On Starting My First One-A-Day HIV Regimen

June 26, 2019 By Shawn Decker

Yesterday I started my first ever once-a-day HIV drug regimen in Biktarvy. This isn't an endorsement, nor are any of the treatment options I've chosen. I just really wanted to discuss this in the context of the long road it took me to get here.

Being diagnosed in 1987 at age 11 was tough. Even a heaping bowl of Fruity Pebbles couldn't sugar-coat it. There weren't any effective treatments available, so my mom got a little resourceful. She wasn't part of a buyer's club but she was tracking down any information she could about anything that provided even a hint of hope in extending my life.

I remember this butter-like substance that she would put on toast. And I remember her reaction when I said something like, "I like butter better." Whenever she made me "A Shawn Shake!" as she called them, she would delight in the fact that I sucked the whole thing down every time and never once complained about it's taste. There were little grains in there, almost like tiny seeds, just one part of a recipe that surely included some things that she thought would help stave of HIV. And, well, if it did nothing then she at least got to see her kid enjoy a hearty milkshake.

After AZT was approved, my doctor was hoping that I'd try it. My mom asked me if I wanted to. I asked her if it would cure me. She truthfully said that no, it wasn't a cure and that it would mean more visits to the doctor for labwork. I didn't want to take anything that only guaranteed more needles going into my arm and I hated the labwork, I couldn't understand why anyone wanted to track my t-cells. The less I heard about HIV the better.

I was 13 or 14 at the time.

I'd say my health was okay. My t-cells fluctuated a bit but always stayed right around that danger zone that probably kept my parents on pins and needles. If I got a cold it would just last longer then if my big brother got it. Strep throat visited at least once a year for a few years, but by high school things seemed to level out. After I graduated, I did notice a dip in my energy levels. A couple of years after I graduated is when real HIV treatment options were available.

It was 1996, the same year I decided to go public with my status.

Once again, my doctor implored me to consider taking HIV drugs. But I was in a different

headspace, way more worried about updating my website or turning in my latest Positoid column for POZ. Even after a really nasty bronchial infection that lingered for close to two months, I still didn't consider HIV medications. Perhaps my resistance stemmed from the fact that treatment for hemophilia had introduced me to hepatitis B, HIV and hepatitis C. But mostly it was because, for once, I viewed myself in a positive light for being positive. And subconsciously I believed that the bigger battle had been won when I decided to open up about HIV.

Things took a turn for the worse in 1999. I got the flu or something akin to it, and lost about 30 pounds over the course of three months. My borderline t-cells were plummeting. My attitude on the labwork had shifted, for a couple of years I was running a contest for my friends in the office at POZ: The Labtest Contest. Whoever guessed closest to my actual t-cell count would get a signed (by me) copy of me with a random celebrity I'd gotten a picture with at some time in my life. I believe the late, great Stephen Gendin won the picture of me with Danny Bonaduce.

As my health was failing and my long-time doctor was retiring, I finally agreed to take something: marinol. Synthetic THC. I'd never smoked pot- even after attending Beach Week with my fellow Waynesboro High School graduates where "Wake and Bake!" was the afternoon alarm clock.

Marinol was quite the parting gift from Dr. Lyman Fisher. My appetite increased dramatically. While out at dinner with my new girlfriend, Gwenn, the waitress was coming to ask if we needed anything else. "Just the check-" I cut Gwenn off and requested a chocolate milkshake. She was surprised as my lack of appetite had become the norm. That was the first night of the first day of taking marinol.

And yes, I got totally high, too.

Although my appetite came back, my t-cells continued to crash and burn. I was down to 32 t-cells by the time I met with my new doctor. He didn't ask if I wanted to take HIV drugs, and he asked when we were starting. I knew it was time, and I was pretty scared when I started my first combo, which Gwenn has reminded me was more than just 6 pills as I just posted on Twitter. With viracept alone I was taking 6 pills a day, and that was just one of the three drugs.

After just 6 weeks on treatment, my viral load went from around 900,000 to 800. The increase in t-cells was more gradual, but even my doctor was shocked at how fast the treatment was working. After a few months on medication, my energy levels came back. And soon they were exceeding anything I'd felt since high school. I realized just how long I'd been running on fumes.

Still, it was the right time for me to start even though it was a little late. Mainly because I was ready for the commitment of taking the pills everyday.

I was on my first combo for 10 months, and the side effects were pretty rough. Nausea and diarrhea. I made my first switch, which resulted in fewer pills and no side effects which affected my stomach. That was great, because soon after I made the switch, Gwenn and I were traveling extensively across the country to speak to college students about HIV. I couldn't imagine making

those flights and drives on Viracept, which had me asking Gwenn to pull over on a couple of occasions so I could throw up.

And they said romance was dead.

After a few years on the second combination, I noticed the mental fog. I just didn't feel right, mentally. Around that time I was starting to work on my book, My Pet Virus. I really wanted to think straight, and I was reading some blips and blurbs about something called a "Structured Treatment Interruption". I encouraged my doctor to let me give it a go, and we agreed on a week on/week off strategy. Seven days on HIV meds, seven days off.

And it worked. Even when I went in for labs on the seventh day off, my viral load was either undetectable or close to undetectable and my t-cell count remained stable. I really felt like I'd cracked some kind of code. My doctor was even surprised. Emboldened by my success, I thought I could take a month of my medications to finish my book, which had a looming deadline. After a month off, I went in for labs: I was shocked. My viral load was close to undetectable, but my t-cell count had dropped a little. Not too big of a deal, I thought. By the end of two months off my meds I ended up in the hospital, because the virus had rebounded and the effects of my immune system going into hyper-defensive mode caused a few problems.

For one year after that self-induced debacle, I was on constant uninterrupted treatment. I'd gotten the last story in my book, though, about how Gwenn and I had to postpone our honeymoon because I'd ended up in the hospital. But I'd learned my lesson: HIV is tricky little stinker. After a year I went back to week-on-week-off with less of cocky attitude.

The next switch was from week-on-week-off to less drugs, but daily. I'd take a main drug with a 100 mg "booster" of Norvir. My viral load remained undetectable on 600 mgs of Prezista and 100 mg of Norvir. And for the most part that's what I've been doing for the last several years.

One consistent side effect of my HIV medications has been elevated cholesterol levels. Two years ago, I met with a new primary care physician. "This is the highest number I've ever seen in one of my patients!" I started taking a drug to lower my cholesterol, but that caused my liver enzymes to be elevated so I stopped taking it.

The one-a-day pill for HIV that I just started supposedly will not have a negative impact on my cholesterol. I sure hope that's the case. As you can see above, I'm more comfortable with a "less is more" approach to medication. I'm lucky that what I've tried has worked so long as I don't push the boundaries or let my guard down. Now, I'm old enough to know better. I'm hopeful that, six months down the road, I won't be my primary care doctor's Champion of High Cholesterol anymore.

All in all, though, I feel so fortunate because, if this doesn't work to reduce my cholesterol, there are other options out there. Which is a far cry from the those magical butter days.

Positively Yours,
Shawn

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