Up All Night

Long-term survivor and workaholic Kiyoshi Kuromiya logs in on AIDS

January 1, 1998 By Manjula Martin

I was a little annoyed with Kiyoshi Kuromiya. For days, I'd left messages on his voice mail, e-mail and pager – no response. I tried calling one last time. He answered in a smooth, leisurely voice that belied his hectic schedule: "Sorry I didn't call back, I've been at a conference for a week. But let's talk now, because I'm going to Toronto tomorrow for another conference. I haven't checked my e-mail yet. I have about 2,000 messages to read before I leave." My irritation dissolved.

As the founder and only full-time employee of Philadelphia's Critical Path AIDS Project, Kuromiya staffs a 24-hour treatment hotline, runs a massive and website, publishes a quarterly newsletter and provides free Internet access and e-mail to more than 1,000 people. Kuromiya has consistently made himself, his life and his advice accessible to PWAs since 1989. This has included coauthoring, with the late Jonathan Lax, ACT UP/Philadelphia's HIV Adult Standard of Care, a widely respected guide now in its 12th revision. The former *POZ* cover boy (February/March 1996) breaks down his history of treatment decisions.

How have you – one of the most AIDS-informed people imaginable – made decisions about what works best for you?

I have a pretty good idea of how my body works. I know how to read the scientific literature and make my own decisions. And I've been a risk-taker. It's done well for me.

I'm also a survivor of cancer – I had metastatic lung cancer in 1977 and an upper lobectomy, which is essentially removing part of your lung.

I believe I was infected around 1979 to 1981. I wasn't tested until 1988. At the time, my CD4 count was 256. By 1992, it had dropped to 32. In 1994, I decided to begin low-dose [300 mg] AZT along with ddI. At the time, ddI was really hard to take. It was like chewing two sticks of chalk every morning. I used to stay in bed an extra 20 minutes just to avoid it. My CD4 count was around 100 soon after starting.

In mid-1995 I added Crixivan [indinavir] and 3TC to the AZT, while dropping the ddI. This was prior to Crixivan's release, but a couple of my friends were in trials and had extra pills. I was doing 1,800 mg [the earliest trial dosage] with food, three times a day. Now we know not to use it with food. So I was what we'd now call "noncompliant" for my first nine months on Crixivan, until we

got it approved with the correct food advice. But as of this March my viral load was down from being off the charts to 3,500.

What about complementary therapies?

My only complementary therapy is marijuana. I've tried Marinol [the pill version], but if you have appetite loss, you want to deal with it immediately. Marinol doesn't kick in immediately, and honestly, it's not as effective as pot. I'd smoked pot before, and I enjoy it. It's essential in preventing weight loss. When I was in Yokohama in 1994 for the International Conference on AIDS, I couldn't get any pot because of Japan's strict laws. Without access to marijuana, I lost 18 pounds in 18 days. I also operate the only cannabis buyers club that distributes marijuana for free. We distribute half an ounce every two weeks to 30 different clients.

Have you ever experienced any side effects from your current meds?

Since taking Crixivan, I've had three kidney-stone attacks. This despite drinking the recommended amount of water to avoid kidney stones – although in my own way: I think I'm the only adult in the world who drinks tow quarters of Kool-Aid a day. I never had surgery – I passed the stones and dealt with the intense pain myself. I tried self-medicating with morphine, but I found that only regular Advil [ibuprofen] worked.

But I'm feeling great; I've felt good all along. I've worked 20 hours a day all through this. Something that my mentor, Buckminster Fuller [the late, visionary philosopher/engineer/ecologist], said is that using technology, you can do more with less. We have a complete grass-roots organization with only one full-time employee and one part-time systems administrator. The community has to do what the federal government should be doing in terms of public health. At Critical Path we scan information that has been translated into many Asian languages and put it on our website. The CDC has not published information in any Asian language since the surgeon general's brief prevention pamphlet in 1987, and they've never done so for treatment information. We have to pick up where they leave off.

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