Mirror, Mirror: Is HIV's Future Reflected in My Genes?

April 18, 2007 By Laura Whitehorn

Julian Awad has a tempting proposition: If you take his genetic screening test, the results might unlock the secrets of your body's ability to fight HIV, now and in the future. His HIV Mirror test detects CCR5 mutations, the genetic glitches that permit some lucky positive people to stay healthy for years without HIV meds, slow HIV progression in others who are on meds—and likely allow negative people endowed with two mutations to stay negative forever.

The test is not without controversy, though. Critics say the results rarely provide information of any real use—yet. Then there's the risk that it may confer an exaggerated sense of invincibility to positive and negative people alike. (One Australian company advertised its gene test as a sign of "HIV resistance.")

It is in part because of these medical and moral gray areas that Awad and his company, Smart Genetics, have decided to get some help with this tricky public relations challenge. They are running a contest for students at the University of Pennsylvania in Philadelphia to come up with a socially responsible HIV Mirror marketing campaign.

Awad has already rejected one proposed slogan—"We know more about your body than you do"—because it over-promises. Among the student ideas still on the table are a reality TV series featuring five HIV positive people taking the HIV Mirror test and a small hand mirror bearing the HIV Mirror logo and an HIV awareness message. (The test is not marketed to negative people at all, and the web sitesays a double mutation "does not tell you if you are immune to HIV.")

Still, scientists and HIV advocates wonder whether tests like HIV Mirror are worth all the fuss. Researchers tend to agree that genetic characteristics will govern much of medicine in the future. But are we there yet? And is there a socially responsible way to market a test if it isn't medically useful?

Mark Harrington of New York City's Treatment Action Group says no on both counts. He calls the CCR5 test "bullshit" and says, "It doesn't provide information that can help you make informed treatment decisions to help your health."

One positive veteran of the test told *POZ*, on the other hand, that taking a CCR5 test gave him peace of mind, greatly relieving his anxiety about waiting to start meds. And that's what Awad

says he found when he polled some 400 HIV positive people before offering the gene screen. “People said they wanted to know what their genes had to say about how they’ll do as they go through treatment—even though they knew it was only one piece of the health-status puzzle,” he says, pointing out that Gay Men’s Health Crisis (GMHC) will be listed as a counseling resource for HIV Mirror test takers.

Awad and his business partner, microbiologist Richard Watson, hatched the idea for HIV Mirror two summers ago while drinking beer on Watson’s Philadelphia porch. The result was a simple DNA swab, the same kind marketed by hundreds of genealogy and forensic testing labs throughout the country—except that HIV Mirror is the only commercially available test delivering HIV-related info. (Independent Forensics, a company that offered a similar test, has put its on hold until it can rewrite the educational materials accompanying the test.)

How might this test be used to help people make better treatment decisions? Watson says someone with a CCR5 mutation might, for example, need to adjust their dose of one of the new entry inhibitors (EIs). (The first pill in this class, Pfizer’s Maraviroc, has its FDA review next week). And he cites research that suggests possessing the mutation may affect how your HIV reacts over time to an EI (or any other HIV med).

Six researchers familiar with EI drug development told *POZ*, however, that it’s premature to think that the studies mean CCR5 mutations will influence the way patients take EIs; there is no such evidence yet. (The FDA has reportedly asked some companies to “investigate the association” with CCR5 mutations in EI trials, however.)

Bruce Walker, MD, who heads a study of “viral controllers” (their immune systems seem able to suppress HIV without meds for as many as 29 years), says CCR5 mutations do help predict HIV progression, but only at what he calls “a population trend level. It’s still all averages and trends,” he says, “not what’s going to happen on an individual level.”

If your genes can’t help you make specific treatment decisions, perhaps peace of mind is the only reason to spend $99 on an HIV Mirror test. But then why not get one at your doctor’s office—along with your drug resistance tests? For one thing, the CCR5 test is not widely available yet. Monogram Biosciences, perhaps the country’s main source of lab tests affecting HIV, does not yet offer the screen. “Before we do that, we want to make sure the results have some clinical significance,” says Monogram’s Chris Petropoulos, PhD.

Until then, the makers of HIV Mirror invite customers to practice their own form of social responsibility: Those asking for the test will be urged to enroll in Walker’s viral controllers study—the research that may eventually offer HIV treatment’s best mirror.

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