



# *A New National Positive Women's Network*

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*According to a report by the Joint United Nations Programme on HIV/AIDS, approximately 300,000 women are living with HIV in the United States. To the Oakland, California–based organization WORLD, these are 300,000 invaluable sources of insight into the strengths, priorities, and needs of HIV positive women, and the gaps in women-focused HIV prevention approaches.*

*WORLD wants to put this insight to work across the country through their new initiative, the National Positive Women's Network. Naina Khanna, National Advocacy Coordinator for WORLD, spoke with BETA about this new organization.*

## **BETA: First, what does “WORLD” stand for, and what does the organization do?**

**Naina Khanna:** WORLD is “Women Organized to Respond to Life-threatening Disease.” We are a Bay Area–based organization that was founded in 1991 when Rebecca Denison unexpectedly tested positive for HIV and was unable to find any resources specifically for women. She tested positive, couldn't find anything, and started contacting doctors, nurses, and positive men's support groups, saying, “Do you know any other positive women? I'm trying to find someone in my situation; can you please give them my phone number if you find them?”

Through doing this, she did meet a few other positive women, and they started a support group in her living room. The first thing they did was raise a couple hundred dollars to put together a newsletter, which today goes to 87 countries and has a readership of over 14,000 people. WORLD is an organization that exists to inspire, support, and advocate for women living with HIV.

## **BETA: What can you tell me about the new Positive Women's Network that WORLD is launching?**

**NK:** WORLD is an organization that operates on a peer-based model. We believe that women living with HIV are the experts in their own lives, and a big part of our mission is to develop leadership among HIV positive women and ensure that women living with HIV are making decisions when it comes to programs and policies and things that are actually affecting their lives. The Positive Women's Network is the next step: we see the need for a national unified voice for HIV positive women.

This is something that we've heard from organizations and individual women across the United States—that there is

no unified voice that is reflective of a wide community of positive women's needs, and therefore positive women are not being represented at decision-making tables, in policy discussions, even when it comes to something like developing a national AIDS strategy. There is no entity that is saying, “We represent the voices of thousands of positive women who are living in the United States.”

## **BETA: Your website mentions that the network will develop a leadership model that fits women's lives. What issues specific to women's lives call for a unique leadership model?**

**NK:** I think there are a lot of them. Obviously there are biological and physiological differences between women and men, and the virus is both transmitted and can be prevented differently and progresses differently in women's bodies.

Then there is the socioeconomic context of women's lives, as well. For example, according to a Kaiser Family Foundation report, 76% of women with HIV have a child under the age of 18 living at home. That is not the case for men with HIV. That means that for an HIV positive woman, child care as well as other factors in her life are important when it comes to making medical appointments, being present at meetings, the hours that a meeting will be held, and whether or not she's going to be able to show up at them. That is just one example.

## **BETA: And the Positive Women's Network will take those factors into account?**

**NK:** Absolutely. It means that we may need to find times when mothers are available to meet. Women are the centers of their communities—they tend to be taking care of

everybody before they take care of themselves. That is something that absolutely has to be recognized and taken into account in any leadership model.

Another thing is that women living with HIV tend to be disproportionately low-income, and disproportionately on Medicaid at the time of diagnosis compared to men who are HIV positive. All of these things need to be taken into consideration.

**BETA: What are some of the policies and programs that would address the realities of women's lives?**

**NK:** We want to make sure that there are positive women represented at the table anytime that decisions are being made that will impact them. That is one policy: the principle of the meaningful involvement of HIV positive women.

We also want to substantially commit to developing leadership among women, particularly from communities that are most impacted, as well as developing accountability within our own movement. It is one thing for any positive woman to get on a panel or in a plenary or sit in a meeting and say that she's representing positive women. Right now there are no mechanisms for her to actually do that, so we would develop mechanisms to do that by having her sit in that meeting and say, "Well, based on our survey results from talking to 3,000 women across the United States—including the most impacted urban areas, including rural areas, including trans women, young women, immigrant women—this is what we've identified as priorities."

Also, when it comes to policies, I think there are specific things that are absolutely going to impact women in terms of prevention programs. If you look at new prevention technologies like microbicides, that is something that the Positive Women's Network would be interested in advocating.

Also, things like structural interventions. Current interventions that are designed to reduce risk look at a behavioral model and assume that if people change their behavior, that lowers their risk for contracting HIV. We know that is not necessarily true for women. It doesn't have anything to do with them making decisions about their behavior—in some cases, they don't have a choice about whether to protect themselves, whether to use a condom. In many cases, women are married or in a monogamous relationship, but there are many factors leading to the HIV epidemic—particularly among low-income women of color—that need to be addressed.

**BETA: What kind of response have you seen, and how can people get involved?**

**NK:** We've seen a lot of excitement. Women are very ready for this; they believe it is time for a change and they believe that they have something to say.

Anyone living with HIV who identifies as a woman can be a member. Anybody who wants to support our work can join as an ally. The way you can do either one is by going to our website, [www.womenHIV.org](http://www.womenHIV.org), to get more information about the Positive Women's Network. There is contact information there. There's also an email address: [pwn@womenhiv.org](mailto:pwn@womenhiv.org).

The other thing we are doing is supporting local work. We launched our first affiliate group here in the Bay Area, the Bay Area Positive Women's Network, which has started meeting and is identifying local and regional priorities in terms of the work they want to do. They kicked off with going up to Sacramento to testify on the ADAP [AIDS Drug Assistance Program] budget cuts. Those are examples.

What we are interested in creating is more a model of women's empowerment and leadership, and a part of that is to hold people accountable for values rather than telling women what they should be working on. It's more a way to support women's own leadership.

**BETA: What do you hope the network will look like a year from now?**

**NK:** A year from now, I hope that we'll have at least a couple thousand members. I hope that we will have two to three local or regional affiliate groups around the U.S. that are working and collaborating together, because there is already a lot of amazing work going on around the country. One of the goals of this network is to amplify the work that women and organizations are already doing and share it where it is appropriate so that we can actually share skills and lessons learned, and connect and communicate with each other. In a year, I hope that we will be well on our way to organizing a national Women and HIV Conference.

**Selected Sources**

Henry J. Kaiser Family Foundation. HIV/AIDS Policy Fact Sheet: Women and HIV/AIDS in the United States. May 2008. Available at [www.kff.org/hiv/aids/upload/6092\\_05.pdf](http://www.kff.org/hiv/aids/upload/6092_05.pdf).

UNAIDS. 2006 Report on the Global AIDS Epidemic. Available at [www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2006](http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2006).

**Learn More about WORLD**

WORLD offers a number of programs and services designed to support and empower women living with HIV. These include a free AIDS Resources Library, advocacy for positive women in prison, and "HIV University," a 12-week HIV treatment education and community outreach program with over 100 graduates and 40 pilot programs nationwide.

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