

Ryan White's mother speaks at Center

by Yasmin Nair

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According to the Illinois Department of Public Health (IDPH), the latest statistics on HIV indicate that the populations at greatest risk for new infections are African-American men who have sex with men, and African-American women. This is a marked shift from the early years of the epidemic, when HIV/AIDS was perceived—and stigmatized—as a white gay men's disease.

Jeanne White (left) and Shelly Lindahl. Photos by Yasmin Nair

IDPH and the Center on Halsted teamed up on National HIV Testing Day, June 27, to provide information on HIV, along with testing services. Modesto “Tico” Valle, executive director of the Center, began his introduction of the morning's sessions with a reminder: “Let no one say that AIDS is over. We are called to do more, to ask for more, as long as AIDS is among us.” State Representatives Greg Harris and Sara Feigenholtz spoke about the importance of prevention and regular testing.

Following them was Jeanne White, the mother of Ryan White, the Kokomo, Ind., native who was born a hemophiliac in 1971. White told of her son being treated with Factor VIII, a clotting agent made from blood. Unknown to the doctors and the Whites, the batches used to treat Ryan were contaminated with HIV and he was diagnosed with the virus in 1984. The Kokomo school board ruled that the teenager could not attend classes, claiming that he would infect his classmates. The family endured continued hostility from the townspeople, which included a bullet through their living room window. The Whites relocated to Cicero, Ind., where Ryan White died in 1990.

Jeanne White spoke of this history, as well as her increasing connection to the gay community, and of having becoming disillusioned with what she had hoped would be a supportive church. Instead, she said, “I saw the church back away,” and she found herself calling amFAR (American Foundation for AIDS Research) for help and advice on treatment options. In concluding her talk, she echoed the need for doing a better job at prevention.

The Whites successfully contested the school board decision, and celebrities like Michael Jackson and Elton John lent their names in support. Ryan White's story, and the media attention it garnered, became a pivotal point in reducing the stigma attached to AIDS. But while much of

the stigma has vanished, the rates of infection among women have risen, and African-American women are among the hardest hit. The “down-low” phenomenon is often suggested as one cause for this. According to some, large numbers of African-American men secretly engage in unprotected sex with men, become infected with HIV, and pass it on to their female partners.

Shelly Lindahl, a physician's assistant from Dallas, Texas, began a morning break-out session on “Women and HIV” by debunking what she considers the myth that most women are infected in this way: “We want to make it about down-low, but a much bigger picture is that of drug use and the recidivism rate.” She pointed out that given that many men in prison engage in a high rate of sex—either for protection, or because they're manipulated into doing so, or because of the “pecking order,” “they're not going to talk about it.” (Many prison reform activists advocate for distribution of condoms in prisons, which would prevent the spread of HIV.)

Lindahl's talk focused on how women who contract HIV through unprotected heterosexual sexual could prevent the spread of HIV once diagnosed with the virus. According to her, by the end of 2004, 27 percent of those newly infected with HIV were women. The specific challenges in addressing HIV in women, for Lindahl, have to do with addressing socio-economic and cultural factors. For instance, women are less likely to feel empowered in condom negotiation and, therefore, more likely to engage in unprotected sex.

Once infected, women are sometimes apt to not stay on their drug regimens, usually because of side effects but other contributing factors might be that they're often the primary caregivers for children and neglect their own care. Lindahl noted that pregnant women are usually rigorous about taking their medications during pregnancy, but falter afterwards. She recommended adherence to medical regimens, and that women keep in touch with a provider who would answer their questions. If, for instance, a doctor changed medications even when they seemed to be working, it was imperative that the woman know the reason for the change: “Every patient has the right to ask why.”

Lindahl also spoke about the necessity of health maintenance in the form of regular check-ups and continued protection during sexual activity, as well as forming support groups. In response to a question about the differences in dealing with HIV, between lesbians and straight-identified women with HIV, she said that lesbians tended to be more aware of the risks and had built-in support groups due to their connections to the LGBTQ community.