Late Date

Why, despite the benefits of regular HIV testing, do some people learn of their status so late?

April 1, 2008 By Derek Thaczuk

In 2003, Yvette Ogletree began having health problems—headaches, fatigue, weight loss, dizziness and some double vision. But she wrote them off to the stress of working two jobs while raising two teenagers. Ogletree's doctors wrote them off too: Though such symptoms may indicate HIV, neither her regular physician nor her gynecologist proposed a test.

That summer, when an infection sent her to the emergency room, a nurse asked Ogletree if she wanted to be tested for HIV. "I said sure, whatever—I just wanted to get home," Ogletree recalls. Two weeks later, she got the results: She was HIV positive. Devastated, exhausted and "looking like I was dying," she landed in the hospital a month later with cryptococcal meningitis. That's when she got her first CD4 count: 27. She started HIV therapy immediately.

Now back on her feet (and working as an HIV research advocate), Ogletree says she nearly died because she and her doctors hadn't considered her at risk for HIV. "We should get rid of the term 'high-risk,'" she says, "and just talk about any risk." Many doctors, for instance, still fail to recognize signs of HIV in women—who may need to insist on being tested.

Ogletree is one of a growing group of people who simultaneously test positive not only for HIV but—because they've unknowingly lived with the virus for so long—AIDS as well. Recent studies have found that the number of these "late presenters" swelled to as many as 40 percent of new HIV diagnoses in 2005.

From the dawn of the epidemic to the early '90s, when HIV was widely seen as a death sentence, some people thought, *Why bother getting tested when there's so little I can do if I'm positive?* But now that effective treatment options and better support and social services are available, there's a more urgent reason for knowing one's HIV status.

Earlier diagnosis typically means higher CD4 counts and less risk of imminent illness—and if people can suppress their viral load, less chance of infecting others. What's more, studies have shown that those who choose to start meds when they have lower CD4 counts are more prone to such serious problems as cancers and heart, liver and kidney disease. (In 2007, U.S. treatment guidelines raised the lowest recommended CD4 count for starting meds from 200 to 350 CD4s; one presentation at the Conference on Retroviruses and Opportunistic Infections this past

February suggested considering a start point of 500.)

What explains the late-diagnosis phenomenon? “We don’t understand all the reasons,” says the San Francisco Department of Public Health’s Sandra Schwarcz, MD, the author of a late-diagnosis study. “We’ve gathered data telling us *who* is likely to test late, but we don’t yet fully understand *why*.”

The *who* includes immigrants and women, Schwarcz says. Ogletree and a 28-year-old we’ll call Dwight (who asks that his real name not be used) illuminate the *why*.

Unlike Ogletree, Dwight—who lives in Detroit—belongs to a demographic heavily targeted by HIV-awareness and testing programs: the African-American gay community. Yet Dwight says he got tested only “from time to time, if there was a campaign going on.” After he developed a case of shingles, his doctor suggested an HIV test, and Dwight tested positive in October 2005—with a low CD4 count. He says he now realizes that “we’re all at risk.” But Schwarcz says there’s often a fuzzy line between our understanding of group risk versus personal risk. “Some people may not think their individual behavior is risky,” she says “even though they are in a traditional ‘risk group.’”

Since his diagnosis, Dwight has seen good results from his HIV meds: His CD4s are up, and he’s “pretty healthy and happy.” Indeed, he adds, “People who don’t have HIV don’t know how much the treatments have improved.” That’s why, he believes, many people still choose not to get tested. “The commercials tell you to get tested, that ‘you’re better off knowing,’“ Dwight says. “But they don’t tell you *why* you’re better off.” Many people, he says, still think, “If you get HIV, you die.”

Even potential testees who do have access to all the latest HIV information sometimes get cold feet. For them, it might help to know that treatment today can help you regain your health—even if you learn you have HIV and AIDS at the same time.

Slow Testers—or Fast Virus?

Not everyone counted in those late-tester stats is, in fact, a late tester. When Reginald Davis tested HIV positive in October 2006, his CD4 count had already dropped to 150—despite a negative test less than a year earlier. “I went straight from HIV negative to AIDS,” says the 25-year-old. “I felt like, as long as you have HIV but not AIDS, you’re still OK,” Davis says. “But I did have AIDS. It was like staring death in the face right away.”

Charles Hicks, MD, of Duke University Medical Center, says he has seen “a handful” of cases of quickly plummeting CD4 counts. He says they may result from “some very unfortunate combination of a particular virus and a susceptible immune system.”

On meds, Davis is now undetectable and healthy, with a CD4 count of 216. That makes him a new kind of stat: people diagnosed with AIDS but now living and thriving with HIV.
