The Specialty of HIV

March 24, 2015 By Aundaray Guess

It was a normal day when I saw my pharmacy calling me. It wasn't unusual to receive a phone call from my pharmacist. Sometimes they would call to remind me my prescriptions were ready and yes, even check-in to see how I was doing. I was fortunate as I frequent them often for my prescription needs. They have been so much part of my life in the last eleven years that I even wrote about them in a previous blog post. For those who are unfamiliar with that blog, I spoke of how the people at the pharmacy helped me find my new HIV doctor, encouraged me to seek a simpler medication regimen and the greatest help, connecting me to the AIDS Drugs Assistance Program (ADAP). At that time I was struggling to pay my co-pay which was rising faster than my paycheck. So when my phone rang I wasn't expecting to hear anything bad from them. Unfortunately it was the beginning of my hell and my unfortunate introduction to 'specialty pharmacy service'.

Specialty pharmacy service basically limits how and where you can get your prescription filled based on your disease. For me, according to New York University (NYU), the issuer of my medical coverage, my HIV diagnoses fell into the specialty category. That meant my only choice was to receive my prescriptions by mail or visit any national CVS drugstore. The small neighborhood pharmacy I frequented for the past years would no longer be able to fill my HIV prescriptions. So instead of walking the three blocks in my neighborhood, I'm now forced to ride a subway to a pharmacy twenty blocks away. In addition instead of the specialized care one gets from a local pharmacy, I'm now one of thousands at a national corporation. What's so special about that?

The other option for me is the mail delivery option. This is a monthly drop-off service of your pills at your doorstep. This may sound ideal but for those who have yet to share their status or living in a situation where it's not safe to reveal, this is not an option to consider. And since each package has to be signed for, the added expense of a P.O. Box along with the additional cost, makes it less attractive. Besides anyone who has a package delivered by UPS, knows the frustration of getting a pink slip letting you know you missed them. This often leads into a frustrating game of playing tag to get your package so you won't have to miss any dosages. There is also an option of delivery to your work space but again if your co-workers don't know about your status they may start to wonder about the regular shipments of pills.

I wanted to opt out of the specialty care program and continue my relationship with my current pharmacist. I first had to discover where this mandate came from. That meant my first call went to United Healthcare, the name of the insurance company on my card. They informed me

their hands were tied and I had to speak to the HR department at NYU as this order came from them. From there I went into representative hell as the people I called were the first line to protect the decision makers. I knew the frontline staff wouldn't be able to help but I had to start somewhere. It was an endless game of repeating my frustration to each person as I was shifted from one to the next.

I was always polite as I knew it wasn't their fault. I called so much they even knew me by name and we would talk about the weather. Some also sympathized with me and felt it wasn't right I was being pigeonholed. One rep even wanted me to keep her updated on my battle. I finally made headway but only by letting NYU know that I was planning a protest of this decision. My protest would consist of me refusing to set up new service at CVS which of course meant that I would be without meds. I was prepared to not get my meds refilled and inform NYU that their decision was affecting my health and life.

It was a gamble but it worked as I finally spoke to a senior official in the HR department. She told me that NYU was doing me a favor by making it easier for me to obtain my pills and they were doing this for me. It was as if she had the script prepared for this conversation. I wanted her to know I found this discriminatory to those with HIV and in a way a punishment. I asked her where she got her prescriptions filled and was met with a non-response as I'm sure she could go anywhere, even if it was a local pharmacy three blocks away. NYU is not looking out for my health as she claimed. They are looking to save money. That's the only reason this was decided. Their ability to save dollars overruled my health.

I have yet to have them reverse their decision as it's a waiting game. They don't have to worry about their refills running out. So those who are in the processing of fighting this requirement often give up as they're interrupting their medication regime, something strongly advised not to do.

As usual my local pharmacy provided me with good insight as they have seen other HIV customers simply give up fighting. I'm not the only one. There are others like me with HIV who has spoken out against specialty pharmacy programs and tried to remain with their local pharmacy instead of a chain. In fact last year New York passed the Anti-Mandatory Mail Order Pharmacy bill. The bill closes a loophole in state law that currently allows the health insurance industry to prevent local pharmacies from qualifying to fill prescriptions deemed "specialty" by the industry, even if they match the cost. Unfortunately for me since NYU pays full coverage they have found a loophole to allow them to discriminate.

Claims of discrimination may seem harsh but there's no other way to look at it. There's no other word that describes the fact that because you have a certain health condition you have these limited options versus others who have the same insurance but because they don't have HIV, have a range of choice.

And that's what it comes down, choice. And I feel simply because I have HIV my choice shouldn't be taken away, especially so someone can make a profit. At this moment my battle

continues to restore that choice and I hope in the end to help others like myself who are forced to fight for the right to choose where they get their prescriptions filled.

I would love to hear from others who were forced into specialty pharmacy programs and how you handled it. The more sharing of this blatant discrimination, the more ammunition can be used to defeat this practice.

So shame on you NYU for treating me like the 'other' and adding to the stigma of HIV.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/blog/the-specialty-of-hiv