New Adventures in HIV Medication

July 30, 2013 By Shawn Decker

(update: Check out Shawn's lab results here.) In 2002 I made a decision regarding my HIV medications- I'd been on combination therapy for 3 years after receiving an AIDS diagnosis in 1999, and the HIV medication most certainly brought my health back. But at the same time, I was feeling the side effects and was concerned about long-term side effects.

At the time, I'd read a couple of things about structured treatment interruptions and heard Larry Kramer rant about HIV drugs at my friend Stephen Gendin's memorial. Larry yelled, "I have no ass because of these drugs! We should all take our medication for one week, then take a week off so they get half the profits!" Needless to say, he was pissed off about more than just losing a friend that day...

I'm fortunate that my doctor and partner, Gwenn, were okay with giving a structured treatment interruption a try. I was quite relieved when my t-cell count continued to climb, even with a week off, and my viral load remained undetectable or very close to it. In 2009 I wrote a column for Poz about my experiences with week on/week off therapy. You can read it here.

All in all, I've been happy with the results of the experiment. But last year, it felt like time to try a new combination. So I switched from Norvir, Reyataz and Truvada to Complera, continuing the week on/week off schedule. After six months of experiencing changes in mood, from being more angry than usual to feeling depressed, I through in the towel and decided to go back to my previous combination. But the lack of energy on that combination- which was quite severe during the first week of July- left me a bit shaken...

I was texting with a trusted friend about all of this, and asked how he dealt with side effects. "I don't really have any," he replied. I followed up on email because I had so many questions, and he confided that he approaches HIV medications the same way I do, but has implemented the strategy a bit differently. Instead of a break from HIV medication, he takes less than is normally prescribed but doing so under the guidance and knowledge of his doctor.

Needless to say, I was intrigued.

So I spoke with Gwenn about it at length and once again huddled with her and my doctor, who researched the idea. We've all agreed to give it a shot, and for the last week I've been taking 800 mgs of Prezista with 100 mgs of Norvir. In about five weeks, I'll be going in for lab work to see how things are going.

Am I scared to experiment with this? Not really. Partly because of the last ten years of how I've been taking my medications. In terms of effectiveness, every combo I've been on has done it's job of attacking the virus and neutralizing its ability to wreak havoc on my health. I'm convinced that far better

treatments- and possibly a cure- are on the horizon, and it’s not insane to think that could be ten to fifteen years off. But I’m not interested in sitting idly by- I know I have a great shot at being around for the next big breakthrough in HIV treatment, but I want to be in the best position to enjoy the time between now and then. I don’t like living in a haze, or feeling like I need a nap after a fifteen minute conversation with friends.

I know a large part of my health is simply the culmination of living with this virus since 1984. But I also know that decisions regarding treatment can also affect how I feel. And, simply put, in my heart and mind I know it’s time for a change. I don’t mind not having that week off from taking my pills, and am not worried about forgetting to take them every day.

I’ll keep you guys updated. Wish me luck, and I sincerely hope this finds you well.

Positively Yours,
Shawn

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