Read It Or Weep

Ignore those fine-print drug package inserts at your own risk.

June 1, 2005 By Allen Huff

In 2004, while helping out at the Democratic National Convention, I was introduced to former secretary of state Madeleine Albright. Impressed, I reached out to shake her hand—and almost found myself with a handful of her right breast.

This was no wardrobe-malfunction moment: For more than five years, I had suffered mysterious vision loss, groping for causes with six New York and LA ophthalmologists. The verdicts ranged from “getting older” to“degenerative eye disease inherited from your mother’s family.”Finally, a specialist at UCLA named one of my HIV meds, the nuke Videx (ddI), as the culprit. Had my doctor or I bothered to read the tiny print on the Videx **Patient Information Insert**, I might still be able to…well, read the tiny print. Today, Videx inserts warn users to have periodic retinal exams.

I first took Videx after my AIDS diagnosis in 1996, continuing on and off for four years. The med nauseated me, yet I needed it to control a high viral load and low T-cell count. In the summer of 2001, after a bout of acute pancreatitis, I bid Videx a final adieu.

Too late: It had already eaten away at receptor cells in the back of my eyes, leaving holes in my vision. This cannot be reversed, and I am now legally blind.

In hindsight, I could also have found this rare Videx side effect—and reported my own case—at MedWatch, a free, confidential and voluntary system for doctors, nurses and patients to report adverse med reactions directly to the FDA (800.332.1088 or www.fda.gov/medwatch). You can search the website for side effects, though you’ll need patience and a medical dictionary.

While we wait for the drug companies to make better meds, we can keep current ones from damaging us. It takes some work, but it’s better than waking up one day to discover you’ve been groping retired government officials.

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