Positive on PrEP

Meet three guys who got HIV after starting Truvada as pre-exposure prophylaxis. How does this happen, and how are they doing today?

May 16, 2016 By Trent Straube

If you take Truvada daily, the antiretroviral pill reduces your chances of contracting HIV by 99 percent. The FDA approved Truvada as a pre-exposure prophylaxis (PrEP) in 2012, but the drug only recently gained traction, with more than 40,000 people now taking it in the United States; thousands more have taken it in clinical trials and studies. In all those cases, no one got HIV while adhering to the daily regimen. That is, except "Joe," a Toronto man whose case was detailed earlier this year at an HIV conference. POZ had the exclusive interview with Joe—you can read his sexually frank Q&A here—but he is not the only one to test HIV positive after starting PrEP. Here, we speak with two others. Their three stories offer insight into how this happens and what it means for HIV prevention.

Anthony's Story

As a sexually active, openly gay grad student in Baton Rouge, Louisiana, Anthony Basco didn't think he was at risk for HIV. But then one of his sex partners contracted syphilis and told him to get tested. Although easy to cure, syphilis can be deadly, so Anthony got checked out, despite not showing signs of infection. The test made a lasting impact. "When I realized I had syphilis, it was a reality check," he says. "I thought, I need to do more to protect myself because I'm not invincible."

While getting his syphilis treatment—a series of shots—Anthony asked his doctor about PrEP. The physician wasn't well versed on the subject but promised to research it. They decided Anthony was a candidate, and after taking two HIV tests a month apart to confirm his negative status, Anthony started Truvada in September 2013. "Immediately, I experienced flu-like symptoms that I attributed to side effects," he recalls. "So I discontinued the medication without consulting my doctor." A few weeks later, he gave it another try; this time he felt only mild and short-lived gastrointestinal distress. He figured his body had acclimated to the Truvada.

That December, he went in for his three-month checkup, as is recommended for everyone on PrEP—docs look at kidney function, which is a possible concern for Truvada users, and for sexually transmitted infections (STIs). "It was the first time I didn't have anxiety about it," Anthony says. But he tested positive for HIV. As instructed, he stopped taking Truvada while genotype testing determined what type of HIV he had and which treatment he needed. When he got the news, he called up friends. "They came over and stayed the evening," Anthony says. "It helped a lot. Plus, I

was already working in the HIV field, so I knew it wasn't a death sentence."

Within a month, Anthony began a new regimen and has been undetectable since March 2014, though he says the meds have caused him to gain weight. Today, the 25-year-old works at HIV/AIDS Alliance for Region Two and its affiliated Baton Rouge Wellness Center, where he helps people navigate their sexual health needs, including access to PrEP.

"I never blamed PrEP for my seroconversion," he says. "It probably happened because I didn't talk to my doctor. I have accepted that." Nowadays, he arms clients with the crucial info he lacked. Such as? First, there's understanding the window period, the time when an HIV test may give a negative result despite recent infection. Then there's knowing the differences between Truvada side effects, such as nausea and stomach issues, and the flu-like symptoms of an acute HIV infection (fever, aches, rash). "I had cookie-cutter seroconversion symptoms," he says, "but I was like, Oh, it must be the meds."

Anthony also stresses to clients that Truvada takes about a week of daily adherence before it offers full protection. Similarly, if you skip four or more doses a week, you get less protection (women must adhere even more strictly), and if you miss a week or two, then you must double-check that you're still HIV negative before you begin again.

All this is important because if you take PrEP when you have HIV, your virus can develop levels of resistance to emtricitabine and tenofovir, the two meds in Truvada, and you may unwittingly spread this strain. Both are common and well-tolerated meds that people with HIV take as part of treatment (generally, it takes three or more meds to treat HIV but only two to prevent it). If your HIV has mutated, then you're often left with more complicated regimens (translation: more pills, more expenses, more side effects). Anthony's virus had the M184V mutation, a resistance to emtricitabine.

Scenarios such as Anthony's aren't unheard of. "Depending on the underlying rate of new infections, approximately 1 in 100 to 400 people might have an acute infection when they start PrEP," says Robert Grant, MD, MPH, a researcher at University of California, San Francisco who leads PrEP research. And it's easy to miss doses, especially if you don't plan ahead for your refills and you lack the required paperwork.

HIV can mutate another way: when people diagnosed with HIV stop their treatment or experience a viral rebound (meaning they've become detectable despite taking meds).

Does this mean that resistant HIV is flourishing and that Truvada is useless against it? Hardly. Viral rebounds occur in less than 5 percent of people on treatment, and they don't always cause resistance. A recent meta-analysis Grant did for the World Health Organization found that only 3 percent of seroconverters on PrEP had a resistance to emtricitabine and that none had resistance to tenofovir. Tenofovir resistance is more common among the HIV treated, notably in Africa. Even so, when HIV is resistant to one medicine in Truvada, it's usually more susceptible to the other med. Plus, mutations don't always result in 100 percent resistance—it could be only partial, meaning the meds may still offer some protection.

What's more, Grant says, "multidrug-resistant HIV must be less infectious because we see it so rarely in recently infected persons. Full resistance to both tenofovir and emtricitabine is very rare, requiring multiple mutations." Then there's this statistic: Grant has estimated that for each resistant infection caused by PrEP, 25 HIV infections are prevented.

Michael's Story

Raised in the rural Midwest, 24-year-old Michael moved to New York after landing an internship. He also scored a boyfriend who happened to be HIV positive but undetectable. Michael was interested in extra protection but hadn't heard about PrEP until he saw the ad campaigns across the city. "It was basically, like, Take PrEP and you won't seroconvert," he recalls. So he spoke to a doctor, who required some education on the topic, and began taking Truvada in November 2014.

The boyfriend didn't work out, but Michael stayed on PrEP because he remained sexually active. He continued to use condoms, he says, unless it was with a regular partner who was up-front about his status.

In June 2015, he went in for the every-three-months panel of tests. He was on the subway when he got the phone call. "They said, 'We can't refill your Truvada because you're HIV positive.' In my brain, I was like, There's no way." Michael says he had never even had an STI, so he figured this was a false positive. But the test had detected an acute infection that occurred two to three weeks earlier. Michael was baffled. Recounting the questionable sexual encounter, he says, "I know for a fact that we used a condom. I was penetrated with a condom." What's more, Michael says, he took Truvada "religiously."

His virus, like Anthony's, showed the M184V mutation. Michael's current doctor, Laura Jean Guderian, MD, an HIV specialist with One Medical Group, says it's impossible to know whether he contracted a resistant strain or developed the resistance. For his part, Michael decided not to obsess about the unknowables or the guy responsible for his HIV. "That's not me," Michael says. "I'm upset he lied, and it's going to cost me a ton of money, but I don't have hate in my heart. Life goes on. Life's going to throw punches, but I'm going to get back up. If I want to be undetectable, I can choose to take the pills every day. It's an empowering journey."

Indeed. Michael now takes three pills once a day but is undetectable and has had "zero" side effects—except when he travels. At one airport, he "was questioned for about 45 minutes about what the pills were," he says. And hooking up has become an "interesting experience," he adds. "I'm up-front about it on Grindr—positive and undetectable—but there's still so much stigma."

His main beef is with New York City's PrEP campaign. "It makes it seem like a miracle drug," Michael says. "This is problematic, especially for millennials who think that condom use isn't a thing anymore as long as you're taking PrEP." He thinks that people starting PrEP should have to take a training course that explains the statistics. "There are risks," he says. "And that wasn't clearly noted."

Joe's Story

It’s extremely rare to come across someone who has HIV that’s resistant to both meds in Truvada and who also has a detectable viral load. But that’s exactly what happened to Joe, the 44-year-old Canadian who seroconverted on daily PrEP, then became the subject of a much-publicized case study.

Joe’s PrEP seroconversion is unusual because he has lab tests and pharmacy records that show adherence. But as Joe notes, “I could have been OD’ing on Truvada and it wouldn’t have made a difference.” He tested HIV positive in May 2015. Once the news settled, he decided to initiate treatment right away; within three weeks, his viral load was undetectable.

He says that PrEP was liberating. “Once you’re on PrEP, you’re more comfortable,” Joe says. “You feel safer.” He decided to nix condoms altogether, and he still does. “I believe in personal accountability and responsibility for your own health,” he says. “I’m open and up-front with all sexual partners, from my status to my dislike of condoms.”

And he’s undeterred by the anti-PrEP chorus, as seen in a Facebook post he encountered: “Enjoy your AIDS, PrEPsters.” “I don’t know if it comes from fear or hatred or whatever, but some people feel vindicated that PrEP isn’t 100 percent,” Joe observes. PrEP advocate Damon Jacobs offers insight into such attitudes. Among many gay men, he says, “there is a deeply held core belief that condomless intimacy and semen exchange must inevitably result in pain, punishment and despair.”

We are “in an era where gay civic virtue can no longer be equated with old-fashioned safer sex,” adds Gus Cairns of aidsmap in the United Kingdom. England just nixed making PrEP widely available, so to Cairns, focusing on the one case where Truvada didn’t work is missing the big story: how to get PrEP to those who need it, like black gay men in the South.

Joe’s doctor, David C. Knox, MD, an HIV specialist in Toronto, says that although “cases like Joe’s are likely to remain rare, just how rare is not yet known. Physicians who prescribe Truvada as PrEP need to be vigilant for breakthrough HIV infections.” He stresses that Joe’s story “should not discourage anyone from talking to their physician about starting or continuing PrEP if it is right for them.”

“PrEP’s a calculated risk,” Joe acknowledges. “If I had to do it all over again, I would. I just wouldn’t have sex with that specific person. I tell people, ‘PrEP didn’t work for me, but I still think it’s great.’”

Negative Results

Truvada isn’t 100 percent guaranteed to keep you from getting HIV. But take these extra steps and you’ll get close.

If You're Not Taking Truvada as PrEP

- Don't Underestimate Your Risk. "People tell me, 'My risk behaviors aren't bad. I don't need PrEP,'" says Anthony Basco who works at a sexual health clinic in Baton Rouge, Louisiana, "but then they'll test positive for rectal chlamydia, and I'll say, 'Let's have this conversation again.'"
- Don't Assume You Can't Afford or Access It. Basco has helped over 100 people get PrEP at no cost, even people with no insurance or with high deductibles. He has also helped young people on their parents' health plan access PrEP while protecting their confidentiality.
- Stare Down Stigma. Many people are afraid to talk to their doctors about their sex life. Others fear what people will think if they take Truvada or go to a sexual health clinic. Basco tells potential clients: "Would you rather people think you have HIV, or would you rather actually have it?"
- Don't Be Scared of Side Effects. Folks are afraid to try Truvada because "they think they'll be nauseous or irritable 24/7," Basco says, "and it's not like that." About 10 to 30 percent of people starting PrEP experience side effects. They're typically mild and last a few days or weeks.

If You Are Taking Truvada as PrEP

- Look Into the Window Period. This is the number of weeks or months an infection must be present before the HIV test can detect it. Newer (often more expensive) tests have shorter window periods—they can spot more recent infections. Be honest about any HIV risk you encounter during the window period; otherwise, you may get a false negative.
- Give It Time. Truvada takes about a week of daily use to become most effective. Don't ditch the condoms the night of your first pill.
- Get Tested, Tested, Tested. PrEP protocols recommend HIV testing every three months. "If you stop using it for a period of time," warns PrEP advocate Damon Jacobs, "do not restart without a

confirmed HIV-negative test."

- Know Your Side Effects. Truvada can cause gastrointestinal issues and headache. Symptoms of acute HIV infection are similar to the flu: sore throat, fever, swollen glands. If you develop these, call your doc right away. In fact, call your doc with any questions any time.

- Plan Ahead. Don't wait till you're on your last pill before you refill the script. Know ahead of time what paperwork must be filled out. And if blood work is required, don't go on a party bender beforehand; you'll just have to redo the tests, which could delay your script.

- Don't Think With Your Heart. Love is an HIV risk. People might want to stop PrEP when they start a new relationship and feel safe. HIV researcher Robert Grant recommends waiting up to six months into the relationship before establishing agreements about outside partners, PrEP and condom use.

- Get Into the Daily Grind. Truvada won't work if you don't take it. Duh. Taking two to three tablets a week can reduce your risk of getting HIV by about 84 percent, notes Grant, who has seen people seroconvert on those doses. What's more, he says, don't skip your meds "because you mistakenly think Truvada can't be taken with alcohol or other substances."

- Don't Forget Condoms. Recent seroconversions on PrEP "have been in patients who have not been using condoms consistently," notes HIV specialist Laura Jean Guderian, MD. "The most effective way to prevent HIV is to use condoms with every sexual encounter and take PrEP daily."

For more about PrEP, read POZ's related cover story "A Tale of Two Cities: Ending the Epidemic in New York City and San Francisco" and the exclusive Q&A "Meet the Man Who Got HIV While on Daily PrEP."

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