



The Positive Side

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AIDS 2010 Highlighted Human Rights; Great News for Women Lit Peoples' Hearts

By Marcie Summers, PWN Executive Director

This summer I had the memorable experience of attending the 18th International AIDS Conference in Vienna. This was the fourth International AIDS Conference I've attended. Each has had its own flavour, themes, highlights and challenges. And each has been incredibly intense, inspiring, overwhelming and larger-than-life. Vienna was no exception.

After being serenaded by Viennese Waltzes at the Opening Ceremonies, the first speakers were interrupted by protestors who took over the stage, bringing their crucial message that renewal of the *Global Fund to fight HIV, TB and Malaria* is more important than ever. The economic

recession has set the scene for many countries to fail to meet their earlier financial commitments, leading to disappointing news regarding the goal of universal access to treatment. Many debates, roundtable discussions, protests and skills building sessions addressed this omnipresent challenge.

Former U.S. President Bill Clinton delivered the Keynote Address. The *Clinton Health Access Initiative* works to expand treatment access in developing countries. Clinton talked at length about initiatives to strengthen healthcare delivery systems in under resourced regions.

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AIDS 2010 cont ...

Taking it to the Streets

The theme of the conference, *Rights Here, Right Now*, inspired a powerful Human Rights March. Walking through the beautiful, historical Viennese streets - surrounded by ten thousand people from all regions of the world drumming and chanting, all committed to the human rights of people living with HIV - is something I will never forget. Following the march, HIV activist and singer, Annie Lennox performed pieces of her Sing Campaign, which focuses on improving health outcomes for women and children.

At the Canadian reception, Minister of Health Leona Aglukkaq, announced renewal of the *Canadian HIV Vaccine Initiative* which features the creation of the *CHVI Research and Development Alliance*. Many Canadian delegates were disappointed that the federal government directed

funding to this project rather than increasing its commitment to the Global Fund. As well, Canada's unwillingness to sign the *Vienna Declaration* (which is a call for science based drug policies) was the source of multiple protests.

Breakthroughs in Prevention

The release of the data from the CAPRISA 004 Study, a clinical trial of a new antiretroviral based microbicide, (a tenofovir gel that is inserted both before and after vaginal intercourse), became THE buzz of the conference. I can't ever remember attending a scientific session during which there were three standing ovations. The trial, involving 900 women in South Africa, found that after one year of use, the gel provided moderate protection against both HIV and the Herpes virus. For those women who managed 80% adherence to the regimen, 54% protection was achieved. This is a

tremendous breakthrough in the effort to create women-controlled prevention tools.

Vancouver's own Dr. Julio Montaner, outgoing President of the International AIDS Society, took every opportunity throughout the week to get out the message of treatment as prevention. The implementation of the *STOP (Seek and Treat for Optimal Prevention)* initiative in Vancouver and Prince George is being watched by people with HIV, scientists, health professionals, and funding bodies around the world.



Women's Voices, Women's Worlds

Violence against women was another theme raised again and again in Vienna. Everjoice Win, head of *Women's Rights at ActionAid International* in Harari, Zimbabwe, delivered a powerful analysis of this particular epidemic, which we are seeing in all regions of the world. In her plenary address, she drew connections among the complex intersection of HIV, violence against women, including the too common practice of rape during warfare, and the lack of effective state policies to protect women. She called on bilateral and multilevel institutions to place violence against women and gender inequality at the center of any HIV response.

Blueprint for Action on Women & Girls & HIV/AIDS delivered its 3rd *Canadian Report Card* (www.womensblueprint.org) at a press conference in partnership with Norway. The conclusions of the Report Card are that due to widespread stigma and discrimination, women and girls in Canada are not being protected from HIV. Blueprint also hosted a workshop in the *Women's Networking Zone* in the *Global Village*, where an updated Manifesto and Blueprint Backgrounder were launched.

The harsh realities of people living in Eastern Europe and Central Asia, especially sex workers (predominantly women) and those who inject drugs, was brought home loud and clear.

Many speakers and sessions, including people from Russia, echoed again and again how draconian government policies erode the basic human rights of people living with or vulnerable to HIV.

Sex Worker Activists played a larger than usual role in the conference, having a presence throughout. It was heartening to witness their voices being heard at such an important, international event.

We're All in This Together

As I mentioned earlier, these huge International Conferences can be exhausting as one attempts to absorb both the global picture *and* the intimate details of peoples' lives. After days of numerous

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AIDS 2010 cont ...

plenaries, oral sessions, video screenings, workshops, Global Village visits, poster displays, and video conferencing - not to mention enlivening protests - everything can become a blur. But when the fatigue and the heat would get to me (the conference air conditioning was challenged, to put it politely), I would always experience a resurgence of energy as I watched the incredibly diverse and interesting crowds of conference delegates and as I, inevitably, ran into people I've known over the years.

It was so heartening to see kindred souls, both those living with HIV and their allies, those who have shared a vision, a world free of HIV, and a world where women are not invisible. As I was reminded of the work many of us have created together - projects, programs, and numerous initiatives over almost 20 years of PWN's history - I felt again and again such pride and sense of community. PWN is a leader around HIV and women in Canada, and it was apparent in Vienna, that women all over the world are demonstrating similar leadership in their own communities.

We are all in this together. We must remain ever vigilant, working to end complacency in government, speaking out against bigoted institutions and individuals, and remaining inspired by all who are fighting the good fight against HIV and human rights violations across the globe.

For more information:

AIDS 2010:
www.aids2010.org

The Vienna Declaration:
www.viennadeclaration.com

Caprisa trial:
www.caprisa.org



Introducing Clinical Trials

By Suzanne MacCarthy, Canadian HIV Trials Network

The CIHR Canadian HIV Trials Network (CTN) is an innovative partnership of clinical investigators, physicians, nurses, people living with HIV/AIDS, pharmaceutical manufacturers and others that makes HIV clinical trials of the highest scientific and ethical standards possible in Canada.

The CTN was created in 1990 by the Canadian government when treatments were needed to save lives but there was no infrastructure to support national clinical trials of HIV therapies and vaccines. Today, twenty years later, the CTN continues to foster new research, engage community and advance care to improve the quality of life for those living with the virus.

Clinical trials: The basics

Clinical trials are carefully designed experiments that allow scientists to test their research questions on people. Many clinical trials evaluate new drugs, but they are also used to test a range of other ways of treating diseases or health problems. In HIV, these include vaccines (preventative and therapeutic), other prevention methods, treatment management and adherence strategies, optimized diets, and nutritional and herbal supplements. Clinical trials allow researchers to test how well a particular treatment works, to compare different treatments and to answer specific questions such as how much of a treatment should be administered and how often. Clinical trials also allow researchers to learn about the side effects, toxicity and interactions of a new treatment, and to determine other potential risks that the treatment may pose to a person's health or quality of life.

Research vs. treatment

Within the realm of treatment, the well-being of the person being treated is the main priority. For example, when you visit the doctor, his/her focus is on treating your ailments and improving your health. However, when it comes to research, the focus shifts to include the interests of science and society in general. Therefore, a research participant should not be viewed as a patient exclusively receiving care. There is a fine line between research and treatment, with ethics helping to keep the wellbeing of a clinical trial participant equal to the advancement of science and medicine.

Participants' rights

Informed consent is a process in which the purpose, methods, risks and requirements of a trial are clearly explained to a clinical trial volunteer or potential participant so that he or she has the information necessary to make a decision about participating in the trial.

From a participant's perspective, the informed consent form is the most important part of a protocol because it helps to protect his or her rights. If a potential participant meets the study entry criteria and is strongly considering taking part in a trial, he or she will be asked to give informed consent. The informed consent form should fully explain in plain language (readable by most people, even people with a low level of literacy) the trial as well as the possible risks or dangers of participating. Even after signing an informed consent form, a participating individual can change their mind at any time and leave the trial whenever they want without compromising their future access and right to health care.

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Intro to Clinical Trials cont ...

Are there any costs to participating in a trial?

There are no costs to participating in a clinical trial. In fact, since some studies can require two or more hours for a clinic visit, any CTN study participant can expect to be reimbursed for reasonable costs incurred from loss of wages, transportation, and babysitting or daycare in relation to their time for the study.

Benefits of Participating In a clinical trial:

- Help others by furthering medical research
- Play an active role in your own medical care
- Receive expert medical attention
- Access medical treatment before it is released to others

What are the risks?

- Physical side effects to the treatments
- The treatment may not work for you
- The treatment protocol may require more of a time commitment from you for appointments or treatments

As a participant you have the right to:

- Leave the study at any time, even after signing the informed consent form
- Have your questions answered at any time during the study
- Know the name and contact number of the main researcher
- Know all risks and benefits of the experimental treatments
- Talk to whomever you want to before signing the consent form
- Keep a copy of the consent form

Community involvement

Beginning in the late 1980's, many people living with HIV expressed a desire to become more active in the decision-making process regarding HIV/AIDS research. The scientific community responded, including the CTN, which established the Community Advisory Committee [CAC] in 1993.

Made up of ten people representing a broad spectrum of Canadians who are living with or affected by HIV, or belong to an organization involved in fighting the epidemic, CAC is an independent committee that exists to ensure proposed research is of relevance and interest to the HIV/AIDS community. In addition, the committee provides a forum for the discussion of clinical trial issues, as well as reviews and makes recommendations regarding the informed consent section of a clinical trial protocol. By injecting a community perspective into the clinical trial process, CAC aims to improve communication between researchers and community representatives.

Where can I find more information about trial participation and enrolling trials in Canada?

More detailed information about clinical trial participation can be found in a booklet published by the Canadian HIV Trials Network (CTN) called *Clinical Trials: what you need to know*, a plain-language introduction to HIV clinical trials, including their aims, procedures, risks and benefits.

For more information on this booklet and about CTN and non-CTN trials currently enrolling in Canada, please visit www.hivnet.ubc.ca or call the CTN's toll-free line: 1-800-661-4664.



Studies enrolling in BC

CTN 254 - Predictive value of inflammatory markers for disease progression in untreated HIV infection
BC sites: Downtown Infectious Diseases Clinic (DIDC), Vancouver

CTN 247 - Canadian cohort of HIV-positive slow progressors
BC sites: St. Paul's Hospital, Vancouver; Spectrum Health Care, Vancouver; Downtown Infectious Diseases Clinic (DIDC), Vancouver; Cool Aid Community Health Centre, Victoria

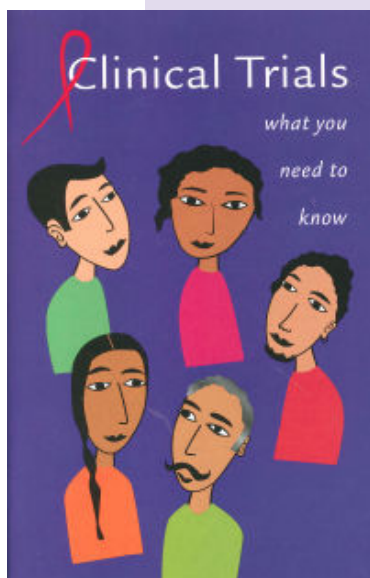
CTN 244 - Seek and treat for optimal outcomes and prevention in HIV & AIDS in IDU (STOP HIV& AIDS in IDU)
BC sites: St. Paul's Hospital, Vancouver

CTN 240 - Valacyclovir In Delaying Antiretroviral Treatment Entry (VALIDATE) trial
BC sites: DIDC, Vancouver

CTN 238 - The MAINTAIN study
BC sites: St. Paul's Hospital, Vancouver; DIDC, Vancouver

CTN 236 - HPV vaccine in HIV-positive girls and women
BC sites: Oak Tree Clinic, Vancouver

CTN 194 - Peg-interferon and citalopram in co-infection (PICCO)
BC sites: St. Paul's Hospital, Vancouver; DIDC, Vancouver



From the PWN Blog:

HIV and Pregnancy Planning Guidelines Rev Up For Release

Why would a couple challenged by HIV be refused fertility services or comprehensive information about getting pregnant? Sometimes it's stigma more than science, fueled by a lack of knowledge of care providers themselves, according to Dr. Mona Loutfy and Shari Margolese. Loutfy and Margolese are the driving forces behind the development of the *National HIV Pregnancy Planning Guidelines*. Not only are these guidelines going to be a great support to couples or singles living with HIV who wish to become parents, but they will also provide valuable information to service providers in general practice, HIV care, gynecology and fertility clinics.

Studies certainly indicate that positive women want to have children. In response to an Ontario survey on fertility intentions, 69% of 475 women responded they would like to give birth. A previous study in BC had shown that positive women's fertility intentions were similar to women who didn't have HIV. In other words, HIV wasn't stopping their dreams.

The pregnancy planning guidelines will provide information for people to assess the level of risk they're willing to take in their pursuit of parenthood.

Read the complete post at www.pwn.bc.ca/blog.

Follow the PWN blog by RSS feed, on Facebook (search for [Positive Women's Network](#)) and on Twitter ([@pwn_bc](#)).



Clinical Trials: Participating with Confidence

By Miriam Martin

For women living with HIV, the pressure to participate in research can feel overwhelming. Here in Canada, women with HIV are a relatively small community and as long as there are questions, Positive Women's Network and its members will be in high demand to help find the answers. Many of our members (especially those who are Aboriginal or have been street-involved) report feeling *overstudied*; yet, women remain seriously underrepresented in clinical research. This is a problem, because we need to know how potential new treatments and preventions affect women – our sexual, reproductive and emotional health and well-being. Just because we know a new treatment is “safe” doesn't mean we know how it might interact with the effects of perimenopause, for example. What are the barriers preventing women from participating in trials and what can we do to make it easier and safer for women to participate with confidence?

Why are women underrepresented in trials?

When we say women are *underrepresented* in trials, it means that even though a quarter of people living with HIV in Canada are women, the portion of women participating in HIV-related clinical trials is less than a quarter. Aboriginal people and people of colour are underrepresented too. Aboriginal women and women of colour are the most obviously absent from clinical trials, except for the ones that specifically target these groups. Of course, there are trials that do recruit enough women, including those that investigate something specific to women, like the studies conducted by the doctors at Oak Tree Clinic which specializes in HIV care for women and their families. There are also trials that make a con-

scious effort to recruit in underrepresented populations, like the American Tibotec-sponsored GRACE Study (www.thegracestudy.com), which looked at whether particular antiretroviral drug combinations have a different effect in women compared to men. Women of colour were proactively recruited for this study.

The most obvious barriers to women's participation in clinical trials are the same things that prevent our equal participation in so many realms. These are social and economic barriers – the simple fact that the vast majority of women still take the lion's share of responsibility for household and domestic tasks as well as caregiving, not just for children but for partners, husbands, parents, siblings, cousins, neighbours ... the list goes on. A woman who carries the burden of responsibility for the care and wellbeing of her children may not have any spare time, and if she does, most people would happily encourage her to have a rest or doing something enjoyable for herself. The pressure on women to “give back” to the community is great, and we may want to contribute more, but that doesn't mean we can do it!

What can we do about it?

Addressing these larger societal issues is not the direct task of those involved in conducting and recruiting for clinical trials. There are things though, that we can do to raise awareness of clinical trials among women living with HIV, and things that the HIV community itself can do to make participation easier. HIV/AIDS service providers can educate themselves about clinical trials in general, specific trials taking place, and about what to look for in considering a trial.



Building Trust

Usually, we are not familiar with the issues and concepts that the trials are addressing. Unless we are experts in a related field, we are unlikely to fully understand what the trial is about until somebody takes the time to explain it clearly, repeatedly, and graciously, with ample time for discussion and questions. We have all had experiences with medical professionals who have not taken this approach to conversations about our health. Unfortunately, we live in a world where many people have had or inherited real experiences that have led them to distrust any representative of “the system”. Canada’s Aboriginal people and women who have come here from war-torn countries for example, have every reason not to automatically trust that researchers are being honest or that their intentions are good.



Many people have had or inherited real experiences that have led them to distrust any representative of “the system”.

The onus is on service providers, researchers and medical professionals to take the time to explain, to embrace *truly* informed consent, and to build trust. As an established support organization, we at PWN feel that we *have* built up a certain level of trust from members and the community.

Because we don’t want to endanger or risk losing that trust, we are often reluctant to endorse clinical trials or encourage our members to participate. What if somebody has a negative experience with a trial we promoted? Other HIV service organizations might feel this way too. But this is where we have a responsibility to educate ourselves on the clinical trials that come up, so that we can encourage and support women living with HIV to participate in the ones that are ethical and beneficial to science and the community. The Canadian HIV Trials Network (CTN) has done half the work for us by ensuring the high scientific and ethical standards of their trials.

Lost in Translation?

One of the biggest challenges for researchers, scientists and advocates is the challenge of language. Most of us don’t speak *Scientificish* and we never will, unless we decide to go get our own university science degrees. It’s unreasonable for anybody to expect us to speak a language we haven’t learned, so why should we be hard on ourselves for not understanding science-speak? It has to be translated; that’s all there is to it. As it turns out, this is not an easy task. Somebody who understands the scientific concepts is not necessarily going to be gifted at presenting it in plain language, and vice-versa. We need to make sure we have people who can do both.

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Participating in Clinical Trials cont ...

Positive Women's Network is working with the CTN to initiate discussion in the community about these challenges. As an organization, we have committed to educate ourselves so that we can help with this "translation" and confidently support women living with HIV to participate in clinical trial.

Why participate in a clinical trial?

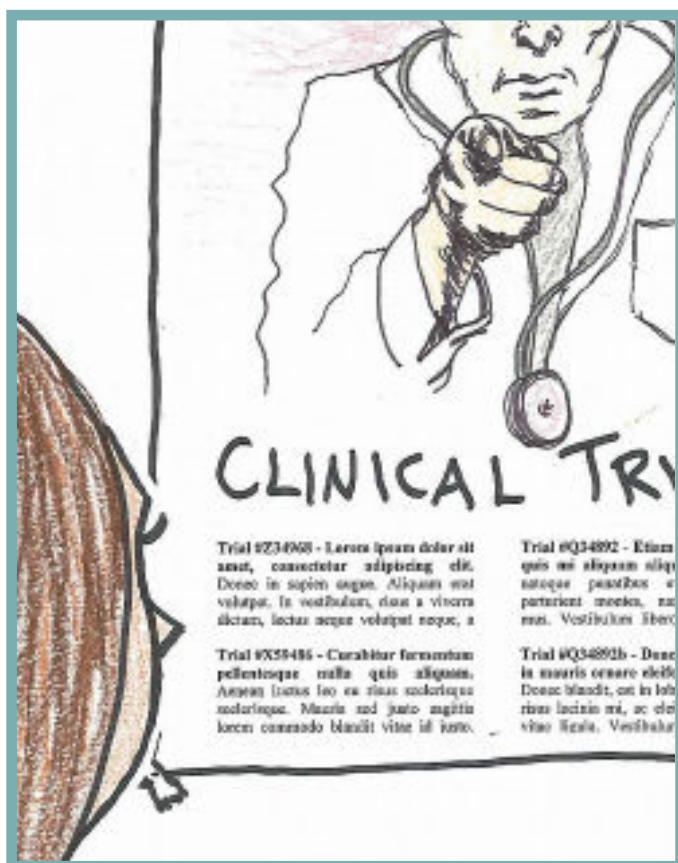
There are as many different reasons as there are people who decide to participate! Most people

say they like knowing they are contributing to society and "giving back" in some way. Before we had the antiretroviral treatments we have now, people had an extra incentive to participate in trials, because it gave them some hope and an opportunity to access treatments that might help them. As treatments have improved to make HIV more manageable here in the West, this extra motivation has become less of a factor. But of course, in a lot of the world, people do not necessarily have access to treatment and prevention, and the hope of having access to treatment is still one of the main reasons to participate in trials. This raises a whole bunch of questions.

The sticky business of Ethics

If people are participating in trials because they think it might improve their health, what if it doesn't? What if this person is receiving the placebo (because some of the participants will)? What if the trial is not successful? This is completely possible. If people are hoping a trial will offer them treatment or prevention opportunities that they wouldn't otherwise have, how do we make sure we're not taking advantage of the fact that they don't have access? These are *ethical questions* and they fit into a complicated and somewhat abstract field of study called *ethics*. Trial ethics are the rules and standards governing how the trial is conducted, and it has to do with socially accepted moral values.

In her piece *Introducing Clinical Trials* on page 5, Suzanne MacCarthy points out that "there is a fine line between research and treatment". When we see a doctor or specialist to talk about our health and to receive treatment or medical care, it's safe to assume that the main focus is our well-



Most of us don't speak Scientificish.



being. In a clinical trial, that's not the main focus (although it is very important). There will probably be people in white coats conducting tests and asking us to follow a regimen that may or may not be an effective treatment or prevention tool, but, as Suzanne puts it "the focus shifts to include the interests of science and society in general". Ethics helps "to keep the wellbeing of a clinical trial participant equal to the advancement of science and medicine".

Weighing what you know

Like almost everything we do in life, there is some risk involved in participating in a clinical trial. At very least, we risk feeling discouraged if the product we are testing is found to be ineffective. At worst, a trial drug might come with unpleasant side-effects, which is something the researchers will be hoping to find out. Like anything else, we want to collect all the information we have,

decide whether we need or want more information, weigh the pros and cons of participating or not participating, and hopefully make a choice that we feel comfortable with. Participating in a clinical trial is a personal choice; nobody should be (or feel) coerced into taking part.

The CTN plays a very helpful role in Canada by bringing together all the different people interested in conducting high quality HIV-related clinical trials and by ensuring the participation of people living with or affected by HIV in deciding whether trials are relevant and of interest. Studies that meet the CTN's scientific and ethical standards are named with numbers beginning with "CTN". This is a good place to start, if you are considering participating or interested in learning more. And of course, don't hesitate to talk to the staff at PWN if you are looking for more information or support.



Events and Program Information

	MON	TUE	WED	THU	FRI
drop-in	11:30-3:30	11:30-3:30	11:30-3:30	11:30-3:30	-----
lunch	-----	12:00-2:00	----	-----	-----
office	9:00-4:00	9:00-4:00	9:00-4:00	9:00-4:00	9:00-4:00

PWN Grocery (for HIV+ women)

Please make a note of the dates our food bank will be operating in the coming months.

The grocery is open from **12:00noon to 2:00pm** on the days noted here. If you are not receiving groceries and would like to, don't hesitate to call a PWN support worker to start getting set up.

OCTOBER:

October 5 Open
October 12 Open
October 19 Open
October 26 (Closed)

NOVEMBER:

November 2 (Closed)
November 9 Open
November 16 Open
November 23 (Closed)
November 30 (Closed)

DECEMBER:

December 7 Open
**December 14 Open – Holiday Grocery
December 21 (Closed)
December 28 (Closed)

PWN Holiday Grocery

The Holiday Grocery is a special day at PWN, when we try to have a little something extra special for lunch and in the Grocery. Join us on **Tuesday, December 14th** between 12:00noon and 2:00pm.

Quest Food Exchange

Did you know? As a person living with HIV, you can access the services of Quest Food Exchange – an organization that operates low cost food stores. They have fresh fruits and vegetables, milk, bread, desserts, canned goods, meats, and even vitamins and household items. With two locations in Vancouver and one in Surrey, this could be a great way to supplement your regular groceries. Talk to a PWN support worker for more information.

Save the Date! May Wellness Retreat

Positive Women's Network will be hosting another retreat **May 27th to 29th, 2011** at Loon Lake. There will be more information in the January issue of the newsletter and applications will be available in February, 2011. Mark your calendars!



Events and Program Information

PWN Raises \$7952 at AIDS Walk!

Thanks to our dedicated team of walkers, we raised \$7952 at the AIDS Walk for Life on Sunday, September 19th. A big thanks goes to Surita Parashar, one of our newest Board members. She was our top walker, raising \$1000 and bringing the BC Centre for Excellence team on board.

AV Wellness Fair on Aging

AIDS Vancouver will be hosting the last of its 2010 Wellness Fairs on **Tuesday, December 7th** from 1:00 to 4:00pm. This is an opportunity to meet with other people living with HIV, learn about services and issues related to aging. There will be food, samples, music and entertainment. Don't miss it!

YouthCO's new location

YouthCO Community Outreach (serving youth living in B.C. with HIV and HepC) has successfully moved into a new space at **#205 568 Seymour Street** (on the 2nd floor).

Young Women's Wellness Retreat

YouthCO is excited to welcome HIV+ and/or Hep C+ self-identified women under 30 to apply to attend their 4th annual Young Women's Wellness Retreat, **December 3rd to 5th** at Springbrooke Retreat Centre in Langley, BC. The retreat is free to all attendees, including travel costs. Priority goes to first-time retreat attendees and young women from rural communities are strongly encouraged to apply. **The Application deadline is Monday, October 25th**; visit www.youthco.org for more information and to register.

YouthCO AIDS Society's Young Women's Wellness Retreat

Held at Springbrooke Retreat Centre in Langley

The retreat is free and open to all HIV+ and Hep C+ self-identified women under 30 years old.

To attend the retreat contact Sharon
E-mail: Sharonm@youthco.org
Phone: 604-688-1441
Phone toll free: 1-877-YOUTHCO

Deadline for Application: Monday October 25

connect with us

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Positive Women's Network, a partnership of women living with and affected by HIV/AIDS, supports women in making informed choices about HIV/AIDS and health. We provide safe access to support and education/prevention for women in communities throughout British Columbia. The Positive Women's Network provides leadership and advocacy around women's HIV/AIDS health and social issues in the national and local health care communities.

Thanks to our Supporters!

The work of Positive Women's Network is made possible by grants from the **Provincial Health Services Authority of BC**, the **Public Health Agency of Canada/AIDS Community Action Program**, and **BC Gaming & Enforcement**, as well as the following sponsors:



Abbott Virology is the exclusive pharmaceutical Sponsor of SpringBoard.



Bristol-Myers Squibb for sponsoring our upcoming Positive Players pocket guide.



Merck Frosst Canada Ltd. for supporting our food program.



RBC Foundation for supporting our Wellness Workshop Series.



Our portable housing subsidies and food program made possible by support from **Shooting Stars Foundation**.



Tibotec for sponsoring our lunch program & holiday lunch.



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DISCLAIMER

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Unless otherwise noted, all materials and graphics in this newsletter are written and produced by the PWN Health Promotion Team (janetm@pwn.bc.ca).