considered.

I feel compelled to write so, because I know it's just not on the table. God, I think I read it somewhere and somehow my doctor agreed to monitor the results. But it was only because that thought or ideal was out there. And now it's not. And I don't think my improvements in health and lessened side-effects are some major fluke. So here's my Green Week Challenge to the Pharmaceutical Companies or the Bill and Melinda Gates Foundation or Oprah or anyone else with hundreds of millions of dollars and more than a passing interest in HIV/AIDS: Fund major studies on week on/week off HIV treatment.

Positively Yours,  
Shawn

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