



## *Giving Advocates a Voice: An Update on the U.S. Positive Women's Network*

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*According to the U.S. Centers for Disease Control and Prevention (CDC), women account for roughly 25% of the U.S. HIV epidemic. Yet women are often under-diagnosed, and they regularly face discrimination and limited access to care and treatment.*

*Since launching in 2008, the U.S. Positive Women's Network (PWN), a project of Women Organized to Respond to Life-threatening Disease (WORLD) in Oakland, California, has worked to unite HIV positive women across the country and give advocates a cohesive voice. PWN coordinator Naina Khanna and communications coordinator Sonia Rastogi recently sat down with BETA to give an update on the network's current and upcoming activities.*

### **BETA: Why is a network for HIV positive women needed in the United States?**

**Naina Khanna:** The U.S. Positive Women's Network exists because there's a huge gap in a couple of things. One is applying a "gender lens" to the HIV epidemic domestically, and the other is applying an "HIV lens" to women's health issues and issues of women's rights in the U.S.

The PWN—which is a national membership body of women living with HIV working for federal policy change—is seeking to fill gaps by doing a few things: building leadership among HIV positive women, working on specific campaigns to change policies, and building capacity for collective action among women and HIV advocates.

### **BETA: How has the Positive Women's Network grown since it first launched?**

**Naina Khanna:** The PWN was founded in 2008 by 28 really diverse HIV positive women all around the country. We

had women from urban areas and rural areas, transgender women, younger women, and older women who came together to collectively envision what it would take to build a sustainable leadership "pipeline" and have an impact on achieving gender-sensitive HIV policies here in the U.S. It was really quite a historic moment because, for years, women had been working in isolation or in small-to-mid-size organizations or trying to do their own organizing but always being an outside voice in the HIV epidemic.

So it was really a powerful moment when all of these different advocates came together. There were newer advocates and more experienced or seasoned advocates—but one thing we all had in common was that we were all HIV positive—coming together to say, "There are some real issues coming up on the horizon. We're in a historic election year and we need to bring these issues to the attention of our administration. There are major issues around achieving women-centered services at a prevention level and at a care level, and to ensure funding is attributed equitably, to name a few.

There were things that came up at that first meeting about ensuring that people living with HIV/AIDS could get access to life insurance, for example—those kinds of justice issues. The PWN has always been focused on a human rights and social justice lens applied to the epidemic.

Since our founding, we've expanded to a membership of about 2,500 women across the country. We have women in almost every state and territory. We have strong regional groups that are organizing in a handful of places—we have a really great, active group in Philly, we have a group that's organizing across the state of South Carolina, we have women organizing here in the Bay Area and in San Diego.

Those are some of our more active local and regional organizing groups, and then we have other women doing things actively, either through their planning councils or other mechanisms at a local level. [For more on the history of the PWN, see "Women & HIV: A New National Positive Women's Network" in the Summer 2008 issue of *BETA*.]

### **BETA: What activities and events has the PWN participated in or organized?**

**Naina Khanna:** Like I said, being founded in a historical election year gave us a lot of work to do and a lot of opportunities. At the time we were founded, there was advocacy going on around having a first-ever National HIV/AIDS Strategy. Once President Obama was elected, one of his key priorities was health care reform, and these are issues that are obviously of huge importance to our constituency. We took a really active role in both of those processes.

I think one of the things we're most proud of is that we were able to mobilize HIV positive women across the country to participate in the Na-

tional AIDS Strategy conversation. We mobilized women for town hall meetings. For women who weren't comfortable showing up and giving their testimony at the town hall meetings, we created a focus group template, and we had women administer it at women's organizations...to find out about their priorities with the National HIV/AIDS Strategy. We compiled all of that information and submitted it to the Office of National AIDS Policy.

We also organized, with the White House, a consultation on women and HIV issues, where there was a significant presence of HIV positive women, as well as providers and other advocates for women living with HIV and women affected by HIV. After the strategy was released in July, we created a gender-monitoring tool to look at and assess the strategy... We wanted the administration and people taking further action to know we had big hopes for the strategy, so we made a set of recommendations about how it could be strengthened, from a gender and human rights perspective. That kind of policy and mobilizing work is a good example of the type of things the PWN has done.

**Sonia Rastogi:** This year we've been looking at the PWN's future. There's a bigger need from women in different states, now that they've seen the Positive Women's Network nationally. I got a call from Ohio the other day, and I got a call from Michigan another day—women are calling and saying, "I want to get more involved with the Positive Women's Network. I hold a support group, I'm trying to mobilize women in my town." We're now at a point where we're able to provide more regional organizing tools and strategies.

Where the gender audit fits in is that we'd like to make it adaptable to states and local regions, so [PWN members] can take it to their local and

state governments and say, "These women are living with HIV, and these are their needs. We have this gender audit and we'd like to do an evaluation of the services."

The gender audit is composed of six different sections: What are the women-centered services, and what are the needs in that arena? What are the needs of women living with HIV—the research needs around medication and treatment, and prevention justice and meaningful involvement?

**Naina Khanna:** Our vision is to ensure that HIV positive women's experiences—*lived* experiences—are informing policy. The way we do that is to turn out women for things that are already going on—like health care reform conversations, National AIDS Strategy conversations—but we also recognize that nobody is necessarily working on some of those things that need to be done.

One of the things we took on last year is, we created a human rights survey for HIV positive women. We've had about 140 positive women take it so far, and it's really documenting patterns of discrimination, patterns of reproductive rights violations, attitudes about criminalization, employment issues—some really key lived experiences that are helping to inform our policy priorities and the work we do moving forward.

Subsequent to that, we also are providing human rights training for women living with HIV to train them on how to use a human rights framework in their advocacy and community mobilizing. ... We work with women to ensure they understand there are human rights that are globally recognized, and there's a whole global context in which our work is applicable, whether we're fighting for prevention justice, access to treatments, access to quality of life, or quality of care. That's some of the work we do.

I also think the work that Sonia has done around training HIV positive women to tell the story of HIV is a key component of the work that we've done.

**Sonia Rastogi:** Looking at the past year and a half, what the Positive Women's Network has been able to do is really give women a venue to talk about their experiences and also connect what their personal stories and experiences mean to these bigger structural issues, like reproductive justice, or criminalization, or racism, or violence against women. [The PWN is] able to give women a voice, and to support them in developing personally and as advocates. We've been able to put out blogs for specific events, like the National HIV Testing Day or at the U.S. Conference on AIDS last year.

[In terms of] leadership development, which is really an integral part of the PWN, this year we're launching communications and media trainings, which are also going to be coupled with more, "How do you community mobilize? How do you do organizing?" Because the two go hand-in-hand. This will be following our human rights trainings, to give women more tools and resources in order to make their stories, experiences, and needs heard.

**Naina Khanna:** I just want to add that I think what's unique about the work that Sonia is doing is that, in some places, HIV positive women are trained to tell their stories, but it's usually with a message of "Don't do what I did, use a condom!"

The difference is that we are working with women to train them to use their personal experience as a tool for political change—to insert their life experiences into policy conversations and advocacy conversations and say, "I was missed for testing three different times over a five-year period and consequently my health outcomes are

worse than they needed to be, and that's a problem because the reimbursement rates for testing are not effectively meeting women's needs. We need to fix the testing reimbursement." It's that level of conversation that we're moving women to.

### **BETA: What is the relationship between WORLD and the U.S. Positive Women's Network, and how has the Positive Women's Network changed WORLD?**

**Naina Khanna:** That's an interesting question. WORLD has been around since 1991. We've been an organization by, for, and about HIV positive women, mostly providing direct services. What some people don't know is that WORLD has also done advocacy throughout our history. We have old photos of our founder, Rebecca Denison, marching [with a sign reading], "Women don't get AIDS, we just die from it." WORLD has a history of doing advocacy, especially in the local community and nationally on treatment access and clinical trials.

Our explicit relationship is that the PWN is a project of WORLD. The relationship for both organizations has been extremely beneficial in a couple of senses. One is having PWN housed at WORLD ensures our policy work is not disconnected from people with lived experience, because we are at an organization every day where people are coming in and receiving direct client services. We're informed by the actual experiences that HIV positive women are having in a city such as Oakland.

In that sense, it's been really beneficial to WORLD to maintain a "pipeline" of leadership: Women come here for support, they get interested in advocating for themselves, they get better health outcomes, and WORLD provides training for women to learn

to be better advocates for their own health, through our peer advocacy training program.

WORLD also provides training through our Lotus Project for women to learn to be peer advocates for other women. It's a natural next step that from there—from advocating for other women—you go to the stage of advocating for your community for structural solutions. That's the level at which the PWN can come in and bring the human rights framing, the media and communications work: "This is how Ryan White funding works, this is how you participate in a planning council meeting, this is what the priority of setting an allocations process looks like, this is how you testify and impact it." It's a natural relationship.

I think the other way that we've been able to really complement each other is that WORLD has been in this community for so long and has really rich relationships at local and state levels. PWN's focus has been more at the national level, so we're able to apply and translate lessons learned.

A specific example would be the tool that we created for gender monitoring in the National HIV/AIDS Strategy. Our next step is to adapt it for state and local organizers. This is something that we're going to be sharing with our regional organizers all across the country, and they're going to help us to inform and adapt to their context. Our steering committee member in South Carolina is going to need to be thinking about what's going to make the most sense for them in South Carolina. We're going to need to be thinking about what is going to make sense in Oakland.

We really have opportunities, at a local level, to share regional organizing experience and share applicability. Everybody's in a battle for ADAP [AIDS Drug Assistance Program] dollars, for example. California is in a battle around co-pays, and in South Carolina [and 12 other states] there's a waiting

list. So, how can we share our best practices and share our knowledge and wisdom and resources?

**Sonia Rastogi:** What I've found is that, with the PWN being housed here and with our women that come here, there's exposure every time they come. They get trained one time; they hear Naina do a speaking engagement, or they hear their peers do a speaking engagement—it just keeps on encouraging that community to be built, and also their confidence to turn into really effective advocates.

**Naina Khanna:** The first time, a woman might come here for a support group. The next time, she might come and meet with her peer advocates. A year later, she might show up because we're having a rally at City Hall because of the ADAP funding crisis, and six months later she might be *speaking* at the next rally. Maybe a year after that, she's presenting at the United States Conference on AIDS about treatment access for women.

That's the trajectory that we're working with and that we're trying to build on.

### **BETA: How will health care reform affect HIV positive women in the U.S.?**

**Sonia Rastogi:** I think there are a lot of great things coming with health care reform, where a lot of women are underinsured or uninsured, and with health care reform they'll be able to be taken up and get access to services.

**Naina Khanna:** We're still in some struggles with health care reform: Number one, to make sure it doesn't get repealed, but then number two, how a lot of things are being interpreted. Preexisting condition insurance pools obviously are going to have a huge impact for people with

HIV. If we're able to eliminate discriminatory insurance practices, that's going to be a huge benefit to women with HIV and their kids, some of whom may be HIV positive or have other health conditions.

Other things that are considered preexisting conditions that a lot of HIV positive women may intersect with can be mental health diagnoses, having experienced domestic violence [considered a preexisting condition in eight states]—and we know that these are all co-factors for HIV, and these are things that our women are facing. There's huge potential for women's access to care to be dramatically transformed.

There are a couple of critical pieces to this, as well, around Medicaid expansion. If we're able to expand Medicaid eligibility, so that you don't have to have an AIDS diagnosis and be disabled to qualify for Medicaid—just an HIV diagnosis is enough—that offers a lot of opportunities for people with HIV regardless of gender. Right now we have a system that incentivizes people to get sick, basically.

In some states, you have to have an AIDS diagnosis to qualify for ADAP; in some places you have to have an AIDS diagnosis to qualify for housing or for other kinds of benefits.... It's just completely backwards—it's a sick-care system, not a well-care system. I think health care reform provides a lot of opportunities around that.

### **BETA: How do you expect the National HIV/AIDS Strategy to affect women in the U.S.?**

**Naina Khanna:** There are a few things that I would say about that. One is that, overall, the National HIV/AIDS Strategy is predicated on the implementation of health care reform. With the current environment and all the challenges that are happening with health care reform, if it's not able to be implemented as it was designed, then

the National AIDS Strategy won't have a foundation to stand on.

This is especially important in terms of expanding testing, expanding prevention education, and also linking and retaining people in care in order to meet the goals of the strategy. We need health care reform to be implemented and increased investment overall, and unfortunately there is limited funding tied to the strategy. A recent Institute of Medicine report showed that HIV care systems are already burdened, and increased HIV testing is placing an even a higher burden.

Specifically with reference to women, I think there are some opportunities. The recently released United States Department of Health and Human Service Operational Plan talks about continuing and scaling up the integration of testing at the Title X Family Planning Clinics, which we think is great. It also mentions specific stats for increased linkage to care at those same sites, which is a huge step forward.

The one thing the strategy did not address is, for women who are already HIV positive and already in systems of care, how are we setting up HIV care systems to be more inclusive of women's unique needs? That means sexual and reproductive health care, for example, throughout the life spans of women, supportive services, psychosocial support, and the kind of culturally relevant and peer-based programs that we know are so important to keeping women in care.

### **BETA: Naina, in addition to your work with the PWN, you are also a member of the President's Advisory Council on HIV/AIDS (PACHA). What are some of your current activities?**

**Naina Khanna:** PACHA is looking at how to make the National HIV/AIDS

Strategy [NHAS] effective. What kind of political will is needed, and what is the level of investment required to break the back of the epidemic?

PACHA members are working in subcommittees to ensure the NHAS is successful—for example, we have a prevention subcommittee tied to the NHAS goal of reducing incidence. We also have an access-to-care subcommittee, a subcommittee focused on reducing HIV-related health disparities, and a subcommittee focused on global issues.

**BETA: The PWN was recently chosen to be a local community partner for the 2012 International AIDS Conference. What does that involve?**

**Naina Khanna:** We are one of two local community partners, along with the Black AIDS Institute [BAI]...and we're really honored to be a part of the local community partners along with BAI.

Our commitment is to make sure HIV positive women and women vulnerable to acquiring HIV in the U.S. and

North America are really represented at the conference, and that the issues that women are facing globally are included in the programming—in plenary sessions and abstract-driven sessions—and that we make the community as responsive as possible and really increase participation of HIV positive women overall in the conference.

**BETA: How can people get involved with the PWN?**

**Naina Khanna:** There are many ways to become involved in the Positive Women's Network, whether you're a positive woman, whether you're an ally, [even if] you're not a woman—anybody can become involved.

One of the things that we are focusing on in 2011 is organizing in local and regional areas through community mobilization around state issues and around ADAP. Other ways that people can get involved are through our listserv, or getting our newsletter, which we'll be putting out three times a year.

People can also join our work groups—for example, our policy work group, which allows people to have

meaningful involvement and also give their input into the policy directions or where we would like to take certain issues that we're working on, such as criminalization, or economic justice, or women-centered care.

There are amazing women doing work all over this country, and we're trying to highlight and bring those women together, because a lot of times women are working in isolation or feeling unsupported or alone.... We hope that women will connect with the PWN, because we can connect them with other women in their area or other women around the country—because you don't have to be alone.

**Jennifer Heflin** is a writer, photographer, and activist living in San Francisco.

**WANT TO ADVOCATE FOR HIV POSITIVE WOMEN IN YOUR COMMUNITY?**

The U.S. Positive Women's Network is a grassroots advocacy organization whose goal is to improve the lives of women by providing advocacy training, support, and information through their work groups, website, listserv, blogs, and *Speak Up* newsletter.

To learn more about how you can participate, visit [www.pwn-usa.org](http://www.pwn-usa.org) or contact the organization at:

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