



Is HIV stigma worse than ever?

Pennsylvania HIV Justice Network forms to combat social, racial and political injustice

By Louie Marven

Since July 3, 1981, when the *New York Times* published its now iconic story "Rare Cancer Seen in 41 Homosexuals," so much has changed.

And much remains the same.

HIV stigma is alive and well even though medications first rolled out in the mid-90s and since then keep the deadly virus at bay for those infected. In fact, the World Health Organization, US Centers for Disease Control, and the International AIDS Society formally state that *Undetectable = Untransmittable*. In other words, a person living with HIV (PLHIV) who has an undetectable viral load does not transmit the virus to their partners.

Better still, PrEP (Pre-exposure prophylaxis), a pill-form medication taken daily, keeps uninfected people from getting infected with HIV. But alas, stigma strikes again. Those who reveal taking the drug are often called "PrEP Sluts" for taking responsibility for their sex life. (PrEP does not protect against any other sexually transmitted infections like Syphilis, Gonorrhea, Hepatitis B and C, and others.)

That's why PLHIV networks are forming all over the nation. In the crosshairs of a polar vortex last February, 18 individuals, almost all people living with HIV, met in Milford, PA, to form the Pennsylvania HIV Justice Network.

"We came together to develop a mission statement and create a steering committee to guide future goals for the working group," said Teresa Sullivan of Positive Women's Network – USA. Sullivan believes that "the group of people that were at the gathering are the right folks to accomplish justice for people living with HIV in Pennsylvania that goes beyond treatment goals. Our goals also include social justice, racial justice, and electoral campaigning for 2020."

Waheedah Shabazz-El, also of Positive

Women's Network – USA, described the initial convening as breaking the ice and coming to group agreements, including "that our advocacy can be more impactful if it were strategic and intentional, to form a working group that could identify gaps in services that impact quality of life, and to form a group who could imagine what can be possible as far as strategic collaborative advocacy."

Shabazz-El emphasized the need to affect change "throughout the state in urban, suburban, and rural counties."

The newly-formed network, which invites other PLHIV and allies in Pennsylvania to join, will be fiscally-sponsored by The Sero Project. Sero is a national network of PLHIV that fights HIV criminalization and supports the creation and strengthening of statewide PLHIV networks. Sean Strub, who founded POZ magazine, is Sero's executive director, as well as the mayor of Milford, PA, where Sero is based.

Strub stresses one significant change

since the early days of AIDS. "Earlier in the epidemic, generally the most important priority immediately post-diagnosis was to connect the newly-diagnosed person with other people living with HIV, to help them build a supportive environment, get questions answered, etc.," Strub explains.

There were support groups and HIV networks everywhere for this purpose.

"The LGBT community back then accepted the epidemic as a collective responsibility and wrapped its arms around the newly-diagnosed person, smothering them with love and a 'we will get through this together' message," Strub says."

He contrasts that collective responsibility with today, where the response to diagnosis is to prioritize treatment to stop transmission.

"Support groups and networks are cut way back or eliminated; facilitating PLHIV getting together with each other isn't a priority for most HIV service providers."

Furthermore, "the LGBT community has gone on to other issues and a newly-diagnosed gay man is as or more likely to encounter judgment, if not scorn and abandonment, from other gay men, as he is to find the support that once was the hallmark of our community's response," Strub laments.

Shabazz-El also evoked history in describing her hopes for the network.

"I would like to see people living with HIV in our network grow confidence in their leadership by using the Denver Principles," she said, referring to the iconic 1983 statement developed by pioneers in the HIV self-empowerment movement.

Externally, Shabazz-El hopes the group can establish a lobby day in Harrisburg, provide "a rapid response when a bill is entered that may have negative impact on our communities" and help advance progress in the state legislature.

Helping with legal and other aspects of HIV reality in Pennsylvania are Adrian Lowe and Ronda Goldfein from the Pennsylvania AIDS Law Project.

"Stigma discourages people living with HIV from asserting their legal rights," said Goldstein, the law project's executive director. "We have talked to clients who have endured discrimination, but don't want to pursue their claims because they are afraid of being identified as living with HIV. We hope the PA HIV Justice Network will help people feel more connected and empowered."

Therein lies the network's challenge: changing long-held attitudes about HIV. "Because the epidemic is less visible today, it doesn't mean it is gone. And despite the profound progress on the biomedical side, on the social and cultural side, HIV stigma is worse than ever," said Strub.

"There is no pill to treat stigma. The most successful anti-stigma strategy is to focus on empowering the stigmatized, which is what networks help accomplish."



Eighteen individuals met in late February at the Hotel Fauchere Meeting Center in Milford, PA, to form the Pennsylvania HIV Justice Network. Front row, from left: Susan Mull, Waheedah Shabazz-El, Michelle Kohler, Teresa Sullivan, Brenda Goodrow, Rhonda Goldfein. Back row, from left: Andrea Johnson, Kevin Burns, Barbara Whitney, Adrian Lowe, Julie Graham, Sean Strub, Gail Thomas, Heshie Zinman, Cindy Stine, Jeff Haskins, Chris Bartlett and Central Voice publisher Frank Pizzoli.