



Front and Centre

Toronto's AIDS 2006 conference finally put positive women's issues at the forefront. Activist **Shari Margolese** looks at what was accomplished... and what needs to happen next.

The XVI International AIDS Conference

—dubbed AIDS 2006 by almost all in attendance—swept through Toronto last August, bringing with it the usual hopes for news of promising new drugs, treatment strategies and a renewed global commitment to universal treatment access and prevention. News in most of these areas was less than impressive.

The good news, though, is that the topic that garnered the lioness' share of media attention was the call to deliver "AIDS Action Now" to women and girls. This may well be the event's most important message. HIV-positive activists from around the world echoed the theme, sharing the stage with global leaders such as former Irish President Mary Robinson, Her Royal Highness Crown Princess Mette-Marit of Norway and former UN special envoy Stephen Lewis. Other media grabbers demanding action for women and girls included billionaire philanthropists Bill and Melinda Gates and former US president Bill Clinton.

Big names aside, women from all over came together in Toronto to find common ground, to mobilize and to create and energetically convey messages to policy makers and the media. In doing so, they succeeded in making AIDS 2006 the "women's conference" for which many international activists had hoped. As never before, positive women were politicking, reporting, organizing, networking, leading and attending sessions in the conference's Global Village. There, the international community of people living with HIV gathered to share their successes and challenges in providing and accessing care, treatment and support.

Global Village

One such woman, Zimbabwean Sophie Dilmitis, is HIV and AIDS Coordinator for the World YWCA in Geneva. Diagnosed as HIV positive in 1999, she had already attended three previous International AIDS Conferences. This time, she came with a specific agenda in mind—as did many other positive women. "I don't go to an IAC to learn about treatment. I can get all the information I need over the Internet," she says. "I go to meet people and network." Dilmitis, who was featured in the book *If I Kept It to Myself*, which was launched in the women's networking zone by the Crown Princess of Norway, found that the most rewarding part of attending the IAC was being in the Global Village. "It really did feel like a global *village*—meeting old friends, making new ones and connecting with people from around the globe."

For Dilmitis, this was the most important and inspiring aspect of the Toronto conference. "This is something you don't get while sitting behind a computer communicating with the world through e-mail. Actually engaging in conversations with women about what they need and want made a huge difference to me," she enthuses. "What I saw, time and time again, is that women are not sitting around waiting for the outside world to intervene.... Women know what will bring change; they just need support making it happen."

María José Vazquez, a Spanish positive woman and chair of the International Community of Women Living with HIV (ICW), says that support is what has been so sorely lacking in the past. "We are often invited to the table but there is no real effort to facilitate our participation," she says, referring to the fact that organizations serving HIV-positive women are generally under-resourced, making it difficult to participate in events such as these.

The success of this conference's international collaboration and organization of women didn't happen by chance. Led by the women's networking zone coordinators of



ATHENA, Blueprint for Action on Women and Girls, Voices of Positive Women and the ICW, work began months before the conference took place. The groups created key discussions throughout AIDS 2006, working to define a global movement based on common ground. Violence against women, access to sexual and reproductive health services and other human rights violations against women such as forced marriage and mandatory testing were key topics.

From these disparate threads emerged a uniting theme: the world must recognize the link between violence against women, HIV risk and access to testing and care. Women from around the world pointed to existing gender-related norms that condone men's violence against women and grant men the power to initiate and dictate the terms of sex. These norms make it extremely difficult for women to protect themselves from HIV and from violence—and prevent many women from being tested and subsequently accessing treatment.

Power and Access

Many discussions focused on the social determinants of health—including how poverty and gender inequity affect

access to treatment and health care. Other talks looked at how political and economic power imbalances affect women and children. “Where power lives, HIV does not, and where power is not, HIV lives,” said Louise Binder, Canadian cofounder of Coalition for a Blueprint on Women and HIV, during her plenary speech on women and girls.

According to Binder, who was diagnosed HIV positive in 1993 and is now a global leader in treatment access, women from around the world should be concerned that new testing recommendations from the US Centers for Disease Control and Prevention could become the international standard. The CDC now recommends HIV testing for

women. CCR5 inhibitors are also promising as a new class of drugs.”

Binder was also encouraged by the number of new drugs offering options for treatment-experienced patients such as herself. But unfortunately, she commented, “we learned that vaccines have gotten nowhere.” Still, she expressed optimism about the likelihood that microbicides will soon be available. Microbicides will have the ability to reduce the sexual transmission of HIV and other sexually transmitted infections (STIs) when applied topically. A microbicide, which is similar in consistency to a spermicide, could be produced in many forms, including gels,



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all healthcare settings, unless the patient declines (an approach known as “opt-out testing”). It also removes from HIV diagnostic testing the requirement for prevention counselling and recommends routine testing of all pregnant women. “Blanket HIV testing of anyone—including pregnant women—is a human rights violation. And it isn’t even good prevention policy,” says Binder. She also cautions that the US President’s Emergency Plan for AIDS Relief (PEPFAR) restrictions, including requirements that one-third of all prevention funding be dedicated to abstinence-until-marriage programs, are “retrogressive and not good for women.”

HAART and Science

As for the conference’s scientific sessions, many agreed that treatment news was limited, albeit encouraging in some areas. The important new developments that did emerge could be summed up in just a few sentences, says Binder. “Integrase inhibitors are an exciting new class of drugs, which could mean fewer side effects for

creams, suppositories, films or as a sponge or ring that releases the active ingredient over time. Because using microbicides would not require a partner’s cooperation, the product would put the power to protect against infection into women’s hands. This is vital, since many women lack the power in relationships necessary to insist on condom use and fidelity, or the freedom to end relationships that put them at risk for HIV infection.

“What we need is more research around how HIV affects women and we need urgent access to microbicides,” notes Sophie Dilmitis, who works with women around the world. “This is going to take funds—which means commitment.” She hopes that as microbicides are being developed, researchers will take into account HIV-positive women and not just think of microbicides as a prevention technology: “For example, how will they affect vaginal ecology, and will they interfere with antiretroviral medications?” As well, she feels strongly that researchers need to consider women who want to have children but still want to be protected from HIV.

Decisions, Decisions

For those women who attended AIDS 2006 looking to ask personal treatment questions, finding answers was a challenge. Dilmitis, whose undetectable viral load and 580 CD4+ count have been achieved with a well-tolerated regimen of Combivir (3TC and AZT) and efavirenz (Sustiva), was not really looking for treatment options for herself. “It was all so rushed and I was just too busy.” Her doctor in Geneva has suggested switching from Combivir to Truvada (tenofovir and FTC) and while she intended to speak to doctors in

women who want to plan pregnancies, particularly those in need of fertility assistance, like herself. This is a serious healthcare access issue, she notes—fertility services for HIV-positive women in Canada are very hard to find.

Maintenance therapy, which reduces the number of drugs a person takes once viral suppression has been achieved with a more potent regimen, was another widely discussed treatment strategy. Louise Binder, however, warns that it will be “very important to consider which drugs are included in a reduced drug regimen, particularly

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Toronto for other opinions, she did not meet with any new ones. She did see her former doctor at the conference, who agreed she should switch. “But who knows how I am supposed to make this decision?” Dilmitis says. “Sometimes conference treatment sessions can be too scientific for laypeople like me to understand.”

Danielle Layman-Pleet, executive director of Voices of Positive Women in Ontario, was one of the lead coordinators of the women’s networking zone at AIDS 2006. Layman-Pleet, who was diagnosed in 1991 and is treatment naïve, has a CD4+ count of 380 and a viral load of 80,000. She is considering treatment in the next year. Concerned about side effects and long-term toxicities, Layman-Pleet wonders, “How am I going to feel taking pills?” Referring to a study she learned of that suggests three drugs might be as good as four in initial therapy, she finds the possibility of fewer meds promising. While she is glad to see that pharmaceutical companies are “finally looking at alternative ways to use HIV meds,” she hopes that fewer pills will mean fewer side effects and will help her to stick to her regimen once she starts treatment. One personal disappointment for Layman-Pleet was the lack of information at the conference for

if we use 3TC as one of the drugs. Its role is not fully understood in therapy.”

Mixing Recipes

Treatment for co-infections was another strategy covered at the conference. For Brannadie St. Denis of Brantford, Ont., juggling treatment decisions for her co-infection with HIV, hepatitis C (HCV) and tuberculosis is a full-time job. Toronto was St. Denis’ first IAC. While she didn’t attend science sessions, she looked instead to skills-building workshops for answers. “There were so many interesting topics to choose from, but I concentrated on those that discussed co-infection.” With a current HIV viral load of 155,000 and a CD4+ count sitting at 560, St. Denis feels her HIV is well enough controlled to treat her hepatitis. Reducing her HCV load, which is in the millions, is “definitely a priority right now.” Her liver enzymes are also elevated beyond an acceptable level.

Since her diagnosis in 1993, St. Denis has been on several HIV regimens and was resistant to many drugs before starting treatment. “My HIV treatment options are limited not only by my super-strain of HIV but also by my liver.” Her

other worry is that hepatitis C treatment, which she is about to start, will increase her susceptibility to lung infections, something she is already prone to as a result of her TB. St. Denis hopes the hepatitis C treatment will work and that her liver will recover enough to increase her HIV treatment options. “You need to get information,” she says, “but it is easy to become overwhelmed, confused and scared with information overload.” While she left the conference nervous about starting treatment, she also felt hopeful and better informed.

it helpful to talk to other parents of positive kids, especially about disclosure and adherence to medications. Another anonymous mom from South Africa had cause for celebration as she shared her son’s success on recently available second-line antiretroviral therapy, without which she was certain he would not be alive today.

Simple Equation

Several attendees pointed to another positive development. After years of working at cross purposes, it seems

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Stephen Lewis looks on as author Shari Margolese addresses the March for Women and Children.

Many of the positive women who came looking for treatment answers were looking not only for themselves but also for their HIV-positive children. Interestingly, many found that the most important exchanges about children took place outside of the main conference sessions. Georgina MacDougall, a nurse from Toronto’s Hospital for Sick Children’s HIV program, puts it this way: “If it weren’t for the Teresa Group symposium prior to the conference and for the Global Village, I would have been disappointed with the lack of coverage of children’s issues.”

While the announcement of generic fixed-dose therapy was exciting treatment news for children in resource-poor settings, there was very little news for kids in North America. “At least doctors in resource-poor countries are finally talking about the need to provide paediatric treatment and are providing it,” observes Dr. Jason Brophy of the Sick Kids HIV program. For many parents of positive children, whose fears of stigma keep them from disclosing their children’s status, the conference was disappointing. “There was no new information about treatment for my son,” commented one mother from Vancouver. She did, however, find

that the “treatment vs. prevention” controversy may finally have come to a draw, with both sides conceding that one cannot be successful without the other. According to the United Nations program UNAIDS, treatment delivery has increased more than fivefold—from 240,000 PHAs to approximately 1.3 million between 2001 and 2005, but treatment is still only reaching less than 30 percent of people who need it in low-income countries.

“If we continue to treat 30 percent of the people who urgently need antiretrovirals, we will have no impact,” says the YWCA’s Sophie Dilmitis. “It costs more for society not to treat people than to treat them. For every dollar that is spent on ensuring lifetime access to treatment, we save two dollars.” Although it seems to be a simple equation with a simple solution, she says, governments fail to respond adequately and urgently. “We must abolish laws and customs that preserve gender inequities and gender violence, which fuel the spread of HIV.”

Amaranta Gomez of Oaxaca, Mexico, is hopeful that the strong message on women’s issues from Toronto will be brought forward to AIDS 2008 in Mexico City. For her, the key issues will be giving a strong voice to indigenous people around the world and bringing violence against women to the world’s attention. “Violence is the number one issue for women in Mexico,” says Gomez, “and indigenous women such as me are the population most affected by violence and HIV.”

Women from around the world who attended and organized AIDS 2006 activities are determined to advance the work that was begun in Toronto. As Dilmitis says, “HIV thrives on secrecy, embarrassment and ignorance. The more we can do together to abolish gender inequities and gender violence, the more we will reduce HIV infections. Now that we finally have the world’s attention, it’s time to take it a step further and determine where our leadership can make the greatest impact.” +

Shari Margolese is an HIV-positive advocate and writer living in Ontario who has been recognized for her work by induction into the Ontario AIDS Network and Voices of Positive Women honour rolls. She received the Queen Elizabeth II Golden Jubilee Medal in 2002 for “outstanding and exemplary contributions to her community.”