

# THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

FALL/WINTER 2006/2007  
VOLUME 8 ISSUE 2

## WOMEN'S VOICES

Are they finally being heard?

Shari Margolese on the lessons from  
AIDS 2006—and where we go from here

**PLUS:** LOOKING FORWARD

- ▶ *TREATMENT LITERACY*
- ▶ SCIENCE BREAKTHROUGHS
- ▶ *WHAT DELEGATES LIKED—  
AND DIDN'T LIKE*



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## EDITORS' LETTER

Welcome to another issue of *The Positive Side*, CATIE's magazine about, for and by Canadians living with HIV/AIDS. In this issue, we are pleased to present a variety of perspectives and opinions on the massive International AIDS Conference (IAC), which Canada hosted last summer.

Take our cover story, for instance. As a positive woman, writer and longtime activist, Shari Margolese is uniquely positioned to report on the conference, which adopted women's issues as its "unofficial" theme. In her article on page 10 ("Front and Centre"), Shari considers then-UN Special Envoy for HIV/AIDS in Africa Stephen Lewis's calls for greater attention to the impact of the epidemic on women and for a heightened role for women in confronting the epidemic. As she and many of her interviewees see it, this was undeniably valuable, but the fact is that it is only the beginning and there is a very, very long way yet to go.

The same can be said of the Aboriginal perspective. As you will read in the article by Charlene Catchpole and Michael Bailey on page 23, there was great disappointment among participants: the feeling was, for a conference held in Canada where Aboriginal issues are so critical, there was very little of concrete value. Fortunately, the conference was preceded by the International Indigenous Peoples' Satellite, which created a forum for discussion, knowledge exchange and solidarity among Indigenous peoples from around the world. The good news is that organizers instituted a plan for similar gatherings to occur around each IAC.

These are undoubtedly timely improvements. Despite its origins as a scientific conference, the IAC has evolved into something quite different. Of course there were some important developments (see CATIE staffer David McLay's article on treatment advances, "Good News on the Horizon," page 18, for a survey). As important though, for the IAC of today, is the extraordinary spirit of unity, connection and camaraderie that permeated the Global Village, without a doubt the beating heart of the conference. That may be the real legacy of the event: valuable linkages were made amid a shared spirit of optimism and resolve that this is indeed the "time to deliver," as the conference motto declared. Perhaps though, the enduring message remains: "Together, we fight on." —The Editors

## THE POSITIVE SIDE

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## Live and Learn

What do these seven PHAs have in common? All attended AIDS 2006 as participants of CATIE's Learning Institute, a project designed to enable community delegates from across Canada to maximize their experience at the conference. Now it's "time to deliver" their lessons from the world's biggest AIDS confab.

Interviews by **Ronnilyn Pustil**

### JOHN BAKER, 39

Outreach coordinator, AIDS Committee of Newfoundland and Labrador St. John's  
Diagnosed in 1993



**HIGHLIGHT:** I felt connected to AIDS on a global level and learned what it's like to live with HIV in other parts of the world. I met some wonderful folks from many countries and heard their stories on how they access treatment and get—or don't get—what they need.

**TREATMENT INFO:** The work on microbicides is very interesting. Now, for the first time, we may have an opportunity to put some power over this virus in the hands of women.

**TAKE-HOME MESSAGE:** We have the knowledge and the will to stop this virus. We need the G8 leaders to keep their promises. It's "Time to Deliver!"

**ACTION PLAN:** For those of us able to stand up and fight for the rights of PHAs, we must. There are whole populations being destroyed because of stigma and discrimination. In the West we must fight for those who are unable to do so locally and globally.

**LASTING BENEFITS:** I can now see the AIDS epidemic from a global perspective.

### HARLON DAVEY, 42

Master's student, University of Toronto Toronto  
Diagnosed in 1990



**HIGHLIGHT:** Seeing friends I haven't seen for a while and networking with people from around the globe who share a

similar vision and hope to educate, inform, prevent and address the complexities attached to HIV/AIDS—and ultimately find a cure.

**TREATMENT INFO:** Entry inhibitors represent a new treatment strategy that prevents the HIV virus from docking on the CD4 receptors and entering the CD4+ cell. Intuitively, it seems like a logical strategy.

**TAKE-HOME MESSAGE:** To reduce the spread of HIV, we need to address global issues, such as the disparity of wealth and power, universal access to medical treatment, gender inequality and the stigmatization of marginalized groups.

**ACTION PLAN:** To talk about HIV and give it a face so it carries less of a stigma.

**LASTING BENEFITS:** Attending a conference with so many dedicated and inspiring people and powerful voices has given me courage and confidence.

### PIERRE DUBOIS, "over 60"

Active member of MIELS-Québec and COCQ-Sida Quebec City  
Diagnosed in 1995

**HIGHLIGHT:** I felt a sense of belonging to this large community of PHAs and those affected by HIV/AIDS. It was very emotional for me. I was proud that this event took place in my country. I felt at home as soon I arrived in Toronto.

**TREATMENT INFO:** Without a doubt, it was the necessity to intensify research on new treatments, as so many PHAs have an urgent need for new agents to counter mutations and therapeutic failure.

**TAKE-HOME MESSAGE:** "Time to Deliver," the conference theme, suggested

that it's time to bring our knowledge and experience to the whole world through prevention and treatment access programs. The speeches by Bill and Melinda Gates and Bill Clinton were high points, supporting research to allow women around the world to take control of their bodies through prevention technologies in development.

**ACTION PLAN:** The participation and commitment of PHAs has

been very important in forcing decision-makers to enact prevention and treatment policies providing universal access. We must not abandon this commitment. We



have to continue being present at different levels of decision-making in order to bring about policies that give greater access around the world. Also, frontline activists should be able to cede their places to a new generation of PHAs born after the 1980s with their own viewpoints and ways of dealing with the epidemic.

**LASTING BENEFITS:** The knowledge and experience have broadened my horizons.

### B.C. ZEPHYR (pseudonym)

Retired; Volunteer AIDS activist Vancouver  
Diagnosed in 1995

**HIGHLIGHT:** The fact that the two Bills—Gates and Clinton—are throwing the combined financial weight of their incredibly large foundations into the search for a vaccine and, hopefully in the future, a cure for HIV.

**TREATMENT INFO:** As there is not much hope of either a cure or vaccine

within the foreseeable future, prevention advocates are recommending two approaches until an effective vaccine can be found: for females, microbicides, which will be a major benefit to women in Third World countries; for males, the old STD prevention measure used by American forces in World War II—circumcision. Both have proved to reduce but *not* eliminate transmission rates.

**TAKE-HOME MESSAGE:** In countries where government leaders provide active and knowledgeable leadership instead of ignoring the problem and hiding as far away from this disease as they can, the rates of transmission decrease and the rates of HAART adherence are way higher. Botswana (which has strong governmental support for AIDS services) and Zimbabwe (where the government offers very little support) are textbook examples of these opposites. In Canada, the Conservative government follows more in the style of Zimbabwe.

**ACTION PLAN:** Safe injection sites save people's lives and prevent HIV and HCV transmission. It's time our government leaders overcame their hang-ups about the ethical and moral objections to these sites. I've written several newspaper articles criticizing the government about this. We need to write and pressure our local MPs or community leaders to support these projects.

**LASTING BENEFITS:** I've been asked to do some workshops and presentations where I can use my knowledge of HIV to help in the daily lives of PHAS and maybe even prevent a few cases of further transmission.

### **DANIELLE LÉVESQUE, 51**

Member of Women's Health Promotion Committee, MIELS-Québec  
Quebec City  
Diagnosed in 1986

**HIGHLIGHT:** Bill and Melinda Gates' speech—with their realistic vision, influence and defined commitment—gave a lot of hope. As I was hospitalized for three days, I didn't attend as much as I had hoped.



**TREATMENT INFO:** Microbicides provide a glimmer of hope, especially for Africa. Being so unobtrusive, they may prove an efficient prevention method that women could use without having to explain anything. I was disappointed, in fact shocked, that there were no lipodystrophy workshops.

**TAKE-HOME MESSAGE:** The fight isn't over yet. Despite all the research and effort from groups around the world, AIDS and its outcomes are moving faster than we are. We need to intensify our efforts and continue the battle.

**ACTION PLAN:** To be on the lookout for new information, keep on top of the issues, share knowledge, expose inhumane situations and get loudly indignant about any injustice.

**LASTING BENEFITS:** There is this compassion and solidarity that unite all the different countries, and it is strong. Despite all the obstacles, so many men and women are ready to jump into action. I feel motivated to continue the fight against AIDS with my peers. I realize that it is really worth getting involved given the possible results. And that's encouraging.

### **EDWARD W. STEELE, 65**

Retired; Volunteer peer support  
Counsellor, Vancouver Island Persons  
Living with AIDS Society  
Victoria  
Diagnosed in 1987

**HIGHLIGHT:** The incredibly strong, clear and dynamic role of women and children's programs (lectures, abstracts, marches). I also was inspired by overseas actions in South and Eastern Africa spearheaded and supported by Stephen Lewis and his foundation.

**TREATMENT INFO:** Integrase inhibitors in Phase II trials show much promise. And when it comes to adherence, in Africa and East Asia health professionals are using various tools to help patients take their drugs effectively.

**TAKE-HOME MESSAGE:** There is much to be done in the underdeveloped world in small community and regional areas—creating access to affordable drugs, centralizing rural services, addressing poverty, providing clean water and empowering

women. There is greater need for follow-through for funding in terms of treatment options and services, of which women are most in need. Canada must do more regarding generic drugs, specifically for pregnant women.

**ACTION PLAN:** I'm mentoring people in younger generations to carry the torch in the area of treatment information and expanded knowledge.

**LASTING BENEFITS:** Sharing the accumulated information with BC's communities through newsletters, meetings and regional conferences.

### **GUY LAFRAMBOISE, 45**

Health Promotions Committee  
Volunteer, MIELS-Québec;  
Board member, CPAVIH  
Quebec City  
Diagnosed in 1993

**HIGHLIGHT:** The PHA Lounge allowed me to meet people from all around the world. I sat at a table with a guy from Texas, a couple from San Francisco and another guy from Mauritius—all PHAS.

**TREATMENT INFO:** We have to get behind vaccine research. One day it will revolutionize treatment for those recently diagnosed and those who have been on triple therapy for years.

**TAKE-HOME MESSAGE:** In Bill Gates' speech at the Opening Ceremonies, he stated that if the issue of AIDS had been in women's hands it would have been resolved long ago. I'm glad to have had the opportunity to hear this straightforward and generous man.

**ACTION PLAN:** Imagine—wearing a condom is still a taboo in Texas in 2006! So now when I speak in high schools in the province of Quebec, I tell them to protect themselves. I'm adamant that young people use safer-sex practices. I use a condom while still having good, healthy sex!

**LASTING BENEFITS:** All 24,000 delegates were on an equal footing. Whether PHAS, doctors, scientists or celebrities, we were all there to move things forward—and will continue to do so. +

# Through a Long Lens

Photographer **Jake Peters** has attended every International AIDS Conference but one since 1989. Here are his impressions—and images—of the most recent.

**I**t was through my cousin Andrew Zysman, a San Francisco emergency room doctor and a member of Bay Area Physicians for Human Rights and ACT UP Golden Gate, that I attended the 5th International AIDS Conference (IAC), my first, in Montreal in 1989.

I interviewed. I photographed. I created a new career for myself. I witnessed anger, frustration, desperation, pleas for help and understanding and the first warnings of exponential disaster.

I have attended all IACs since then except Geneva in 1998.

At IAC Berlin in 1993, activists who had suffered the virus for five years demanded recognition as “long-term survivors.” It was the first time I had heard that phrase. Most of them, many friends, co-workers—and my cousin Andy—are dead.

In 1994, 10 years after my initial HIV exposure, I began a year-and-a-half-long battle with opportunistic infections that nearly killed me.

My recovery began with a paper bag full of saquinavir capsules given to me when I left Toronto’s Wellesley Hospital in February 1996. The hospital is gone—I’m still here.

Though sick, I was determined to participate in the 11th IAC in Vancouver. I attended, and showed 30 photographs in an exhibit entitled “HIV Phobia.”

The 1996 Vancouver Conference remains the most significant for me, as it is for many. That was when highly active antiretroviral therapy was introduced.

That too was the beginning of the tragic false hope and confusion that ensnares so many in the mistaken belief that they can indulge in the sexual habits of the ’70s, pretending that AIDS is no more than a social

irritation. There is too little discussion and too much stigma while new infection rates rise.

The 16th IAC this past summer in Toronto did not impress me. Having attended so many conferences and watched the pandemic expand over the decades, I see failure: still no prevention policies; still a lack of resolve by those who can and ought to do something to halt this out-of-control roller coaster.

The greatest success I saw in Toronto was the brave and heartfelt actions by Treatment Action Campaign delegates from South Africa together with then-UN special envoy Stephen Lewis. They embarrassed that government into finally taking responsibility and reversing its deadly policies. South Africa is belatedly joining the battle—but what about Canada? What about the rest of the world? What advances can be realized before the next IAC in Mexico City in 2008? I expect to be there to find out.



Elizabeth Gold, Canada



John S. James, US



Michael Cress and Glenn Betteridge, Canada



Dr. Irene Silva, Francisco Porto Ribeiro & Vera Avelaira, Portugal



Edgar Carrasco and Renate Koch, Venezuela



Protest March



Grange Park



Dr. Jane Aronson

## LET THE PROTESTS BEGIN

The stage was set in Grange Park, not far from the AIDS 2006 conference site. There, under a hot mid-August sun, Terri Ford, director of Global Advocacy, AIDS Healthcare Foundation, introduced speakers from around the world. The goal of the event was to mobilize delivery of AIDS treatment—a quarter century into the epidemic—to where there is little medicine and service available for those who need them desperately.

In succession, speakers appealed for an end to the roadblocks and delays. The theme of the protest was “AIDS Treatment Now.”

Speakers from India, Rwanda, Uganda, Cambodia and Mexico described being among

the fortunate few who are able to get anti-retrovirals to ensure their survival and health. They pleaded for the same opportunities for the survival of the helpless populations infected in their countries.

Among the speakers from wealthy countries, Barbara Lee, a congresswoman from California, and Dr. Jane Aronson, president of the Worldwide Orphans Foundation, urged listeners in the park to pressure their governments to solidify and realize policies that will speed up delivery of AIDS treatments, education and prevention, and to reject “abstinence only” moral postures which don’t work.

Canada has hosted three IACs: Montreal,

1989, Vancouver, 1996, and Toronto, 2006. Only once has a prime minister deigned to visit. That was Brian Mulroney in Montreal.

At the Toronto IAC, 1,000 pillowcases with stenciled messages criticizing the absence of Prime Minister Stephen Harper were distributed among delegates for display during the conference opening ceremonies.

One member of government I spoke to defended the prime minister, asking, “Should he attend and be booed?”

Perhaps, if he faced the public, if he showed leadership and tried to do the right thing, he would be cheered. But we’ll never know—he didn’t give us the opportunity to find out.



Sokun Sann



Terri Ford



Dr. Penny Lutung with clients



Karabo Moraka and Bob Phato

## A SHAMEFUL DISPLAY

South Africa, richest of the sub-Saharan nations, has paid an astronomical human cost with nearly 1,000 AIDS-related deaths every day since the Durban IAC six years ago. “If these deaths were the result of aggression by another country,” remarked Dr. Francois Venter, president of the South African HIV Clinicians Society, “we would be on a war footing.” Instead, South African police have been known to shoot Treatment Action Campaign (TAC) protesters demanding AIDS treatment.

At the conference I approached two official representatives of the South African government, Bob Phato and Karabo Moraka, in their exhibitor’s booth. On the wall they showed examples of their controversial lime/garlic/beetroot treatment. A

bold sign read, “South Africa’s response to AIDS: the most comprehensive in the world.” I asked them to justify that statement. They could not. It made me wonder why they bothered to attend an AIDS conference in the first place.

TAC activists protested at the booth, highlighting the failure of the government to help its people, damning their health minister, Manto Tshabalala-Msimang, and rejecting their AIDS denialist conspiracy theories. Protester Mandla Majola held up fistfuls of female condoms that had been on display, pointing out that they are unavailable in rural areas and too expensive for those who need them.

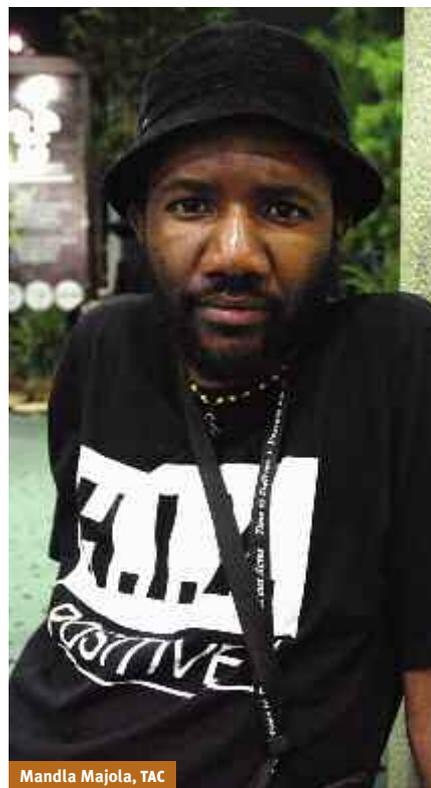
At the conference closing ceremonies, when Stephen Lewis excoriated the South

African government for its inaction, Phato and Moraka had disappeared.

Postscript: In November, the portfolio for HIV/AIDS was moved from the South African health minister to Deputy Minister of Health Nozizwe Madlalala-Routledge, who immediately acknowledged publicly the weakness of government leadership on HIV/AIDS in the country. TAC announced: “The eight-year struggle to end government HIV denialism and confusion has ended. A renewed focus on local and global mobilization and the country’s painful embarrassment at Toronto created the space where government and civil society are jointly facing up to the challenge of saving lives.” +



Linda Mafu, TAC



Mandla Majola, TAC

# FROM THE FRONT LINES

What's happening at AIDS Service Organizations across the country.

## PACIFIC

### Treat Me Right

Keen to know about one of the tools doctors use when deciding on what drug combination to prescribe? Go to the Web site of

the **British Columbia Centre for Excellence in HIV/AIDS**, [www.cfenet.ubc.ca](http://www.cfenet.ubc.ca), which has released an update of its HIV treatment guidelines. Offering the latest expert opinion on how to use anti-HIV drugs to keep the virus in check, the update outlines advice that is similar to international guidelines on many areas of treatment, such as the preferred drug combinations for people beginning treatment. It also includes new drugs such as tipranavir and duranavir, which hold the promise of helping treatment-experienced people living with HIV/AIDS to keep their viral load undetectable.

The BC guidelines are the only Canadian guidelines published to date, though a French version is soon expected from the Programme national de mentorat sur le VIH-SIDA (National HIV/AIDS Mentorship Program). The BC Centre can also be contacted at 1.604.806.8477.

## PRAIRIES

### Traditional Healing

"When we stop looking at *how* HIV infection occurs and start looking at *why*—the emotional and spiritual factors that lead to infection—then the magnitude of this issue becomes evident in Aboriginal communities," says Ron Horsefall, Aboriginal PHA coordinator at **All Nations Hope** ([www.allnationshope.ca](http://www.allnationshope.ca)), a provincial Aboriginal HIV/AIDS and hepatitis C network based in Regina, Sask. Every day, Horsefall sees the problems that have led to an infection rate among Aboriginal people that is triple that found among other Canadians.

To coincide with World AIDS Day, the network teamed with **AIDS Programs South Saskatchewan** ([www.aidsresourcesask.ca](http://www.aidsresourcesask.ca)), to host a two-day conference that looked at both Aboriginal and non-Aboriginal approaches to the epidemic. While participants learned about safer ways to inject drugs and about treating HIV

with antiretrovirals, they also explored Aboriginal healing traditions, including the Medicine Wheel, which is an outward expression of a deep inward belief. "One aspect of the Wheel concerns the mental, physical, spiritual and emotional—and is a way to deal with the trauma and the layers of grief and loss that exist in Aboriginal communities," Horsefall says. "If these are not addressed infection rates will continue to rise unabated. Returning to traditional ways can bring healing to Aboriginal communities and PHAs."

## ONTARIO

### Power Up!

A new program by the **Ontario AIDS Network (OAN)** is empowering PHAs to lead the fight against HIV/AIDS. The network's four-day leadership program brings PHAs from across the province together to find and strengthen the community leaders within themselves. To start, participants review the HIV/AIDS movement in Ontario by making a timeline with more than 80 events from around the province. They then add their personal history of HIV. Over the following days, PHAs discuss and work on various issues to define their leadership style and learn tips about how to put it in action. The lessons can be applied to many roles, from advocacy work to governance.

According to Thomas Egdorf, PHA program director at OAN, the free program, which runs several times a year, was developed by PHAs for PHAs and is delivered by PHAs. At the end, participants are encouraged to go back to their communities and work to promote positive change. Egdorf invites PHAs interested in the program to visit the network's Web site at [www.ontarioaidsnetwork.on.ca](http://www.ontarioaidsnetwork.on.ca) or to call the network's offices at 416.364.4555 or (toll free) 1.800.839.0369 for more information or to get involved.

## QUEBEC

### Listen Up!

The cyberworld of francophone PHAs has taken on a whole new sonic dimension with the launch last summer of **Radio Fréquence VIH** ([www.frequencevih.ca](http://www.frequencevih.ca)), a Quebec-based Web

site dedicated to telling the stories of French-speaking PHAs. Albert Martin and Luc Gagnon created the site to give a voice to PHAs, literally. And with help from the **Comité des personnes atteintes du VIH du Québec (CPAVIH)**, they made their dream a reality this summer, introducing audio reports from AIDS 2006. They have also presented interviews with key players of the Quebec HIV/AIDS community. Visits to the site have grown to about 225 per day, with a third of the visitors from Quebec.

When looking to the future, Martin says the sky is the limit for programming, and he's committed to making HIV treatment information a big part of what's on offer. One thing he's planning is a series of reports on challenges facing PHAs, with lipodystrophy as the first subject. It is scheduled to be online in mid-January. Aply, the site also contains videos and news stories written by and for PHAs.

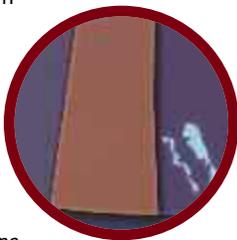
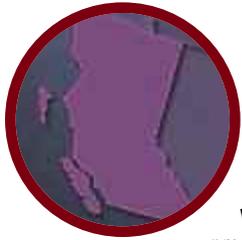
## ATLANTIC

### Are You Negative About Positives?

A new campaign launched in November by the **AIDS Coalition of Nova Scotia (ACNS)** asks the question "Are you negative about positives?" Posters appearing in local newspapers and bars in Halifax and environs address the different ways that stigma—including self-stigma—and discrimination affect HIV-positive gay men.

The group wants to raise awareness among the region's gay community. And, says Executive Director Maria MacIntosh, "we want the campaign to provoke some discussion, maybe change some of the assumptions people have about HIV/AIDS. At the same time, we want to support HIV-positive men who are dealing with this in their daily lives."

Support is key, but knowing where to turn is difficult, especially for people living in rural areas. As part of the campaign, the ACNS Web site ([www.acns.ns.ca](http://www.acns.ns.ca)) offers information on the social, community and legal services offered in Nova Scotia. +





# 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,



**“Engaging in conversations with women about what they need and want made a huge difference to me.”**

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

## Researchers need to consider women who want to have children but still want to be protected from HIV.



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 Brann die 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

## Women are determined to advance the work that was begun in Toronto.



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.”



# Accessible to All

With the recent rollout of access to HAART around the world, more and more attention is being paid to treatment literacy—the whys and hows of each medication. Because if PHAs don't understand it, they won't take it.

**Ann Silversides** offers a global survey.

IN THE GAME JENGA, players take turns removing one piece at a time from a 28-cm-high tower of stacked wooden blocks. Then, each piece must be carefully placed back on the top of the tower before the next player takes a turn. The loser is the unlucky one who pulls out the piece that makes the tower—which has become taller and more precarious—finally collapse.

Among Chinese people with an average grade 4 education, playing Jenga is used to help illustrate the importance of sticking to a treatment regimen for HIV/AIDS: adherence to treatment can make a strong building; non-adherence can make it collapse.

Having fun is an important element in HIV/AIDS treatment literacy initiatives, Jennifer Ho, program manager for TREAT Asia, told participants at the XVI International AIDS Conference in Toronto last August. TREAT Asia began developing a



range of education materials and activities in 2004 when faced with the fact that a high proportion of people who started taking highly active antiretroviral therapy (HAART) did not stick with it. Ho told a conference session that up to 40 percent of Chinese patients who started taking HAART in a free program dropped out within the first three months of treatment. Study findings in China are difficult to assess—but clearly, the availability of HAART is not enough to ensure that it is used appropriately.

The organization collaborated with people living with HIV/AIDS (PHAs) and healthcare providers to create tools, such as a flip chart of culturally familiar illustrations, to help explain in simple images how HAART works, why it is important, what kind of side effects can be expected and when to seek medical help. For example, HAART's usefulness is illustrated by a dying tree that is restored to health; to illustrate potential side effects, a doctor examines a man's rash; and a trampled garden fence is rebuilt to show how the immune system can be improved.

### **Rolling Out HAART**

With the recent rollout of access to HAART around much of the world, and the stated goal of near-universal access to treatment by 2010, policy makers are becoming aware of the urgent need for treatment literacy or, as it is sometimes referred to, treatment preparedness. The United Nations Program UNAIDS acknowledged the vital importance of this area in its June 2006 document *HIV/AIDS Treatment Education*. Providing HAART and related monitoring and laboratory tests by clinical staff is not enough, it notes. Achieving better health will also require "community, institutional and individual preparation and education."

It seems like a rather obvious observation, but in the push to get lifesaving drugs to people it is one that can easily be overlooked. "Most people are illiterate as far as drugs are concerned, and it's not enough for us to tell them 'you have a right to treatment,'" Rukia Cornelius, national manager at South Africa's Treatment Action Campaign (TAC), has said. "We have to explain why, and what's available and how it works." Cornelius made that comment a few years ago when she was director of TAC's newly minted Resource Project. Since then, the Resource Project has developed a wide range of treatment literacy tools in several languages, including colourful posters and a series of illustrated booklets aimed at different literacy levels.

Interestingly, the push to find creative approaches to

**TREAT Asia  
created tools such  
as a flip chart of  
culturally familiar  
illustrations to  
help explain how  
HAART works.**

treatment education in the developing world has parallels in North America, where the challenge is to find ways to communicate effectively as HIV moves into new populations that are typically struggling with issues such as poverty, stigma and addiction and have their own sets of cultural values and norms. CATIE, for example, has been collaborating with several organizations that serve marginalized positive populations and working to develop culturally appropriate approaches to sharing treatment

information. One such population is Aboriginal, a group whose HIV rate is now three times that of the overall Canadian population. To share information, AIDS service organizations in Canada are working with Aboriginal traditions, such as healing circles, talking sticks and the Medicine Wheel, which sums up the cycles of life. An HIV/AIDS Medicine Wheel adapts the traditional wheel to the physical and emotional stages of HIV (See "Traditional Healing," page 9.)

### **Unequal Access**

Although Canada has a well-funded and socialized medical care system that is supposed to provide equal access to care, it is a sad fact that many Aboriginal people are not diagnosed with HIV until they develop an opportunistic infection. "We are hearing of cases of cytomegalovirus, something we thought had pretty much disappeared," says CATIE's Michael Bailey, who works with a variety of AIDS service organizations, including Aboriginal ones, across Canada.

In developing countries with under-resourced and overburdened healthcare systems, healthcare professionals don't have the time to take on the entire task of informing and educating about HAART: how it works, the importance of adherence, side effects and what to do about them. Clinic doctors in South Africa, for instance, typically see about 60 HIV-positive people each day. "It is all push-push, go-go," Prudence Mabele, director of the Positive Women's Network, told the conference. "So what happens outside the clinic is important."

Typically, peer counsellors in South Africa do not call a meeting to discuss HIV or medication. "If you say, let's talk about HAART, they think you are crazy, because this is not their first concern," says Mabele, who was diagnosed with HIV in the 1990s and began treatment a few years ago. Instead, the "entry point" is usually participating in meetings with women around issues such as water and food supply. When the discussion does turn to HAART, "we make

ourselves examples and we tell the truth. If there is a problem with a medication, we talk about it. And we have to be creative.”

Because of stigma, her groups sometimes rename drugs—nevirapine, for example, becomes “Nelly” so it can be talked about in public. And women, who typically experience discrimination because of their HIV status, share ideas such as hiding their daily medication in bananas. Of course, because stigma and discrimination discourage people from accessing services, reducing these kinds of attitudes is another important goal of treatment literacy.

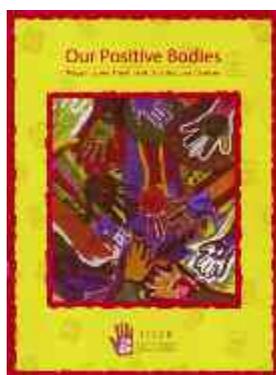
Mabele’s network also engages with traditional healers, as 80 percent of South Africans rely on them. “So why not explore African medicine?” she asks, and think about ways that the use of herbs can be incorporated with HAART. On the other hand, when peer counsellors go into homes where people believe that a bottle of olive oil and a lemon will treat AIDS, “we have to explain to them that that won’t work.”

### Women’s Lit

SAFAIDS, the Southern Africa HIV/AIDS Information Dissemination Service, has developed a women’s treatment literacy toolkit—packaged in a colourful, multi-pocketed cloth bag—that peer counsellors use to stimulate discussion and share information. The kit contains items for a range of literacy levels, including picture cards, information sheets, an audiotape and a “gender clock” so women can outline how they spend their time and where medication fits into their lives.

“Part of our role is to keep things positive, for example, talking about staying alive for the sake of the children,” program manager Rouzeh Eghtessadi told conference participants. But a typical session using the toolkit also encourages women to collectively list and discuss “hot topics” such as sexual coercion and abuse, the lack of libido experienced by many on HAART and the pressing issue of women’s lack of inheritance rights. “A husband dies and you’re asked to leave the family home and you lose your own access to treatment,” Eghtessadi explains.

Body mapping, an experiential form of art and narrative therapy involving full-size self-portraits, is another approach to exploring issues around HIV/AIDS and treatment, as well as women’s overall health and well-being. This use of body mapping, pioneered in African countries, was showcased at the conference by two different groups—TICAH (The Trust for Indigenous Culture and



## Reducing stigma is another important goal of treatment literacy.

Health), based in Kenya, and REPSI (the Regional Psychosocial Support Initiative), which provides support to organizations in 13 African countries.

“The hospital pretends they know all about us,” Amina, an HIV-positive woman from Kenya, told a TICAH session as she stood next to a colourful life-size self-portrait of her entire body. But Amina prefers to rely on her own approach to guarding her health, and the painting outlines the way that she is taking care of herself and managing her HIV with good nutrition and herbal remedies. “My children give me strength, hope, reason to live,” reads the caption under a picture of three children, drawn just underneath one of her hands. Art, she says, “opens your heart. It brings up fears and hopes and aspirations. . . . To disclose this way takes the weight out.”

### Drawing on Hope

Those profound benefits have been documented by Jonathan Morgan, REPSI’s knowledge network manager, in the book *Long Life*, which showcases the body maps and accompanying narratives of several South African women. One of those women, a young widow named Noloyiso, has drawn herself lying on her side. The dots on her body represent rashes she’s had, and one lung is black because of her diagnosis of a TB co-infection. “HIV, it’s like one word but lots of sickness,” she writes in a narrative accompanying her painting. “I represent HIV like a storm. If a storm comes there is heavy rain, thunder, storms, lightning and wind. I represent HIV like that. I did have rash, thrush, falling of hair, coughing and headaches.”

CATIE has recently entered into a partnership with REPSI with the goal of marrying treatment information expertise with the psycho-social body mapping approach. (Visit [www.catie.ca](http://www.catie.ca) for more on body mapping.) The hope is that such a partnership will help address, in community-based support settings, some of women’s social, emotional, health and also HIV/AIDS treatment information needs. As part of that collaboration, two South African women with extensive body mapping experience will be coming to Canada to conduct workshops with HIV-positive women. It is, after all, a global pandemic, and one that calls for sharing on many levels. +

Ann Silversides is a Toronto freelance writer who specializes in health policy. She has written extensively about AIDS and is the author of *AIDS Activist: Michael Lynch and the Politics of Community*, a book about the early days of the epidemic in Canada.

# GOOD NEWS ON THE

**David McLay**

reports on some promising new drugs... for the treatment naïve and the treatment experienced. Plus: understanding the viral cycle and how new drugs can break it.

The HIV treatment advances presented at the XVI International AIDS Conference in Toronto have repeatedly been compared—unfavourably—to those unveiled in Vancouver 10 years earlier. It is true that AIDS 2006 offered no “revolutionary” advances like the protease inhibitors presented a decade ago. But a closer look at the Toronto event shows that there are plenty of new drugs that people with HIV/AIDS (PHAs)—especially those who have already been on treatment for a number of years—should be getting to know better.

## PARADIGM SHIFT

Perhaps one of the most underreported stories from AIDS 2006 concerns PHAs with drug-resistant virus. Showing the first signs of a shift in attitude about treatment options, some researchers have stopped talking about “salvage therapy” to hold people over until something new and better comes along. They think new and better drugs are arriving now and point to the promising results of entry inhibitors (such as maraviroc) and integrase inhibitors (such as MK-0518) as evidence (see page 20).

In fact, some doctors have suggested that perhaps it is time to aim for the same goal for PHAs starting their third or fourth regimen as we currently do for those starting their first: an undetectable viral load and stable or increasing CD4+ counts. This optimism however is still guarded because these

drugs are new. We know from past experience with lipodystrophy and other metabolic complications that long-term side effects only emerge with long-term use.

## NEW DRUGS

Current wisdom about fighting HIV says that PHAs need to take at least three anti-HIV drugs from at least two classes to make an effective combination (also called a drug regimen or highly active antiretroviral therapy—HAART). Having more drugs and, more importantly, new classes of drugs increases the number of possible regimens.

So, it was big news at AIDS 2006 that researchers reported on three new classes of drugs, all of which target different steps in the viral reproduction cycle. The **entry inhibitors**—notably maraviroc, vicriviroc and TNX-355—block HIV from getting into the CD4+ cell. The **integrase inhibitor** MK-0518 works by keeping the HIV genetic material out of the cell’s genetic material. Finally, the **maturational inhibitor** bevirimat scrambles the new HIV particle so it cannot infect other cells.

From within the drug classes we already have, there were reports of several new experimental medicines: a new non-nucleoside reverse transcriptase inhibitor (NNRTI), TMC125; two new protease inhibitors (PIs), darunavir and brecanavir; and a new formulation for a once-a-day pill, Atripla. To put these drugs in context, take a look at the diagram of the virus life cycle on page 20.

# HORIZON

New classes  
of drugs could  
give hope to people  
creating their third  
or fourth regimen.

## RESISTING RESISTANCE

All of these new drugs mean new treatment options now and in the future. “With people living longer, we need more new drugs,” says Ryan Bureyko, Treatment Resources Coordinator at Toronto People With AIDS Foundation. This is because over time the virus becomes resistant to the different drugs, forcing PHAs to change their combination again and again. And, usually, once a drug has been used it can’t be re-used, making it harder to build a new combination. More drugs improve the chances of success. Bureyko helps clients, regardless of their level of treatment experience, to understand their treatment options. He deals with PHAs who have used up several of their options and are worried about how to create a new regimen. He also helps PHAs who are beginning their first regimen.

Fortunately, because there are fairly good firstline combinations, “newer drug classes don’t necessarily apply to those who are taking antiretrovirals for the first time,” Bureyko says. “However, new treatments and drug classes are absolutely essential for those already treatment experienced.” Regardless of whether it’s the first or third regimen, adhering to it is still critical to success. But adherence can be hard work—PHAs having trouble should ask for help from their family, friends, support workers, nurses and doctors.

New classes of drugs could give hope to people creating their third or fourth regimen. “Many people seek my

support regarding treatment when they find themselves in the ‘two strikes and you’re out’ category,” Bureyko explains, “meaning that if you are resistant to two medications in a category, you are resistant to them all.” Left with a shrinking number of choices, “these people end up reverting to the same fear, anxiety and depression that they probably haven’t faced in years,” he adds.

But it’s not just treatment-experienced PHAs who worry about putting together an effective regimen. A growing number of PHAs become infected with virus that is already resistant. Jean-Marc from Montreal found out during his diagnosis in 2005 that the HIV he had was already resistant to all the NNRTIs. “Learning that HIV is something you’re going to have to live with from this point on is a shock,” he says. “And then I learned that my virus had developed resistance to a whole class of medications. Even though I didn’t fully understand the diagnosis, it was upsetting.”

For PHAs like Jean-Marc, conference reports about the new NNRTI TMC125 were exciting. Phase III clinical trials show that it is safe and effective at bringing down viral load. But best of all, it works against virus that is resistant to other NNRTIs. “It’s very good news!” Jean-Marc says. “I am newly infected and I’m not yet on meds. But, I feel better knowing that when I do start, there may be an NNRTI that I can use to help me fight the virus.”

► *continued on page 22*

# WHEN HIV COMES KNOCKING

Here's how anti-HIV meds make the virus feel unwelcome.

News from AIDS 2006 expanded our list of potential antiretroviral drug classes by three, with the addition of entry inhibitors, integrase inhibitors and maturation inhibitors. Here's a summary of the different drug classes, where they work in the viral life cycle and the key messages about the new players. A version of this material is available in workshop form. Contact CATIE for more information. Also, check out our *Practical Guide to HAART*.

## 1 Entry inhibitors Sorry, door's locked; nobody's home

**HOW THEY WORK:** By making it hard for HIV to grab on to a cell and get inside

**THE ONES YOU KNOW:** T-20

**NEW PLAYERS:** maraviroc, vicriviroc, TNX-355

**THE LOW-DOWN:**

- The CCR5 antagonist **vicriviroc** (Schering-Plough) failed initial tests in treatment-naïve PHAs but is showing some success in treatment-experienced PHAs; however, five cases of cancer among 83 people taking the drug has led to concerns about safety
- **Maraviroc** (Pfizer) is being tested in treatment-experienced patients; this CCR5 antagonist helps improve the immune system but is no better than rivals at beating down viral load; it is also being tested in treatment-naïve patients
- **TNX-355** (Tanox) is an antibody that sticks to the CD4 receptor so that HIV can't; Advantage—drug stays in the blood a long time and can be given every two weeks; Disadvantage—given by 30-minute intravenous infusion

## 2 Reverse transcriptase inhibitors We don't speak HIV

**HOW THEY WORK:** Jamming viral reverse transcriptase and stopping the conversion of the virus's RNA (ribonucleic acid) into DNA. Think of reverse transcriptase as an interpreter—without it, RNA language isn't translated into DNA language and so the CD4+ cell can't be hijacked into doing the virus' work. There are two classes: NRTIs and NNRTIs

**THE ONES YOU KNOW:**

NRTIs – AZT, ddI, 3TC, d4T, FTC, abacavir, tenofovir

NNRTIs – nevirapine, delavirdine, efavirenz

**NEW PLAYERS:** Atripla, TMC125

**THE LOW-DOWN:**

- **Atripla** is the long-sought dream of HIV treatment; one pill once a day; it combines three drugs—the two NRTIs tenofovir and FTC and the NNRTI efavirenz; not yet available in Canada
- **TMC125** (Tibotec) is a new NNRTI that works against HIV that is resistant to other NNRTIs; its most common side effects include diarrhea and rash

## 3 Integrase inhibitors Please, do NOT make yourself at home

**HOW THEY WORK:** By blocking integrase, so the virus cannot insert (integrate) its genetic material permanently into the DNA of the cell; no integration means no replication

**THE ONES YOU KNOW:** none approved for sale in Canada or elsewhere

**NEW PLAYERS:** MK-0518

**THE LOW-DOWN:**

- Arguably the belle of the AIDS 2006 ball, **MK-0518** (Merck-Frosst) made a splash with news of good results in treatment-naïve patients, which means that one day it might be used as a first-line treatment

## 4 Protease inhibitors Splitting is not an option

**HOW THEY WORK:** By gumming up protease, the enzyme that cuts up a long protein into smaller blocks that will eventually be put together to form another HIV particle; think of protease as scissors cutting the string into several pieces before they are tied together to make a net

**THE ONES YOU KNOW:** amprenavir, atazanavir, fosamprenavir, indinavir, lopinavir, nelfinavir, ritonavir, saquinavir, tipranavir

**NEW PLAYERS:** darunavir, brecanavir

**THE LOW-DOWN:**

- **Darunavir** (Tibotec) was approved in Canada just days before the conference and is available through an expanded-access program; in trials it worked well against virus resistant to other protease inhibitors
- **Brecanavir** (GlaxoSmithKline) was considered the most promising of the PIs in development; phase II trials showed powerful activity to beat down both wild-type and multi-drug-resistant virus, however, in mid-December 2006, the drug's maker pulled the plug on development because they couldn't make a pill that gave consistent levels of drug in the body

## 5 Maturation inhibitors Here's your hat, what's your hurry?

**HOW THEY WORK:** During virus maturation, the final step of HIV replication, all the building blocks of a new virus are collected and assembled. Maturation inhibitors mess with this assembly and the jumbled virus cannot go on to infect other cells

**THE ONES YOU KNOW:** none approved for sale in Canada or elsewhere

**NEW PLAYERS:** bevirimat

**THE LOW-DOWN:**

- **Bevirimat** (Panacos) is in phase II trials and requires further study; investigators are determining the best dose of the drug



### A closer look at CCR5 inhibitors

The CCR5 antagonists maraviroc and vicriviroc garnered much attention at AIDS 2006. CCR5 is one of the proteins on the outside of CD4+ cells. To get into the cell, HIV must first attach to handles, called co-receptors, on the cell surface. One of these co-receptors is CCR5. As antagonists, vicriviroc and maraviroc stop (or antagonize) the interaction between HIV and CCR5, meaning HIV can't grab hold of the cell and work its way in.

CCR5 antagonists target a part of the CD4+ cell, not a part of HIV like most other antiretrovirals. This could lead to some unexpected side effects since CCR5 (the protein on the outside of the CD4+ cells) may also be used by the CD4+ cell in its role as a player in the immune system.



## EXPANDED ACCESS

Hearing about promising new drugs is one thing, gaining access to them is another. At AIDS 2006, news of expanded access programs came concerning two of the drugs currently in development. Drug maker Merck-Frosst announced that its integrase inhibitor MK-0518 will be made available through a worldwide expanded access program for people who have run out of other treatment options and are at risk of getting sick or having their immune system weaken. PHAs interested in the program should talk with their doctor. Physicians who contact Merck-Frosst will be put on a list and then notified once the program is up and running. The Canadian arm of Tibotec Pharmaceuticals also announced that it would make TMC125 available through expanded access.

“Seeing medication like MK-0518 being granted compassionate access is amazing to me, both as a professional and a person living with HIV/AIDS,” says Bureyko. “When Fuzeon and tenofovir were first allowed to people living with HIV on compassionate grounds, I saw first-hand how many lives were saved. Despite all the trash talk about the pharmas, we shouldn’t forget that we’re living longer now, and drugs are part of that.”

## NOTE OF CAUTION

So, with all these promising treatments, is it time to break out the Champagne? Not quite yet, Bureyko concludes. “It’s a necessity to maintain composure regarding new treatments. You have to be a ‘show me the evidence’ person. That’s the key to keeping sane in the wild world of treatment.” The reality is that many drugs, and maybe even some of those presented at AIDS 2006, will never make it to the pharmacy shelf. As a case in point, drug maker GlaxoSmithKline stopped the development of the PI brecaonavir at the end of 2006 due to problems with the drug’s formulation.

In parting, Bureyko offers this perspective: “We should remember that we already have quite a few treatments that work. This isn’t the early ’80s where high-dose AZT had to be rushed onto the shelves, causing more death and illness than AIDS seemed to at the time. If a drug doesn’t make it onto the shelf, it’s for the best.”

## WANT TO LEARN MORE?

This article just scratches the surface of anti-HIV drug development. But if it has piqued your interest, visit [www.catie.ca](http://www.catie.ca) for materials and links where you can learn more. Also, CATIE’s *TreatmentUpdate* is available free by e-mail subscription. Visit [www.catie.ca/ mailing.nsf/subscribe](http://www.catie.ca/ mailing.nsf/subscribe) to sign up. +

David McLay is a writer and editor at CATIE, where he helps manage publication projects and writes accessible treatment information. For this article he worked with CATIE’s Treatment Education and Support Services team.



## Terms you need to know

For better or worse, science has its own language. But that doesn’t mean you can’t understand it. Here are a few terms that often appear in materials about HIV clinical trials. For a thorough list of important terms visit [www.catie.ca/thesaurus.nsf](http://www.catie.ca/thesaurus.nsf).

### Treatment-naïve

describes a PHA who has never taken anti-HIV drugs

### Treatment-experienced

describes a PHA who has taken at least one regimen of anti-HIV drugs

### First-line treatment

the first drug combination given to a PHA starting anti-HIV drugs; the goal of this therapy is to reduce viral load to undetectable levels

### Salvage therapy

a drug combination given to a PHA who has taken several different regimens; the goal of the therapy is to reduce viral load as much as possible

### Efficacy

how well a drug does its job; in the case of HIV, efficacy is almost always a lowering of viral load and sometimes an increase in CD4+ counts

### Safety

whether a drug causes dangerous health problems or unbearable side effects

### Phase I clinical trial

the first step in testing a drug; it looks at the safety of the drug in a small number of people and at how the drug behaves in the body

### Phase II clinical trial

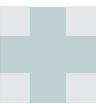
the second step in testing a drug; it uses a larger group of people to look at whether the drug works, and to look further at its safety

### Phase III clinical trial

the third step in testing a drug; using an even larger group of people, this final trial before approval compares the drug with other commonly used treatments while continuing to look at safety and efficacy

### Phase IV clinical trial

after a drug has been approved for use and has gone to market, this trial observes how the drug is used in clinical practice and monitors for potential risks



# Hope and Anger

**From the perspective of  
the world's Indigenous peoples,  
AIDS 2006 was both a terrible disappointment  
and a great success.**

**A**t the XVI International AIDS Conference (IAC) in Toronto last August the stated goal was to create an inclusive event, bringing together and engaging people from all over the world. For many Aboriginal people living with HIV/AIDS (APHAs) who attended, then, it was both a success and a failure. Echoing the opinions of many other non-Aboriginal delegates, there was frustration with the enormity of the event and the limited numbers of scientific sessions that they felt were representative of and relevant to them. Instead, it was a satellite session that preceded the conference, and the whole event's social centre—the Global Village—that were most important to Aboriginal delegates.

#### AN EARLY START

For many, the work started early, at the comprehensive International Indigenous Peoples' Satellite (IIPS), which took place two days before the International AIDS Society (IAS) conference began. Over 300 registrants were able to attend the event, organized by Canadian Aboriginal organizations and co-chaired by Art Zoccole, Executive Director of 2-Spirited People of the 1st Nations, and LaVerne Monette, Provincial Coordinator of the Ontario Aboriginal HIV/AIDS Strategy. "We had Indigenous People from Canada, the United States, Mexico, Australia, New Zealand, Guatemala and Sweden," say Monette. "It was such an opportunity to network and share resources and best practices."

Topics covered over the two-day satellite included: Indigenous Strategies for Prevention, Treatment, Care and Support; Colonization and Its Impact on HIV Risk; Traditional Healing Perspectives among Indigenous PHAs; Stigma and Discrimination; and Homophobia. In addition, attendees were able to meet, discuss issues and share wisdom. The satellite concluded with a Canadian session called "Creating an Aboriginal HIV/AIDS Strategy from the Ground Up!" and an address and invitation from Amaranta Gomez, a planning committee member for the next

IAC in Mexico City in 2008. One of the outcomes was an agreement to create an International Indigenous Peoples' Secretariat to guide the work between IAS conferences and a commitment to a three-day Indigenous Satellite in conjunction with the next IAC in Mexico City. To download reports of the events, check both [www.2spirited.com](http://www.2spirited.com) and [www.aids2006.org](http://www.aids2006.org).

#### AT HOME IN THE GLOBAL VILLAGE

Equally engaging for many APHA attendees was the Global Village at AIDS 2006. "Aboriginal presence in the Global Village was strong," said one attendee. "It became a place to speak and share concerns." That echoed a sentiment expressed repeatedly by virtually all delegates from all over the world: the Global Village was a high-

"The Global Village became a place to speak and share concerns."

light. It was here that people met, introduced, discovered and informed one another. It was here too that APHAs from across the country and around the world could meet.

The Global Village was a positive experience for Duane Morrisseau, who came to the conference representing the Métis National Council, "as a person living with HIV on behalf of my people." He served as a volunteer on Engagement Tours at the Ontario Federation of Indian Friendship Centres offices, showcasing the various programs and services that include HIV/AIDS. "I met people from Australia, New Zealand, Uganda, the United States... It was amazing what was shared...the common elements that make us one."

All Nations Hope AIDS Network's Ron Horsefall, a Two-Spirited person who has been living with AIDS since 1996 "was quite ill at the time... but attended for myself... I met a lot of people who I knew from around the country in the Aboriginal networking area. I met some Maori from New



Zealand and Indigenous people from Latin America,” he says. He was reminded that “there is a common thread of oppression that can’t be separated from HIV when speaking about Indigenous peoples.”

Pitsulala Lyta, an Inuk woman, originally from Iqaluit now working with Pauktuutit Inuit Women of Canada in Ottawa, also found the Global Village valuable as an opportunity to reach out, to learn about other cultures’ responses and to tell her community’s stories. Quite literally. Lyta was involved in the presentation in the Global Village of a performance of “Lived Realities of Inuit Women in Southern Cities,” telling the stories of positive Inuit women homeless in cities in the south, inspired by the women with whom she has worked.

#### A MISSED OPPORTUNITY

Still, while there were a great number of positive remarks about the IIPS, and the more informal and social

Canada, with higher rates of new infection and later diagnosis. What this means is that more First Nations people are not being tested until they get sick, and their HIV disease progresses faster.

Among the great challenges of creating Aboriginal strategies to prevent HIV and treat those already infected in their own communities is that the responses must encompass the impact that colonization and residential schools, in particular, have had on generations of Aboriginal people through the normalization of addictions, sexual violence, mental health issues and poverty.

The criticism of the conference came from all angles. Colleen Patterson, an Aboriginal woman from the Anishnabeg nation, says she was “surprised” that, at a conference hosted in Canada, “the Aboriginal situation was not accurately represented.” There on behalf of BC’s Red Road HIV/AIDS Network as an Aboriginal Youth Advocate, Patterson also served as the Chief Rapporteur for the conference’s youth program. “The general feelings at the time of the conference were that Aboriginal and Indigenous voices were being kept out of the main program and... confined to the Indigenous People’s satellite and the Global Village.” Ron Horsefall agrees: “It was amazing given that the conference was in Canada.” LaVerne Monette saw it as a lack of will: “Despite years of work ahead of time and the support of the Toronto Local Host, we were unable to get the non-Canadian organizers to acknowledge the enormous emerging HIV epidemic in Indigenous communities throughout the world.”

Pitsulala Lyta found the formal conference oblivious to her community. “The conference barely touched the Inuit population,” she says. “I see HIV [in the Inuit community] as a disease in communities that have stigma and fear attached—because of this people are reluctant to go for testing. We therefore worry that this disease may be more prevalent than what we see in statistics.” There’s no accurate assessment of how many members of the

“Aboriginal and Indigenous voices were being kept out of the main program.”

aspects of the conference—the Global Village and the hubbub of genuine exchange—many Canadian Aboriginal delegates felt the academic and scientific component of the IAC ignored important issues. And it left a great number of Aboriginal activists with a bitter aftertaste.

“I see it as a missed opportunity to discuss what should be a very important issue here in Canada. It’s too bad,” says Ron Horsefall, APHA Coordinator at All Nations Hope, an Aboriginal HIV/AIDS and hepatitis C network in Saskatchewan. “That the rate of new infections among Aboriginal peoples is so much greater than our percentage of the population wasn’t really addressed at all.”

The statistics in this case are clear: Aboriginal communities *are* disproportionately affected by HIV/AIDS in





Inuit community are positive. Says Lyta: “There need to be other factors looked at when collecting data. Awareness and education continue to be promoted rather than care and treatment—due to the low number of reported cases.”

Duane Morrissette says with “limited access or awareness of antiretrovirals, few programs and services that are culturally-specific, limited epi and surveillance information, inadequate policies and programs aimed at assisting our population, APHAS are not much farther ahead of those living in developing countries.”

#### A MOVING CONCLUSION

One of the most powerful moments of the entire conference came in some concluding remarks at the Closing

talk about the colonization and cultural genocide of our people. These are very painful topics to talk about.

An international HIV/AIDS conference taking place in Canada would have been an ideal opportunity to do just that, and in doing so create a forum to exchange information as well as treatment and prevention models with other Indigenous peoples. “For First Nations peoples, HIV must be seen,” says Ron Horsefall, “within the context of 500 years of colonization, including the oppression and discrimination, and the ongoing repercussions of Residential Schools. There is still a lack of trust toward people in positions of authority, including healthcare providers.”

Perhaps now, with new attention focused on these issues and the promise of ongoing work by the newly formed International Indigenous Peoples’ Secretariat, real progress will result. +

“This is an epidemic among the First Nations People of Canada.

I will no longer be silenced about this truth.”

Charlene Catchpole is an Ojibway woman from Couchiching First Nation. Based in Toronto, she has worked in the not-for-profit sector in criminal justice, First Nations, violence against women and HIV/AIDS and currently is director of Yorktown Shelter for Women. She works as a volunteer on several committees in the HIV/AIDS and First Nations communities, including serving as president with the Circle of Directors for Native Men’s Residence, a multi-service organization serving Aboriginal men and youth and the homeless in the City of Toronto. She is a recent addition to CATIE’s board of directors.

Michael Bailey has volunteered and worked with AIDS service organizations in Toronto and Montreal for over 15 years. He is a CATIE Treatment Information Educator and is coordinator of the cross-country Capacity-Building Program. For more information on these and other CATIE initiatives and on our treatment education services, visit CATIE’s Web site at [www.catie.ca](http://www.catie.ca), or call 1-800-263-1638.

Ceremonies. They were delivered by B.C.’s Keicia Larkin, an Aboriginal woman and mother living with HIV. Her speech, with her daughter at her side, brought the audience of over 20,000 to their feet. She told the story of her often solitary struggle and her successes despite the lack of resources available for Aboriginal women living with HIV. (For video or transcripts, visit [www.aids2006.org](http://www.aids2006.org)). She also captured the anger and frustration of Aboriginal attendees at AIDS 2006:

This is an epidemic among the First Nations People of Canada. I am here to tell you, yes, it is an epidemic—so very much alive in our communities. I will no longer be silenced about this truth. And in order for us to acknowledge this, we have to



# The Art of Being Positive

CATIE was the proud creator of a national series of exhibits of art by people living with HIV/AIDS. Entitled **art posi+ive**, it culminated in a show that coincided with AIDS 2006. Here we talk to some participants and look to the future of the event.



In July 2005, CATIE, launched art posi+ive as an opportunity to celebrate the lives and creativity of HIV-positive Canadians and to allow them to share their personal artistic expressions of living with the virus. Created in partnership with pharmaceutical company Gilead Sciences Canada, art posi+ive consisted of four installations throughout the year across Canada. More than 40 artists living with HIV responded to three “calls for inspiration.”

The culmination of this year-long initiative was an event at AIDS 2006. As an official component of the conference’s Cultural Program, CATIE hosted a special art posi+ive exhibit at a downtown Toronto gallery to showcase the talents of 14 HIV-positive Canadians. On display were more than 30 pieces of artwork by artists from across the country, each of whom offered a unique take on what it’s like to live with HIV.

The Toronto show kicked off with an opening gala for members of the HIV community and remained open for the duration of the conference to all delegates and the broader public. With the end of the initial project we were determined that the idea live on. And it will: Every issue of *The Positive Side* will feature a new department called—what else?—“art posi+ive,” in which we will feature the work of talented Canadian artists living with HIV/AIDS.

—RonniLyn Pustil

From top: James Huctwith, Gustavo Hannecke, Keith Perrott.



**NELSON FRENCH, 43**

Visual communications and marketing,  
Photographer, Toronto  
Diagnosed with HIV in 1990

**Untitled No. 12**, from the series “Meditations on  
Mortality,” 2004

22" x 30", pencil on collaged and altered digital  
photo print

The “Meditations on Mortality” series is based on police lineup-style portrait studies of friends (as well as self-portraits) mixed together digitally and by hand, torn, collaged, reassembled, sanded-down, drawn over. It reads like a diary, a graphic stream-of-consciousness narrative about the struggle around self-esteem and self-love. This work cannot be divorced from the struggles I’ve had coming to terms with my changing body and my finite self. As a gay man, I struggle to compare my own reflected image and desires with standard notions of beauty and the relationship between the surface and what lies beneath. The urge to do these investigations seemed to build as my body and face reflected outwardly the damage and complications of first-generation antiretroviral therapy.

One of the paradoxes of living is that we simultaneously want to be individuals and also feel part of a larger community. Everyone who struggles with HIV has to continually fight against the urge to shy away. The art posi+ive exhibit offered the opportunity to share and come together, to resist the urge to see ourselves as islands. Isolation can be a terrible thing.



**SHAYO, 26**

Artist, Montreal

Diagnosed with HIV in 1994

**Untitled**, 2006

10" x 8" x 2", wooden box, baby bottle, pills

This work of art represents my own relationship with anti-HIV pills—feeling sometimes too full (the bottle is full of pills, like me) or being dependent (as a baby is dependent, I’m dependent on my antiretrovirals). It also exposes the reality of babies living with HIV. I am a woman living with HIV and I know many women around me with this reality, and babies too. I always try to express the reality of women living with HIV through my art, because that is my reality. For instance, I have made two other works of art out of purses—one is filled with many little bottles of pills spilling out of it and one is made with AZT pills (among the first HIV meds).

Most of the art I make is connected to having HIV. I started making art five years ago because I was very sick. I had lots of things that I wanted to express and I found that creating art was the best way. Art is a way for me to transform things. I like to use objects from my daily life and put them in another situation. I use pills as a material for my art because playing with them and transforming them is a way for me to tame them.

I wasn’t at the AIDS 2006 exhibit but I was at the art posi+ive exhibit at the Harm Reduction 2006 conference in Vancouver last spring. It was a great experience to meet other artists from Canada who are making art about HIV and to exchange ideas about our vision and reality.



**KEITH PERROTT, 55**

"Office work pays the bills, but photography feeds my passion."

Toronto

Diagnosed with HIV in 1991

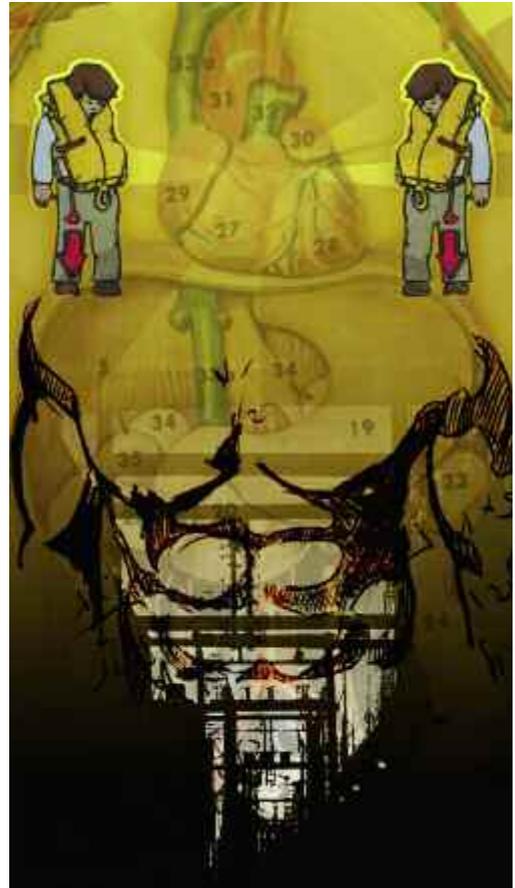
**A Future Awaits, 2005**

18" x 15", photography

My HIV diagnosis took away many things, none so critical as hope. In recent years, my photography has proven an invaluable tool with which to explore the many repercussions of this illness—from fear to anger, resignation to despair, and all the emotions in between. Documenting this consciousness became a way of confronting that which had seemed so overwhelming and, in doing so, taking back control of my life, little by little. It is an ongoing process.

"A Future Awaits" is a digital self-image that represents a turning point in my HIV experience—the change from "dying of" to "living with" HIV. I reached a point in 2005 when I allowed myself, for the first time in many years, to actually contemplate a future, one not exclusively ruled by HIV. I wanted a photo that could illustrate a sense of looking forward, into the future, but not one free of obstacles—a realistic future, complicated and challenging, but also filled with light and life and possibilities.

When I first read about the art posi+ive exhibit, I thought that for me—a photographer who has lived with HIV for 14-plus years—to express visually how HIV actually feels would be quite easy. How wrong I was. Attempting to illustrate how HIV attaches itself to all aspects of your being became a fascinating, frustrating and ultimately very rewarding exercise. Having my work included in this exhibit brought a sense of validity and inclusion and a wonderful sense of peace.



**MORGAN MCCONNELL, 32**

Graphic designer, Vancouver

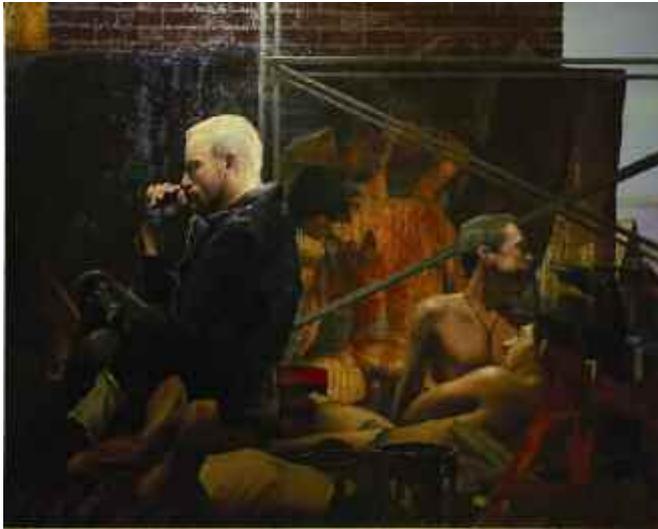
Diagnosed with HIV in 2001

**Sacred Heart, 2005**

17" x 30", Computer, hand illustration, scans of print material, photography, on dry mount

Ironically, my work became brighter and simpler after my diagnosis. My work stems more from the world around me than from the issues within my own body.

"Sacred Heart" illustrates the descent from joy, innocence and health into darkness—and the ability to ascend to those ideals once again. The symbolism of the raw human heart with the glow behind it and the haloed cherubic boys brings forth the iconography of Christianity, a religion that shuns me as a sexual being. The ideal male figure degrading into torn flesh and fading into the alley below speaks to the obsession of the gay male with a perfect body and the potential to lose oneself in that pursuit and subsequent celebration, so that in the end it is all lost. As well, I live in Vancouver's Lower East Side and see the product of drug abuse and poverty daily, in all sexes and sexualities. I believe that drug abuse is a sickness in our society and in gay culture but ultimately one that we can pull ourselves back from.



**JAMES HUCTWITH, 39**

Artist/painter, Toronto

Diagnosed with HIV in the mid-1990s

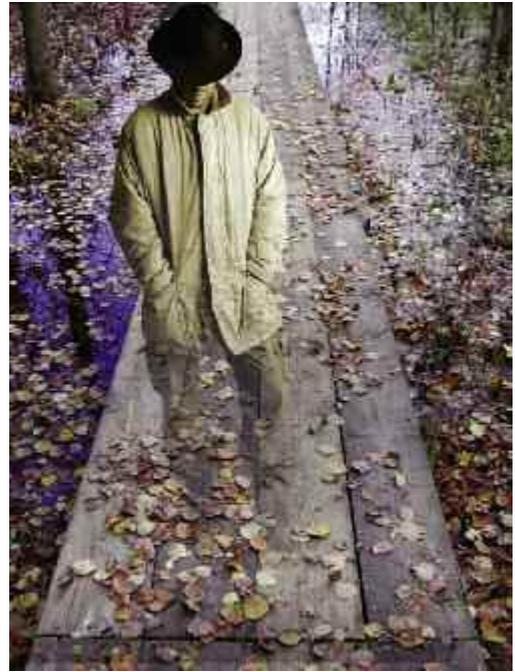
**The Myth of Marsyas, 2004**

4 ft x 5 ft, oil on canvas

This piece is rooted in a Greek myth, in which the shepherd Marsyas challenges the god Apollo to a musical contest. Marsyas inevitably loses, and as punishment he is flayed alive for his arrogance. A scene from this myth is visible as a painting set in the background within the main painting.

When I made this piece I had just resigned from a job as a bouncer, which required me to physically fight with men on a regular basis. (I am the figure on the left of the painting.) The painting is a meditation on hubris and negotiating the limits and results of violence. It also was, for me, a work about sexuality and identity being shaped by forces both within myself and beyond my control, and learning to deal with their impact on my life.

Being in the art posi+ive exhibit was wonderful. Everyone was enormously supportive, sweet and helpful. The martinis were quite tasty, too.



**GUSTAVO HANNECKE, 46**

Community developer/advocate/photographer,

AIDS Committee of Ottawa

Diagnosed with HIV in 1999

**Almost a Ghost, 2004**

13" x 19", digital art

My HIV status determines many factors in my life, from work to relationships to my art. I always try to express my feelings through art, and those feelings are normally closely related to my HIV status and my journey through life being HIV positive. The experiences and feelings sometimes are too complex to express with simple photography, and that's why I prefer to use image manipulation through digital art—to get closer to what I want to express.

"Almost a Ghost" is about loneliness and feeling lost; sometimes the feeling is one of people not noticing me or just barely. Sometimes I feel like I am in the autumn of life, walking through life almost transparent.

The art posi+ive exhibit was a very positive and rewarding experience. As an artist, it allowed me to show my art and gave me exposure in the community. As a PHA, it validated me as a person and as a professional, provided me with dignity and value, which sometimes is so difficult to achieve due to the stigma and discrimination associated with this infection. +

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