Publisher’s Letter

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I’ve failed. Chances are, you have, too. We are all living, breathing treatment failures. (Well, three out of four of us are [see “Spin Cycle”], but you get the point.) Why? Because of drug resistance. Some of you may have just a little -- a few mutations here and there -- but others, like me, have a lot (24 and counting).

When I got my latest resistance-test results indicating that my HIV had wiggled its way around every class of drugs out there, I thought, “Well, there’s nothing left for me to take, so this is it.” I felt hopeless -- out of options and out of luck. In reality, of course, I wasn’t. There are thousands of us who have been on so many meds for so long that we have some level of resistance to everything -- and guess what, Mr. Science? We’re nowhere near dead.

Now, I know that resistance makes HIV much more challenging to treat, and I believe in the benefits of what doctors call “complete, durable virologic control” and HIVers call “being undetectable.” But resistance is a moving target. It’s not a question of all or nothing, yes or no. It’s a question of *how much* and even *how much today*. Even more important is the question of how relevant resistance is to your health. If you are treatment experienced (aren’t we all?), you likely have many versions of HIV. Some -- but not all -- have just the right combination of mutations to make a drug either totally or partially useless. But a partially useless drug is, of course, a partially effective one.

You would never know how relative resistance is from the recent hype about massive viral mutations and looming treatment failure. This disconnect reflects how out of touch most of the media -- and, for that matter, many researchers -- are with the actual lives of people with HIV. *Our* goal of therapy is, ultimately, survival -- which is related to, but not dependent on, being “undetectable.” I can live with a viral load of, say, 10,000 better than my doctor can.

Another example: I just returned from “Retrovirus,” one of the big-three AIDS conferences where researchers gather to show off their new data. For three days and countless presentations, every other phrase I heard seemed to be *length of time to virologic failure*. By the end, I felt like I had barely survived a hail of gunfire: *Failure...failure...failure*. I reminded myself that it was scientific research (nothing personal), but, damnit, they were talking about *me* -- and you.

My anger and frustration come from being *made* to feel hopeless, by tests, concepts, language and, most of all, research goals that are divorced from real-life needs. Resistance is real, no argument. But doctors and patients are increasingly finding ways to avoid, delay, work with and

even overcome it (see the upcoming July/August *POZ*). And the goals of research should be these practical strategies that promise real benefits -- not some mythical “complete, durable virologic control.”

So I’m not out of treatment options and nowhere near the end of the road. And if I’m sick of anything, it’s of feeling defeated or discouraged and that sense of isolation that comes from seeing and doing things differently. That’s one lesson to keep learning: Ever since this epidemic started, the survivors have been the ones who defied convention and took action. We constantly make life-or-death decisions in the absence of conclusive evidence. If we waited for proof or certainty, we’d be dead. This year’s risky experiment is next year’s treatment breakthrough. And, as always, people with HIV are leading the way.

So where does that leave us now? *Failing? Resistant?* Well, OK, maybe a little bit -- to those two words, anyway.

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