At the End of My Hope

A pariah rains on the protease parade

February 1, 1998

They have left me to die. And not just me: Tens of thousands of us have run out of nucleoside and protease options. We're the pariahs in this time of hope; we're the bummer at the party. Worst of all, we're not much of a market. Whatever our numbers, we're nothing compared to the half-a-million-plus people with HIV who've never taken antiretrovirals. It's these fresh faces that the pharmaceutical industry wants to attract. The drugs might actually work for them, and if they do, the profits will keep rolling in. Every time we treatment-experienced folks "fail" on a drug, we've tarnished its image; those big drug makers must hate us. Anyway, why waste valuable research and development dollars on a group that's going to drop dead soon?

Before you dismiss me as hysterically melodramatic, let's examine the facts. I'm writing this after having just returned from ICAAC, one of the big-deal AIDS scientific conferences where researchers premiere their hot data or new theories in order to promote their personal celebrity. Guess what? No one presented any treatment options for us heavily experienced patients. The need to conduct trials—they're called salvage protocols, as in trying to retrieve a sunken ship—got a little lip service, but neither the pharmaceutical companies nor the NIH has anything planned.

Consider it from the industry's point of view: As more powerful compounds crowd the field, your drug has to be the best damn virus slayer in order to stand out. If it can't knock viral load down by at least two logs (99 percent), it's a yawn. With such competition, a company does whatever it takes to make its product look its best, and that means testing it in a population as untreated as possible. Never having been exposed to treatments before, these people generally respond really well. The treatment-experienced, most likely to have developed multidrug cross-resistance, don't.

The legal liability is also daunting. In order to sustain a treatment's success, you have to start on two or three new drugs at once. For someone untreated, it's easy to put together three drugs that we already have safety data on. But for someone like me, right now only three highly experimental agents can be used—no two of which have been tested together, let alone all three. How they'll interact is anyone's guess. The drug companies are unwilling to let me take such experimental combinations for fear of being sued if I die from combined toxicities or strange drug interactions. And the NIH isn't taking the lead by developing, or urging drug companies to develop, new trial designs. Meanwhile, the FDA won't approve riskier trials because its job is to "protect" me. But I have nothing to lose. And I don't have years to wait for safety data.

These obstacles could all be overcome. Unfortunately, pharmaceutical executives, government leaders, most researchers and even many activists are still basking in the glory of the early protease triumph. Yet for the sake of us drug duds, what we should be doing is demanding more: Specifically, earlier and faster drug-interaction studies that test multiple treatments, not just two; and regulation reforms that let us waive our liability and get access to drug combinations before safety data is in. But as activists, we've gotten lazy.

I've come to a very difficult decision about my treatment: I'll start on new antiretrovirals only when I have three new ones to start at once. It's a frightening position to put myself in. As my health gets worse, I'm tempted to grab on to anything at all. Many times in recent months I've almost applied to the Sustiva expanded-access program or signed up for some experimental trial. But I've resisted because I know I shouldn't blow the true power of these drugs in ineffective combinations. I've already made that mistake. For now, I'm treading water, frantically hoping I can get a hold of my lifeline—Gilead's Adefovir, DuPont Merck's Sustiva and Abbott's ABT-378—before my health deteriorates further.

For the tens of thousands of people like me who need to get three new drugs into their very desperate bodies, I urge you to speak up. Too many doctors who should know better put patients on abysmal combinations or just keep adding on one new drug to a failing regimen out of a desperate sense that they must do something. While their intentions are good, their actions are doomed—and will make you even more multidrug-resistant. Lie, cheat, steal—do whatever is necessary to get three new drugs. Enroll in multiple expanded-access programs. Don't stop there—enter a trial if you have to. And start screaming as well. If you attend treatment forums, make the docs and drug-company reps deal with your desperation. Make the community advisory board of your local ACTG design better trials. Because if you don't advocate for yourself, no one else will.
