Trying Trials

How one HIVer successfully sampled experimental meds

October 1, 2005 By Lucile Scott

My reaction when my doctor said I could participate in a clinical trial was “Oh, Lord, I’m a guinea pig, and they want to poke and prod me.” I was diagnosed years before, while in prison for selling drugs. When I was released in 1999, I found out I’d developed resistance to my meds, so I switched combos. In 2003, I was having combo problems again, and my doctor told me about a trial for [the non-nucleoside] Capravirine. For the next two years, I went to Montefiore Medical Center once a month and met with the doctor running the study to report side effects and to get blood drawn and other tests, like an EKG. I became undetectable within four months and successfully finished the trial in July. During the trial, I didn’t feel like a guinea pig. I felt like the doctor was there for me and really cared about me and my health. Despite the side effects, it was worth it.

—As told to Lucile Scott

Home Turf

If, unlike Wilson, you live outside an urban hub, you can still enter trials without a trek. Many new-med programs let docs administer the treatment. So ask if yours will collaborate with a university, or join a clinical-trials network, like the AIDS Clinical Trials Group.

Wilson’s 5 Steps to a Smooth Trial

1. Get Information

“I didn’t really do research. I just signed up. I wanted to be healthy to take care of my 4- year-old granddaughter and liked that I only had to take three pills instead of eight. But I wish I’d gotten more information. You should really read up on it. I found out later that Capravirine caused heart problems in beagles. If I had known this, I probably wouldn’t have participated, but I’m still glad I did.”

Learn about treatment studies from AIDS Community Research Initiative of America, www.acria.org.

2. Get Access

“The people in charge of the study tell HIV docs about it, then docs notify their patients. Most trials have entry criteria. This one required resistance to some combos, a viral load above a certain

level, decent kidney and liver function and that you are over 18. I was worried about my liver because I have hep C, but it was fine. Then, they tell you all about the drug and the trial, and you have to sign an informed-consent form."

Find out about clinics with trials in your area at the AIDS Clinical Trials Group, www.aactg.org.

3. Get Care

"The law requires that you are carefully monitored throughout the treatment. The study paid for my medical expenses. I didn't even have to show my Medicaid card. The appointments took from 15 minutes to two hours. The doctor made sure the drugs weren't having bad effects, and I could have dropped out at any time if there was an issue. They reported my lab results to me and to my doctor, who I also saw once a month."

Learn what to ask a monitoring doc about your trial at AIDSinfo, www.aidsinfo.nih.gov.

4. Get With the Program

"I thought about quitting. I don't like pain, and even though I'd been warned about side effects, the nausea and diarrhea were almost too much. So I skipped doses. The doctor noticed and told me to go to an adherence group. I only had to go once, and soon the side effects got better. The counselors told me how important adherence is and taught me about dividing pills up into boxes and taking doses with you. Now I'm 100% adherent."

Find adherence pointers from Project Inform, www.projectinform.org/fs/adherence.html.

5. Get the Final Report

"They stopped testing Capravirine this summer, right before I completed my trial. While it worked for some people, like me, the results were not as good as they'd hoped. Even though I could still get the drug, I don't want it if it was dropped. But I'm going to start another trial for Kaletra. I like having someone who knows about the drug and can talk to me about it. I like feeling that I have more knowledge about my medicine."

Learn about your HIV treatment from AIDS Meds, www.aidsmeds.com.

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