Meet the Man Who Got HIV While on Daily PrEP

In this sexually frank POZ Q&A, he recounts events around his seroconversion and what he now thinks of Truvada's ability to prevent HIV.

March 3, 2016 By Trent Straube

Ever since July 2012, when the FDA approved Truvada as PrEP, a pre-exposure prophylaxis to prevent getting HIV, its success rate has been, well, perfect. In fact, not a single person adhering to the daily regimen has ever tested HIV positive—and that includes everyone in clinical trials and studies, and the more than 40,000 people taking Truvada as PrEP in the United States. But PrEP researchers, like most scientists, rarely speak in absolutes and guarantees; they've acknowledged that, under rare circumstances, an infection is feasible. Last week, that hypothetical situation became a known reality.

On February 25 at the annual Conference on Retroviruses and Opportunistic Infections (CROI) in Boston, David C. Knox, MD, an HIV specialist at the Maple Leaf Medical Clinic in Toronto, presented data on a patient who, after two years of good PrEP adherence, tested HIV positive (for more on that, read this article by POZ's Benjamin Ryan).

In Knox's presentation, his patient remained anonymous, but many of us in the PrEP and HIV communities had followed his seroconversion story in real time as he posted about it last May in the Facebook group PrEP Facts: Rethinking HIV Prevention and Sex, in which he was an active member. Since then, Joe—as he prefers to be called here—dropped off the discussion boards. I had kept his information and interviewed him earlier this year for a potential POZ feature. At that time, the 44-year-old was excited to put 2015 behind him (more on that later). We chatted about gentrification in Toronto's "gay village," and he described himself as a "foreigner" whose family had lived in Kuwait and Denmark before moving to Canada when he was 11, experiences that resulted in his speaking several languages and working as an international flight attendant for 14 years. Now employed at a telecommunications giant, Joe sounded optimistic about his future job prospects and he was devoting energy to the new love of his life: Oliver, a Lhaso Apso-Maltese-Yorkie mix. Importantly, Joe had acclimated to a new HIV regimen, taking his meds each morning, and his viral load had remained undetectable.

We spoke again after his doctor's CROI presentation, which resulted in Joe's PrEP failure making international headlines. The following interview is compiled from our conversations and has been edited for length and clarity.

Let’s start at the beginning: How did you first hear about PrEP?

In November 2012, my doctor, Malcolm Hedgcock from the Maple Leaf Medical Clinic, which deals primarily with HIV-positive people in Toronto, published an article about PrEP in Outlook, one of the gay rags in Canada. I went to see him, and he said, “You’re the second person to voluntarily want to go on PrEP.” As you know, you have to have an HIV test come back negative, then you can’t do anything risky for three months before you have another HIV test, and if that’s negative you can go on PrEP. So all that happened. I passed all of their tests, and I think I started taking it in February or April 2013.

Did you have problems with side effects or adherence with the daily regimen?

My body tolerated it well. And I have an app on my phone called Mind Jogger that reminds you to do things. I programmed it so that between 11 a.m. and 1 p.m., it gives me 10 notifications to take my medication. My logic was that no matter what day it is or where I am, I will be awake between 11 and 1.

Did you remain on Truvada as a daily prophylaxis, or did you use it, as they say, during “seasons of risk”?

I was on it the entire time. A lot of people disco dose [take it only during risky periods] because of the cost factor. When I took it, in Canada, Truvada was prescribed off-label as PrEP, but my work benefits covered my medication so, for me, it was not a problem. And to be honest, I don’t believe in disco dosing because I think it’s better to maintain the same level of medication in the bloodstream.

I don’t know if it comes from fear or hatred or whatever, but some people feel vindicated that PrEP is not 100 percent effective.

Did PrEP alter your sexual behavior or attitudes?

Yes. I became more sexually liberated. It took away the fear. I mean, that’s really one of the reasons why people behave themselves [sexually]. It’s not because of morals or religion or society; it’s just the fear of getting sick—especially the fear of HIV. But once you’re on PrEP you’re more comfortable. You feel safer.

How would you describe your condom use before PrEP?

It was off and on, depending on the situation. I’m mostly a bottom, but if I was with someone I felt

more at ease with, [we wouldn't use condoms], but it was serosorting of course [having sex with someone of your same HIV status]. But I would say most of the time, it was with condoms.

Did PrEP change your condom habits?

Oh, yes, definitely. To be honest with you, I stopped using condoms after going on PrEP. I was such as big proponent of PrEP that if I was chatting with someone on a hookup site who wanted to use condoms, it was a deal-breaker for me. I was having sex to enjoy it. And if I was wearing a condom or the other person was wearing a condom, I wouldn't enjoy it.

When we first spoke, you said that when you started PrEP you were in a relationship with an HIV-negative partner, but after 11 years that ended (the ex remains HIV negative today). You also said that you were taking antidepressants and that this January was one of the few recent months you didn't end up in the emergency room. What was going on in your life?

Last year was really horrible. In January, I went snowboarding at Whistler Pride, a big gay ski week. It's a lot of fun—unless you fall down the mountain and get a concussion like I did. I was off work for about six weeks. When I went back, I started to develop stomach issues and it turned out I had Helicobacter pylori, a bacteria that causes stomach ulcers. It exists in about two thirds of the population, usually in people from third-world countries or who have visited third-world countries, so it could have been from my being born in Iraq or being a flight attendant. I went on a course of antibiotics, and that was that. But I was still having stomach problems, so I went in for an endoscopy and colonoscopy, and found out my stomach muscle was getting paralyzed and stuck, something called gastroparesis. Basically, it wouldn't digest food. I went on some other medications. Then in April, I broke my pinkie playing dodgeball. Like I said, last year was really horrible.

How are those conditions today?

They're fine. I haven't had any relapses.

An image from the webcast of the CROI presenation by David Knox, MD, about the man who tested HIV positive while on daily PrEP.

This brings us to May 2015. Walk us through the events of your HIV diagnosis.

Just to backtrack: I knew there was always a possibility of becoming infected on PrEP, but the science was in my favor. And my doctor had changed. Dr. Hedgcock had moved and Dr. David Knox took his place.

On May 4, I had the regular quarterly blood test for HIV and STIs [sexually transmitted infections] and kidney and liver function, and all that. On Friday, May 8, at 6 p.m. my doctor gives me a call at home and says, “Joe, your p24 antigen came back positive.”

I said, “OK, what does that mean?” And he goes, “You’re HIV positive.” And it was…it was a bit of a shock. I said, “That can’t be, there’s no way. Are you sure it’s not a false positive?” He said that in 90 percent of cases where the p24 antigen comes back positive, the person is HIV infected.

Subsequent testing confirmed that the infection resulted from a rare strain of HIV that’s resistant to multiple HIV meds. But before waiting for those results, you chose to initiate treatment right away, correct?

I said, let’s nip it in the bud. He put me on a very strong course of medication, and within three weeks my viral level disappeared. Now I’m on a different course of HIV medication, just once a day, in the morning.

To what do you attribute your ability to make it through these challenges? Did you join a support group or anything like that?

To be honest with you, it's being educated in terms of my situation. The biggest condition I have, the worst condition, is still not fatal—it's managed and controlled. But there's no religion or whatever that I can rely on, so really it's science and facts.

In terms of support groups, I have a strong circle of friends, many who have been living with HIV 20-plus years who I can talk to. But my doctor referred me to an HIV psychiatrist, and because I was on certain antidepressants, I think that helped in terms of calming the waves and not having breakdowns.

PrEP didn't work for me, but I still think it's great.

To be honest, I don't wake up in the morning and think of myself as an HIV-positive person. Sometimes even when I say it, it's a bit odd because nothing has changed in terms of my life.

Blood tests pinpointed a timeframe when you contracted HIV. Did you have any interest in figuring out who likely had this virus, or in alerting him about it?

Here's the story. He's in a relationship and "discreet." We met on bbrt [a bareback community], and he says he's negative. I prefer to be with people who are positive and know it and are on meds—I'm on PrEP, you're undetectable, the chances of transmission are like negative 10 percent—but I broke my rule with this guy. So it was with him, I think—it was a bit of a busy period. I reached out to him and he says, "Well, I'm not worried, I'm OK. But I'll go see a doctor." And I checked in with him again: "Have you gone? What are the results?" "Oh I'm really busy and haven't had a chance." I checked in again. "Oh, I'm out of town on work." Checked again, and he stopped replying to me. To be honest, I gave up. I don't need to be vindicated or have him say I'm sorry or whatever. I just wanted to let him know. It's being socially responsible.

And now your case study is making global headlines. Have you been following the press and online discussions?

Normally, I'm involved, but I try to stay away from the social commentary regarding this announcement. There was someone, a Facebook friend, who made a blanket statement about, "Enjoy your AIDS, PrEPsters." I don't know if it comes from fear or hatred or whatever, but some people feel vindicated that PrEP is not 100 percent. And it's the Internet, right? Everyone's got an opinion. To be honest with you, I've been focused on work; I applied for a new position, and there are a lot of expected changes. It's been good.

It sounds like you're not letting the diagnosis and media coverage affect your general health.

Absolutely not. I just got a great blowjob.

What? Wow. Alright then. There you go.

A little lunchtime break.

As a POZ editor, I understand that oral sex is an extremely low-risk, and that your being undetectable pushes it lower still—I even wrote a story on the topic of HIV risk—but it's a bit surprising to hear you be so upfront about enjoying a little afternoon delight. It's also incredibly refreshing and empowering.

I believe in personal accountability and responsibility for your own health. I'm open and upfront with all sexual partners, from my status to my dislike of condoms. I have my own rules and limitations. I don't impose them on others. If we're not a match, then we're not a match. If you have questions or doubts, I'll answer them. But I won't try to convince or cajole you.

Why is it important to get this story out?

Because knowledge is power; the more we know, the better we're prepared. PrEP's a calculated risk. It's important for people to know that there is the possibility as opposed to the fantasy that there have been no recorded infections on PrEP. At least now there is one, so it makes it more real. And I tell people, "It didn't work for me, but I still think it's great." If I had to do it all over again, I would still go on PrEP. I just wouldn't have sex with that specific person.

Finally, what did you think about the other big PrEP news from this week, that the Canadian government just approved Truvada as PrEP?

I was relieved. I thought, "Finally. It's approved!" As PrEP becomes more mainstream, there will be more awareness. Doctors will know more. Patients will know more. Many of the myths will be dispelled. And more people will have smart, as well as safe, sex.

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