Publisher's Letter

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Last April, when my viral load began to rise, I switched from a four-drug boosted-protease combo to something the federal treatment guidelines say "Should Not Be Offered at Any Time"—the old, discredited, somewhat disparaged and poorly understood cancer drug hydroxyurea (HU). My doctor, Paul Bellman, and I paired it with ddI—and nothing else.

I really just wanted to go off meds for a while. But after three treatment breaks over the last six years, Paul persuaded me to try something different. Each break got longer, and we weren't sure what would happen with the next one. So he mentioned HU as a possibility. He was excited about a very small study (of 20 HIVers) comparing structured treatment interruptions (STIs) between HIVers who took HU as part of their treatment and those who did not. The HU group fared better when they went off their meds. And since I'm always bugging Paul about new approaches to treatment, he thought I might be open to trying something unusual. Enter HU.

We had a long talk about the potential side effects, which can be nasty. These and the lack of conclusive evidence about the drug's benefits are why the guidelines give it a thumbs-down. HU targets cells, especially CD4s, and stops them from reproducing. If they can't reproduce, HIV can't reproduce. And because HU doesn't target the virus directly, you don't develop resistance to it. The catch is, your CD4 count doesn't necessarily rise and may even drop, and HU can knock out other good cells too, causing anemia or neutropenia. So it's not for everyone. Still, feeling experimental and curious—but very skeptical—I decided to go for it.

That was seven months ago, and we haven't ditched it yet. I don't know what to tell you about the results. Whether or not it is "working" depends on what you think the goal of treatment should be. I'm not undetectable, and my CD4 count isn't very high. But I'm also not sick. Reviewing my most recent lab results—a CD4 count of 244 and a viral load of 44,000 copies—Paul apologized after calling them "mediocre." But they are, so I didn't mind the word he'd chosen. I told him, "Numbers, mediocre. Clinical health, excellent." I wanted to make sure he sees as strong a distinction between the two as I do. They are not the same thing.

That's not to say that I don't consider my labwork when making treatment decisions—just that I don't think numbers define health or success. They are simply one of many inputs, not the ultimate goal. For example, when I'm on meds and my viral load gets to 5,000 or 10,000, that is a trigger to take action. But off meds or on a combo-lite, I'm perfectly happy to have a viral load of 44,000. In the nearly 10 years that I've been making treatment decisions, I've frequently gone against the grain—if not always against the guidelines. I've taken some risks. I feel strongly that

this may be the most important contribution to my relative good health today. Of course, risk-taking can backfire and be destructive. It's what got many of us here (infected with HIV) in the first place. But there's a big difference between informed, educated risk-taking and all the other crazy things we do.

It helps to have an experienced, open-minded doctor like Paul, who's been my partner and guide through it all. Not that we always agree. In fact, after my number-vs.-health wisecrack, we argued about how no studies are done with clinical endpoints anymore—they are all geared towards surrogate markers like CD4 count and "undetectable." Clinical endpoint studies are much more expensive and might even take decades. But on this unorthodox HU/ddI regimen, I am my own little study—with my *clinical health*, not my numbers alone, as the end point, and the only point. I'll keep you posted on the results.
