Vagina Monologues

The fact that girl-to-guy transmission is nearly nonexistent has turned five women who thought they had killer vaginas into AIDS Inc.'s worst nightmare.

October 1, 2001 By Patrick Califia

Susan Rodriguez and her doctor, Joseph Sonnabend, MD, are an unlikely couple. Sonnabend, 69, is the openly gay "clap doctor" of the 70s who was one of the first to identify AIDS. An elder statesman of the epidemic, he is as legendarily controversial for founding -- and resigning from -- the American Medical Foundation (later amfAR) and the Community Research Initiative (later CRIA) as for pioneering his still-relevant "multifactorial" theory of how HIV causes AIDS. Rodriguez, 42, grew up in New York City's Bedford-Stuyvesant, was married and working as a high-level paralegal when her husband, a secret drug user, infected her. Rodriguez tested positive in 1995, after her middle child, Christina, 9, was diagnosed and before her husband died. In 1998, a year before undergoing chemo for breast cancer, Rodriguez founded SMART University (Sisterhood Mobilized for AIDS/HIV Research and Treatment), a treatment education and advocacy group for women HIVers. Still, the willowy, reserved Rodriguez and rumpled, abstracted Sonnabend are clearly well matched in grit and guts. And it's a good thing, because they will need every bit to open deaf ears to their message that a long-known, much-denied fact -- that women with HIV pose a negligible, nearly nonexistent risk of sexually transmitting the virus to men through vaginal sex -- not only was at the center of a mid-'80s cover-up but has a new, unexpected significance for the course of the epidemic today. As a blushing Rodriguez announced in a June speech in Washington, DC: "I don't have a killer vagina."

SEX, LIES & TRANSMISSION

This month, the SMART Five -- Rodriguez, Mary Hanerfeld, Michelle Lopez, Petra Berrios and Mary Alexander -- will press this message into service of a pie-in-the-sky agenda: to sexually empower women with HIV, to target new prevention to high-risk women, to push for female-controlled microbicides and to make the New York City Department of Health (DoH) and such sacred-cow institutions as amFAR accountable for misinformation. Their "We've Got the Juice" campaign's seed was planted last spring, when Sonnabend, lecturing SMART on current treatment options, mentioned off-handedly that it's very rare for a man to get infected during vaginal intercourse with an HIV positive woman.

The women, stunned, exploded with emotional questions. It was as if, in a single moment, they began to shed their HIV stigma and sexual shame. "For a long time after I got diagnosed, I hated myself," Rodriguez says flatly. "I was in isolation because of the shame. I felt like poison -- I

wouldn't even kiss anybody. And before, I had enjoyed sex," she says with sad eyes and a laugh. "I really did."

Yet Sonnabend's history lesson that evening went beyond the issue of empowerment. He described an intentional deception -- the '80s "heterosexual AIDS" hysteria -- floated by the *troika* of a mostly gay AIDS establishment, a crisis-craving media and a federal government playing catch-up. At the center of this maze is a pile of 15-year-old statistics carefully compiled by the DoH and conclusively showing that women almost never spread "heterosexual AIDS" to men. Men who report "hetero AIDS" get it from gay sex or dirty needles.

"When Joe told us about all this, it really fucked with my head," Rodriguez says. Until that moment, she had assumed that -- because "HIV is an equal-opportunity virus" -- she may well have transmitted the virus first to her husband and then to her child. Her self-blame was staggering. Now Rodriguez began to fit the pieces of her AIDS puzzle into a starkly different picture: Her husband got infected through sharing needles. So, all along, her conviction that she was at no risk for HIV because she was in a monogamous marriage with an uninfected man had been an utter delusion. "I was so naïve and in denial," she says. "If I had known any of this in 1992 -- not from my lying husband but from the lying health officials -- I would have done a lot of things very differently."

THE MYTH OF HETERO AIDS

When I phone Joseph Sonnabend, he sounds wary as well as weary. Since the early '90s, he has mailed out numerous drafts of a paper about this scandal to both the scientific and popular press, only to have *New York*, *Gear* and even *POZ* pass. But as Sonnabend begins his tale, he warms to his topic. "Men get AIDS from women in Africa and other developing nations, but they do not get AIDS from women in the developed world to any great extent," he says, though he emphasizes that men may be exposed to HIV from women (see "Negative Exposure"). "If we are talking about a heterosexual epidemic, transmission efficiency would have to go both ways. It doesn't. It stops with a woman and her children, and while that will be a personal tragedy for the infected, it will not cause an epidemic."

These facts are not new. Two pieces of evidence -- a 1990 CDC study that found "very little" transmission from women to men during vaginal intercourse, and the nation's largest study, a 1997 University of California at San Francisco report that found the risk of transmission from women to men "too small...to calculate accurately" -- were widely reported. The facts do, however, run counter to received wisdom.

"Plenty of people have known and denied this from the beginning," Sonnabend says impatiently. "It all started as a way for AIDS advocates to raise funds because little public or private money was coming in. I know this because the American Medical Foundation [later the American Foundation for AIDS Research, or amfAR], an organization I incorporated in 1983, a year later started putting out the word that 'no one is safe from AIDS.' Very good publicity it was, too," he adds with a harrumph. "They had no evidence to justify the huge public-relations campaign. All they had were predictions by some AIDS researchers. This led to my resignation from amfAR. But,

of course, the terrifying messages worked."

In fact, the messages proved spectacularly successful in raising public panic, or "awareness," and forcing the feds to throw serious money at HIV prevention. The CDC, predicting that the AIDS epidemic could exceed the Black Plague, launched an unprecedented national AIDS alert for heteros. Mathilde Krim, PhD, the amfAR chair, hit the networks with her tireless televangelism, and *Life* published its infamous "Now No One Is Safe" cover. Even Oprah Winfrey opined that one-fifth of all heterosexual Americans could be dead by 1990. Then, in 1987, Surgeon General C. Everett Koop blitzed every American household with his long-awaited "America Responds to AIDS" booklet, which turned out to be ominously devoid of a single reference to drug use or sexual orientation. Still, AIDS had hit prime time.

Sonnabend's reading of history is, by conventional standards, eccentric. Many survivors, mindful of the "by any means necessary" desperation of PWAs, naturally feel that the ends justified the means: Advocates did the right thing in scaring straights -- especially men -- so that an epidemic of fags, junkies and whores could finally get respect and resources. And there were extenuating circumstances, too: phobia of food handlers, threats of quarantine, galloping irrationality in response to limping science. Amidst the babble, amfAR's Krim came to represent the grandmotherly voice of reason. While Krim declined to comment to *POZ*, Deborah Hernan, VP of communications, strongly defends her organization's spearheading of so-called heterosexual AIDS. "In 1984, the scientific community was aware that this disease was spreading heterosexually in Africa," she says carefully. "And while heterosexual transmission was not then a primary factor in the U.S., scientists correctly concluded that it would be a forthcoming factor. Based on this information, amfAR did create a public-awareness campaign to highlight that no one was safe from this disease -- and it has been proven that we did the correct thing."

In what sense history has proved amfAR correct is hard to say, given that, according to the CDC's surveillance report for 2000, of all estimated U.S. AIDS cases, only 3 percent were "heterosexually transmitted" -- hardly a "primary factor" even now. Sonnabend himself recalls that in 1988, when the ACT UP Women's Group was zapping *Cosmo*'s Helen Gurley Brown for running an article minimizing women's sexual risk from men, he notified an organizer about the little-publicized female-to-male transmission facts. The ACT UPer urged him to burn the evidence. Then, as now, it seemed reasonable that men would be less motivated to use condoms if it was common knowledge that barebacking á la Adam and Eve was safe for them.

THE SMOKING STATS

Today, to the extent that female-to-male HIV transmission fears still flame, it is on the fuel of those statistics that Sonnabend says were doctored. In the plainly titled "Heterosexual Men and AIDS," the paper he co-authored with activist-writer Richard Berkowitz, Sonnabend notes that until 1991, the total number of AIDS cases among New York City men was 30,210, while the cases tagged as heterosexually transmitted numbered 92, or 0.3 percent. "[But] in 1991," the writers continue, "The numbers of men acquiring AIDS from their female sex partners started to surge. In a single year, 1991, there were 58 cases! In each subsequent year the numbers kept jumping: 193 in 1993, 271 in 1994, 305 in 1995." In contrast, the cases among women due to sex with an infected

man showed a slow, stable increase.

“What on earth could account for this sudden surge in heterosexually transmitted AIDS in men but not in women?” they ask in mock shock. Their conclusion? “Of course, the rather banal answer is that the DoH statistics...are an artifact of shoddy AIDS surveillance practices. From the earliest days of the epidemic, it seemed clear that female-to-male transmission of AIDS was extremely inefficient and unlikely to sustain a heterosexual epidemic here. Instead of a biological evolution, the sudden surge in heterosexually transmitted cases among men after 1991 probably results from changes in the way the DoH investigated and reported new AIDS cases.” That was the year, Sonnabend explains, when the DoH stopped its practice of categorizing all men who claimed that they were straight and had been infected by a woman as “No Identified Risk.” Until then, follow-up interviews with the man, his family and friends had been required to confirm that he had not shared needles or had sex with men.

“It’s stupid to think people are just going to admit to shooting up or having homosexual sex,” Sonnabend tells me. “So the city health department was pretty smart. They found that in most cases these men turned out to have another risk and could not be classified as heterosexual transmission.” According to one former “No Identified Risk” investigator, Anastasia Lekatas, the interviews rarely confirmed the man’s initial report. “Among the first 15,000 city AIDS cases, there were only eight female-to-male transmissions,” she told *The New York Times* at the time. “And I have doubts about seven.”

In 1993, under the Office of AIDS Surveillance watch of Polly Thomas, MD, the practice of classifying all men who claimed that they were straight and had been infected by a woman as “female-to-male” -- no further questions asked -- became official DoH policy. Although Thomas did not respond to requests from *POZ* for comment, Sonnabend and Berkowitz report that in a 1993 response to Donald Capra, MD, a leading immunologist suspicious of her surveillance data, Thomas acknowledged the new policy -- “Men claiming heterosexual transmission are placed in that category before an investigation” -- and apparently omitted mention that such investigations had stopped. Rosalyn Williams, DoH’s AIDS Surveillance Coordinator, confirmed the change in practice. In an interview with Michelle Cochrane in her *The Social Construction of HIV/AIDS Knowledge* (out from Routledge next month), Williams says, “We stopped investigating all claims of AIDS in heterosexual cases [despite the fact that] most of the men did have another risk. Other places like Florida were classifying [similar cases] as heterosexual men. Why had New York City been using a different classification?”

PREVENTION PAYBACK

That’s why, a decade later, these “statistical shenanigans,” as Sonnabend puts it, may matter more than ever. There is, first of all, the moral question of fomenting a false medical panic. “Quite apart from the fact that it is just plain wrong,” Sonnabend and Berkowitz write, “it may well weaken the desperately needed efforts at targeting AIDS prevention to those who need it most. This most definitely includes heterosexual women at risk from sex, but does not include [their male counterparts].” There is also the issue of scientific accuracy and authority. “Furthermore,” they write, “as there is a street-level realization that this group of heterosexual men are not

getting AIDS in any meaningful numbers, trust is lost in the authorities who overstated a risk. The serious danger here is that other warnings that are in fact real, such as the risk to women, will be discredited."

For Catherine Hanssens, the nationally renowned director of Lambda Legal Defense and Education Fund's AIDS Project, the DoH's shady data collection raises provocative legal questions. "Public health policy has always involved politics," she begins, "and the HIV epidemic has shown time and again that when politics rather than scientifically sound methodology determine how to categorize who's getting infected and how, we get self-defeating measures like names reporting, not to mention too many messages targeting those who are not at risk and too few for those who are. This," she adds, in high dudgeon, "clearly represents an abuse of not only public funds but of public trust."

The myth of heterosexual AIDS has also given cover to each presidential administration's meager HIV prevention outlay to the most stigmatized, highest-risk folks in favor of hand-over-fist waste for the majority essentially safe from AIDS. During the AIDS-at-20 brouhaha, when the new stats showing a disproportionate rate of infection among young gay and bisexual men of color were announced, Hanssens points out, "Just look at the response of Tommy Thompson, Bush's secretary of health and human services. He said that he would increase funding for abstinence-until-marriage prevention. Which effectively tells us that those the CDC has identified as most at risk either don't exist at all or are not worthy of existence."

With the prospect of an effective vaccine still a faint flicker, the only tool for collaring the runaway virus is, of course, prevention. And with the slow-going research into microbicides -- which a woman can use free of a man's consent -- grossly underfunded, the only prevention is, of course, latex. But who controls condoms? When asked whether targeting young women of color with the information that men pose a greater HIV risk to them than vice versa will equalize the power imbalance behind condom negotiations, Rodriguez laughs. "He wants to have sex, and he is in control, and either he's going to wear one or he's not," she says disgustedly. "Come on, let's be real."

PUSSY POWER

In the early '90s, when the English Collective of Prostitutes asked Sonnabend about his research, they were outraged that the truth about unequal risk for women could not be publicized. "'Give us the right information,' they told me," Sonnabend recalls, "'then we can take care of ourselves.'" Right now, the SMART Five are confidently singing the same righteous chorus. "Women need to be put in control of this information," Rodriguez says earnestly. "No matter how the government or AIDS agencies may deny it, if women have empowerment, we are *not* going to be in situations where a man is *not* going to wear a condom."

SMART's platinum-haired, high-spirited Mary Hanerfeld has long worked the female empowerment angle. She is adamant that the truth about girl-to-guy transmission's inefficiency is leading HIV positive women to some much-needed sexual healing. Hanerfeld was diagnosed in 1990, after

donating blood at work. Her husband, a drug user who had lied about his HIV test results, was drinking heavily and acting violent. She was 38; her two daughters were 11 and 16. After leaving her husband and going on a six-month drinking binge, she sobered up and founded a support group for women HIVers, most of whom had stories cut from the same lying-denying-husband cloth. Hanerfeld saw that the women were acutely alienated from their sexual feelings. In response, she began her talks with some version of "I am a magnificent vagina putting out." Ten years later she is still at it. "Sex is the closest we get to heaven," she tells me in her cigarette-gravelly Brooklyn accent. "And they say we shouldn't do this? What are they, nuts?"

Yet with the "We've Got the Juice!" campaign just gearing up, Sonnabend's Angels are only beginning to answer the hard questions. Most practically, how will they translate their consciousness-raising sessions into political action? Even on the prevention front, their task is daunting. At last June's historic U.N. General Assembly on AIDS, expert after expert testified that women in the hardest-hit nations are overwhelmingly afraid to refuse to have unsafe sex with their husbands. But even if there were a magic mantra that made men want to slip on the latex, it would not address the fact that, as Michelle Cochrane points out, the main risk of HIV transmission for straight women is not sex with men but needle-sharing. Still, drug-addiction services for women lag far behind those for men, and there is little harm reduction tailored for women users. Who will advocate for these women?

And who will persuade straight men whose priority is getting high to take precautions to protect their female partners? For several years, health workers have dealt with these men by doing street outreach with drastically lowered goals -- anything other than harm reduction is thought to be too demanding. Hanerfeld suggests that peer education for straight men who shoot up or have sex with other men might be effective, but leading advocates told *POZ* off the record that in their opinion it can't be done. "We have to try," Hanerfeld responds.

Meanwhile, female vulnerability to HIV during heterosexual intercourse remains an international health emergency. The dire need for female-controlled protection ought to be dramatically clear to anyone who understands the implications of Sonnabend's epidemiological sleuthing. But after 20 years, we have exactly one technological innovation in AIDS prevention for women: the so-called female condom. This cumbersome device limits pleasure for both parties; its use is nearly impossible to hide; and it's much easier than a diaphragm for an angry partner to remove. "Tell me why microbicides are not getting adequate funding when they've known all along about the unequal risk to women," Rodriguez demands. "What's that all about?"

Yet Rodriguez is under no illusions about either the ambition of her agenda or the power of the resistance -- not only from men and government officials but from home-grown advocates who are partners in the AIDS struggle. Still, this vivid survivor of abuse, HIV and cancer is in it to win it. "I can't let go of this issue," she says with feeling. "It's crazy. We're fighting the government, AIDS agencies, people in high places who don't want this information out. But AIDS is big business, and funding, careers, even reputations are based on AIDS being a public health emergency for straight men." She shakes her head. "But it just ain't so."

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