The Way We Live Now: Mary Lucey

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Q: What kind of moment is this in the epidemic for women?

A: Let's look at the Health and Human Services HIV treatment guidelines for a minute, which drive this country and the rest of the world. A Johns Hopkins study came out in late '98 showing that women get sicker at higher CD4 counts and lower viral load counts than men. So several people approached the HHS guidelines board with this information. And I looked at this board to see who was taking care of the home front for the women -- because we're different from men. We metabolize drugs differently, we require different dosages. And there are maybe 50 men, including about 30 PWAs, on that board -- and they have *one* woman PWA. One woman, all by herself, advocating on behalf of like 100,000 women in the United States. She doesn't even have a treatment background. Women are 27 percent of the U.S. AIDS population now, and we have *one* woman on the guidelines board? Not OK.

What happens is women's providers use those guidelines, because they're in rural areas or in public health systems, and they have nothing else. So if the guidelines say there's no difference in dosing, those women won't get a fair shake. You've got to ask, Are they intentionally keeping us out, or are they just too damn stupid to figure out how to include us?

Another inequality: A lot of men are using protease-sparing regimens. I'm doing great on one of these regimens, but most women don't even know about them. They don't know that the clinical outcome is similar to protease regimens -- or that the regimen is so much easier to take -- because they're not offered the option. Women come in to their doctors sicker, they let their doctors lead them by the nose, and most of their doctors are not AIDS experts. So treatment is drastically different for women.

You know what else? It's 20 years into the epidemic and we have four treatment studies for women. I have to applaud private industry for finally designing the studies, but they're not stupid. They see that in the near future, 40 percent of their consumers will be women, and those women will say, Did you study *our* dosage? Whereas, even though we know that toxicity and absorption are drastically different for men and women, the FDA still doesn't require different dosing guidelines by gender. They have geriatric guidelines, pediatric guidelines! But they have nothing for women.

So as far as treatment goes, no, I’m not content at all. As long as women take the same dosages as men, knowing there’s a clinical difference, no, I’m not happy. As long as we have four studies in 20 years looking at treatment in women, I’m not happy, because what do we have, 7,000 for men? And as long as women don’t know about their options because they’re not offered by their paternalistic providers, no, I’m not happy.

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