Bad News Bear

If the virus doesn't get you, the drugs you take will.

January 1, 1999 By Stephen Gendin

Having long played the lonely role of Chicken Little, I felt vindicated to hear others proclaim that "the sky is falling" at last season's big AIDS shindig, the annual ICAAC Conference. For the first time since eradication fever gripped the community in '96, the atmosphere could only have been described as morose. There were many grim sessions—on resistance, drug failure, side effects—and little hopeful or helpful data on new drugs or strategies, especially for the "treatment experienced" like me.

Just last summer at the Geneva World AIDS Conference it was possible to maintain an aura of optimism. Now there is no skirting the facts: The drugs we have are nowhere near as powerful as we once thought.

Dr. Mike Saag of the University of Alabama, the cochair of ICAAC's HIV track, started the conference with a rather gloomy message: "Expect failure." His point was that doctors must take more care when choosing when and with which drugs to begin treatment. But this isn't news: Reports of treatment failure have ranged between 20 percent and 50 percent for more than a year now. Researchers and clinicians have been fighting about which number is more accurate. But even one in five is chilling. Would you get on an airplane that had a 20 percent chance of crashing?

And then there are the side effects. If you don't die of a heart attack from the raised cholesterol and triglyceride levels caused by protease inhibitors, and if you aren't struck down by diabetes, you'll almost certainly be disfigured by lipodystrophy syndrome: a big stomach, a huge hump on your back, scrawny, skinny legs and arms.

One conference slogan was "the first shot is the best shot": Your first drug combo is usually the most effective. Because of cross-resistance and other factors, the second regimen will work worse than the previous one, in a continuous downward spiral. By your third, you'll be lucky if you get six months of benefit.

What about all the drugs in the pipeline? There are dozens of "me-too" copycats: more nukes, NNRTIs and anti-protease. Some boast of "unique resistance patterns," but further testing will undoubtedly reveal cross-resistance with those already approved. New drug targets—the tat,

integrase and zinc-finger inhibitors—aren't much further along now than two years ago.

Sadly, your doc probably won't convey much of this info, and if you bring in this article, you'll get dismissive reassurance that the available meds are effective. Who's telling the truth? Consider this: For years doctors watched helplessly as patients died all around them. They struggled, but to no avail. If you think you've felt devastated by AIDS, remember that your doctor may have watched hundreds die. Then protease inhibitors came along, and there was hope. Doctors felt renewed. So when they tell you all is well, they may be doing it less for you than for themselves.

I've encountered this unrealistic optimism in my own doctors. Six months ago, I went off all antiretroviral therapy. I was experiencing severe side effects, yet my viral load was still sky-high, so I figured the medication was doing more harm than good. This was a smart decision: My viral load went no higher, and as side effects disappeared, my quality of life got better. But my two doctors have both been pressuring me to go back on therapy. I've even resorted to less-frequent doctors appointments to avoid the issue.

As I see it, no effective combo—one that will keep my viral load undetectable for two or more years—is out there right now. Anything they give me, I suspect, would simply create more side effects and then fail after only a few months, leaving me in even worse shape than I'm in now. As my doctors see it, being off therapy is doing nothing, and doing nothing is what scares them most. Holding out for new drugs to become available before I get sick or die frightens the hell out of me, too, but it's still the right thing for me to do.

So whether you've failed multiple cocktails and wonder what to do now, or you've never taken therapy and wonder when to start, remember that the available drugs are no quick fix. Take care not to let your need for control—or your doctor's—overshadow a realistic assessment of therapy's risks.

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