Amazing Race

As HIV rates in black communities soar, a genetic discovery may help explain why. But are we ready to talk about it?

October 1, 2008 By Kellee Terrell

This summer, at the XVII International AIDS Conference in Mexico City, the Centers for Disease Control and Prevention (CDC) announced that the rate of HIV incidence in the United States in 2006 was almost 40 percent higher than previously reported: 56,300 estimated cases versus 40,000. But even more dramatic is the fact that 45 percent of those infections were among African Americans—despite the fact that African Americans comprise just 12 percent of the U.S. population.

While many in the HIV world anticipated these high numbers, the question remains: What causes the disproportionately high rates of infection among this particular community? Several studies indicate that black people have no more, and sometimes even fewer, risk factors than white people. For example, black women report fewer lifetime sexual partners than white women, yet they are more likely to be diagnosed with an STD. So the myths of black irresponsibility, promiscuity and rampant drug use are exposed: None of them truly explains the numbers. While we know that certain social conditions and systematic oppression play a role in fueling the epidemic in black America, new rumblings suggest that something else could be in play.

The culprit, it turns out, may be genetic. Matthew J. Dolan, MD, with the Uniformed Services University in Bethesda, Maryland, and a team of doctors conducted a 25-year-long study of HIV-positive Americans and found that a gene, DARC, that once protected Africans against malaria may cause people of African descent to be 40 percent more likely to contract HIV than people of other races. “The impact of this gene is huge. It has accounted for almost 2.7 million infections in Africa,” Dr. Dolan told *POZ*. Ironically, the study also suggests, carriers of DARC are more likely to suppress symptoms of HIV.

While this is a significant scientific discovery, these conversations may stir up mistrust within the black community—based on a history of scientists and doctors using DNA to label people as pathological and inferior in order to justify abominable treatment such as slavery, the Tuskegee experiments (a 40-year study that left 399 black men untreated for syphilis) and forced sterilizations of black women in the ‘50 and ‘60s. More recent reports—like one this year in *The New England Journal* of Medicine about implicit doctor bias toward African-American patients—intensify fear and undermine the medical community’s inclination to discuss genetics in

the black community as it relates to HIV/AIDS.

But if we are unwilling to recognize and discuss genetic racial differences because of suspicions and fear of being politically incorrect, who will pay the price? “Without this type of research, we all lose out: the patients with the disease, the researchers and the medical workers,” Dolan says. “Practicing good science [will help us] better understand the rich diversity of the human race.” Dolan also hopes that the new genetic findings will help develop an AIDS vaccine and refine existing treatment. It could even allow doctors to tailor HIV therapy for each individual, instead of forcing a generic, one-size-fits-all approach on each patient. In addition, he says, these findings could help doctors determine when patients should start HIV meds.

Phill Wilson, the founder of The Black AIDS Institute, agrees. “The more we know about how the virus works in different people, the more successful we are going to be in fighting the epidemic,” he told *POZ*. “What’s also important is that carriers of the gene can suppress symptoms and so many African Americans are diagnosed with HIV when they already have AIDS. This work underscores the need for aggressive testing in our community and the necessity of knowing one’s status early on.”

While DARC offers an answer for why black people may be more prone to getting HIV, it doesn’t eliminate the need to address the social and cultural issues the black community faces that lead to greater risk for HIV. “Although this is an interesting development, this doesn’t change the work that we have to do,” said Helen Gayle, the CEO of Cooperative for Assistance and Relief Everywhere, Inc. (CARE). “We know what it takes to reduce people’s chances of contracting the disease, and we need to make sure that we have more resources for education, prevention and treatment.” If anything, more honest discussions of science, genetics and race may finally spark the heightened response to black America’s AIDS epidemic—the one that has been long promised, but not yet delivered.

SOUNDING OFF!
We asked what you thought about the notion of the black community being genetically predisposed to HIV and whether or not you trust the medical community. Here are your thoughts…

Leatrice Simpson, Chicago, diagnosed in 1992
“This is an incredible breakthrough, and [it] could possibly help prevent more infections and, ultimately, help find a cure. Personally, I am not certain [whether] the high numbers of HIV in the African-American community are because of a genetic defect or because of people being sexually irresponsible. But I tend to think that people are complacent and the sting or fear of transmission has lessened, resulting in irresponsible behaviors.”

Jerry Sheldon, New York City, diagnosed in 1994
“I would just like to know why now? Is this just another smoke screen to get more money for a better med, or is this going to help us find a cure? Instead of diverting the attention from what’s pressing, we need to do more to stop the disease through education, prevention and treatment—especially in the black community. Meet us where we are.”

Archbishop Joyce Turner-Keller, Baton Rouge, diagnosed in 2001
“[I don’t trust the medical community much], especially when it comes to how groups like the Centers for Disease Control and Prevention gather, analyze and disseminate their information. AIDS in the black community is a huge problem—it is our reality that people are dying—but I also feel like black men and women are being targeted and given a bad rap because the same outreach efforts and attention are not given to other communities, especially poor white communities. Don’t come to my house because of my zip code and ignore people who live elsewhere.”

Tim’m West, Houston , diagnosed in 1999
“I trust the research, but I’m not sure that I trust that the research will necessarily reflect particular genetic differences. I also understand the challenges of getting people of color to participate in research studies and clinical trials, given the legacy of Tuskegee [a clinical study, conducted between 1932 and 1972, in which 399 African Americans were studied to observe the natural progression of syphilis if left untreated] and the undercurrent distrust of the medical industry by many black people. Black researchers and physicians need to be at the forefront of promoting advances, so that clients can see that African Americans are involved at all levels. If there aren’t efforts to recruit AIDS researchers who reflect communities of color, I see that as a problem.”

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