



HIV Treatment Primer: Is it Time to Start?

By Janet Madsen

Of those who have tested positive for HIV here in BC, 26 % are women.¹ Yet according to statistics from the BC Centre for Excellence in HIV/AIDS, only 15% of people on HIV treatment are women.² Even if we allow some leeway in the statistics for men and women who've tested positive in other provinces and moved here, it still makes me wonder why this is the case.

HIV treatment can lengthen and improve your quality of life. Is it possible you're missing the boat? This article will explain some of the basics, and help you determine if it's time to get on the treatment track.

Learn about Treatments

Explore some of the lived realities of women on treatment to learn about taking them. What have their experiences been? If they've had challenges, what have they been? Talk to your doctor about what he or she would recommend. Is it time to start treatment? If not now, when should you consider it?

To understand how HIV treatment works, it's helpful to know how HIV itself works. HIV "hijacks" immune cells, and uses them to make more copies of itself. These copies then reproduce, making more copies of HIV that attack more immune cells, and so on. This weakens the immune system over time (the timing depends on each person's circumstances). A weakened immune system makes the body more vulnerable to illness and infection.

The HIV replication process takes several steps, and treatments stop HIV at different

points in this process. Some stop HIV from attaching to, or entering immune cells. Some prevent parts of the replication process within the immune cell. HIV treatment is designed to stop HIV replication so that the immune system has a chance to recover, rebuild, and fight HIV.³

HIV treatments are called antiretrovirals, and are known as combination therapy or Highly Active Antiretroviral Therapy (HAART). HIV can become resistant to treatments over time, so by using a combination of drugs that work on HIV at different stages of replication, chances are higher of controlling it.

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Starting Treatment

First and foremost, you should be ready, as you could take medication for the rest of your life once you start. It's a big decision to acknowledge you have HIV every day by taking pills to control it, and you'll be taking pills once or twice a day. If you're feeling uncomfortable with that prospect, you can talk to one of the Support Workers here at PWN, or your doctor. If you're not emotionally or psychologically ready, it could compromise how well you stick (adhere) to your dosing schedule. And if you're not taking the medications as prescribed on a set schedule, HIV can become resistant, limiting treatment options. Starting when you are ready is really important. See "Am I ready To Take Treatments?" on page 5 to explore your readiness. One exception to this is during pregnancy (see sidebar).

As part of your HIV health care routine, you need to have regularly scheduled blood tests to see how your immune system's doing. Results of these tests will show whether treatment is advisable. In general, the BC Centre for Excellence in HIV/AIDS Therapeutic Guidelines suggest that a CD4 count of 350 or less indicates a need for treatment⁴, but each case is different. Once you've started treatment, your doctor will closely monitor your CD4 (immune cells) and viral load (a measure of how much HIV is in your system) to see how the treatments are affecting your immune response. Ideally, your CD4s will start to climb and your viral load will go down.

Combination therapy stops HIV at different points in the replication process. The idea is to put you on the most effective, least toxic and most convenient set of drugs possible. If you've never taken therapy before, the options are varied.

If you want to see a list of different options, look at the BC Centre for Excellence Guidelines, pages 7- 13 and pages 27-28.⁵

Coping with Side Effects

There can be side effects to antiretroviral drugs and some people tolerate them more easily than others. If they're going to occur, side effects usually surface in the first month or two of treatment and lessen over time. If you're new to HIV medication, ask your doctor what side effects to

Treatment During Pregnancy

If you're pregnant, or thinking about getting pregnant, talk to your doctor. Treatment can significantly reduce the chance of passing HIV to the fetus (baby). Without treatment, the transmission risk is around 25%. With treatment, the transmission risk is about 1%.¹ Even if your immune system is strong, treatment affects pregnancy outcomes. For more detailed information, ask us to send you our **HIV & Pregnancy: Yes You Can** pamphlet, or check our pregnancy information online (www.pwn.bc.ca/hiv-body/pregnancy-and-hiv/). Doctors at **Oak Tree Clinic** specialize in pregnancy planning a prenatal care, so contact them with any questions (604-875-2212).

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expect and how to manage them. Keep your doctor informed about how you're feeling, because it may be possible to switch medications if your side effects seem intolerable. Don't stop taking your medications without talking to your doctor. Common side effects include⁶:

- nausea, diarrhea, and other digestive complaints
- skin rash (some rashes can be a sign of a serious allergic reaction, so talk to your doctor promptly if they develop)
- weird dreams, headaches, depression, anxiety
- weight gain or loss in certain areas of the body (gain in breasts and belly; loss in face, arms, legs)

Some side effects are more common in women. For example, studies have shown that women may be at a much higher risk than men of developing skin rashes as a result of some drugs.⁷ When treatments are being tested, the studies tend to have more men than women, so drugs can be prescribed without knowing all of the possible effects for women.

After approval, side effects can appear (in men or women) that didn't in initial studies, because more people taking the drugs means there is a larger population to observe the drug's effects. Post-approval surveillance is one way of tracking this information, and if you have unexpected side effects, it's good to make sure your doctor reports them. The Canadian Treatment Action Council (www.ctac.ca) is a good source for more information on post-approval surveillance.

HIV resistance can develop when medication levels in your body drop below a certain level. You can avoid this by taking your medication around the same time every day. If your schedule is unpredictable and you can't take your medication around the same time, this could pose a challenge, so talk openly with your doctor about what scheduling challenges you foresee and what kind of regime would best suit them.

Alternative or Complementary Treatment

Along with medication options, there are complementary or alternative therapies you might

want to explore. Complementary (used as well as drug options) or alternative (used instead of drug options) therapies are based on different approaches to health. Reducing stress, improving circulation

and body strength, boosting your nutritional intake and visualizing your own health are all approaches of complementary therapies. Frequently used therapies include:

- vitamins
- herbal remedies
- Traditional Chinese Medicine (TCM)
- acupuncture
- yoga
- massage
- meditation / creative visualization

Vitamins and herbal therapies could interact with HIV medications, so clear your regime with your doctor to ensure you won't do yourself more harm than good.

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Treatment Primer ... cont

Can I Stay Healthy Without Treatment?

The natural course of HIV infection generally leads to a destruction of immune function, decrease in immune response and deteriorating health. While there are some people with HIV whose immune systems stay strong for many years after infection (these people are called long-term non-progressors⁸), most people will experience immune compromise as HIV progresses. Talk to your doctor about your long term health plan. HIV is often called a “chronic manageable illness” these days, but it does damage the body right from infection⁹ so you want to stay healthy as long as you can. Treatment can help.

Questions? These sources can help:

Canadian AIDS Treatment Information Exchange:
www.catie.ca

Canadian Treatment Action Council:
www.ctac.ca

BC Centre for Excellence in HIV/AIDS:
www.cfenet.ubc.ca

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3. Thaczuk, Derek. (2009). Treatments, Managing Your Health, 125-142. Canadian AIDS Treatment Information Exchange. Retrieved from <http://www.catie.ca/pdf/myh/myh2009.pdf>
4. BC Centre for Excellence in HIV/AIDS. (2009, February). Therapeutic Guidelines for the Management of Adult HIV Infection, 6. Retrieved from <http://www.cfenet.ubc.ca>
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8. Carter, Michael. (2009, June 12). HIV non-progressor status established soon after infection. AIDS Map News. Retrieved from <http://www.aidsmap.com>
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Am I ready To Take Treatment?

By Janet Madsen, adapted from our website www.pwn.bc.ca

HIV treatment can dramatically change how you feel, and not just physically. Starting treatment can be very emotional: it means you're reminded about HIV every day, and decisions about disclosure can be more pressing. You could take treatments for the rest of your life, and adherence (taking the drugs regularly and on time) is really important for them to work properly, so it's a commitment to think about carefully.

Exploring how you think and feel about being on treatment can help you move confidently into it, which will benefit your health in the long run. The following questions are some to consider. You may have more. PWN support workers are available to talk about all of this if you like.

- Do I have a comfortable relationship with my doctor? Can I talk honestly?
- Am I okay with being reminded of HIV every day?
- What do I think about taking HIV treatment?
- Am I confident that I can take my medications every day, aiming to never miss a dose?
- Am I physically comfortable swallowing pills?
- Can I deal with the possibility of side effects if it means my health could improve in the long run? (Side effects might include nausea, headaches, diarrhea, rash, insomnia, dizziness, and more.)
- Am I ready to make a life long commitment to taking medications at scheduled times?
- If I'm in a situation where people don't know my status, would I be comfortable finding ways to take my meds on schedule, regardless of where I am and who may be around?
- Have all of my questions been answered? If not, where can I get more information?

Ideally, you and your doctor can talk openly about your questions and concerns. When it comes to HIV treatment, you're the one who has to take it, not your doctor. Making sure you have all the answers you want before you start and a safe and inspiring place to go for answers once you've started is vital.



Many Women Living With HIV Skip Pap Tests Despite Increased Risk For Cervical Cancer

Nearly one in four women living with HIV did not receive an annual Pap test in the year prior to being interviewed, according to a study published in the August 1st *Journal of Acquired Immune Deficiency Syndromes*, Reuters reports. Women with HIV have an increased risk for cervical cancer, which the test detects, the article states. According to Reuters, "To see if guidelines for annual cervical cancer screening for HIV-infected women were being performed, ... [researchers] analyzed information on 2417 HIV-infected women from 18 states. Records showed that 23 percent of those inter-

viewed had not undergone a Pap test during the year before the interview." The article states, "The risk of cervical cancer has not decreased since the introduction of highly active antiretroviral therapy for HIV infection, 'highlighting the continued importance of cervical cancer screening in this population,' health officials from" CDC note in the journal (Reuters, 7/30).

Source: Kaiser U.S. Daily HIV/AIDS Report. July 31, 2009.

Skipping Doctor Visits Risky for HIV Patients

The death rate for HIV patients who miss scheduled clinic appointments during their first year of treatment is more than double that for patients with perfect attendance, according to a recent study.

Dr. Michael J. Mugavero and colleagues at the University of Alabama-Birmingham studied 543 patients who began outpatient HIV care at the school's 1917 HIV/AIDS Clinic between 2000 and 2005. Of the patients, 60 percent missed an office visit in the first year of treatment. Even after controlling for immune system function at the outset and HIV drug therapy in that first year, the mortality rate for patients who made all scheduled visits was one per 100 persons per year, compared to 2.3 per 100 person-years in those who missed appointments. Furthermore, the increased risk of death was similar when patients missed only one, or two or more visits.

"Considering tens of thousands of individuals are newly diagnosed with HIV infection in the

United States annually, and the high frequency of missed visits in the first year of care - which was associated with over a two-fold increase in mortality in our study - extrapolation of our findings to the general population level has profound public health implications," said Mugavero.

"For HIV care providers, missed visits shortly after establishing outpatient care serve as a marker identifying patients at higher risk for poor clinical outcomes - patients who may require closer monitoring," Mugavero added.

The study, "Missed Visits and Mortality Among Patients Establishing Initial Outpatient HIV Treatment," was published in *Clinical Infectious Diseases* (2009;48(2):248-256).

Source: CDC HIV/Hepatitis/STD/TB Prevention News Update. February 12, 2009

Original source: Reuters Health. February 11, 2009: David Douglas



'Tis the Season, and I will survive!

By Miriam Martin

The Fall means many things: shorter days, back to school, falling leaves and cooler weather. It also signals the start of the holiday season. Whatever your beliefs and background, it is pretty much impossible to ignore the holidays altogether. Apparently there are people who love the hype of the season and really do enter the new year feeling joyful and refreshed. I am not one of those people! For the rest of us, it can be a season of high stress and mixed emotions.

Reflecting on the Past

This time of year, for better or for worse, we end up reflecting on the past. Whether our memories of holidays past are positive or negative, they are rekindled and fuel our expectations for this holiday season. Our own expectations jostle for attention among the expectations of others, including children, family and faith. Perhaps the most unrealistic and unattainable expectations come from external forces, such as advertising on billboards, in flyers and on TV. We are bombarded by images and messages telling us what the holidays "ought" to be like. Of course we cannot live up to all of the expectations of the season, but we still try to deliver and it's easy to feel disappointed if we don't.

For some reason the holidays are a time of reflection. Maybe it's because you're spending time with your family or other people from the past, or maybe it's because there's somebody you'd like to be with, but can't. Maybe it's just that sense of having made it through another year and heading into the next. Most people's memories include some pain, sadness and regret. Difficult memories from childhood may be more present than usual in your mind, especially if you

are spending time with family over the holidays. At this time of year, it's also common to think of the ones we have lost. For long term survivors and service providers, this means remembering people who have died of an HIV-related illness. It is very common to feel depressed at this time of year and it's important to find support to get through feelings of loss, sadness or despair.



Does anybody's family gathering actually look like this?

HIV and the Holidays

For people living with HIV, there can be additional stresses associated with the holidays. The busyness of the season can make adherence to treatment more difficult, as can spending time with people who may not know that you are positive, or who do not really understand or

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*Freedom from Want, by Norman Rockwell,
The Norman Rockwell Museum of Stockbridge*

respect your status. If you are having gastrointestinal problems because of HIV or meds, you might need to avoid all of the rich foods available in such abundance at this time. For those in recovery, staying away from celebrations involving alcohol might be a priority and a challenge.

Holiday Money Woes

Perhaps the most common burden of the holidays is the financial one. These days, everyone is feeling stretched and during the holidays we feel like we're expected to spend, spend, spend. Again, we're back to those darn "expectations" that seem to reign supreme at holiday time. There are so many ways in which we feel pressure to spend extra money – gifts, treats, fancy meals, decorating, traveling, entertaining, etc. Even if you find these things enjoyable, they can put additional strain on your financial resources.

Enjoying the Holidays

With all of these stresses of the holidays, there are some strategies for not only coping and surviving, but actually finding joy in the season. You'll find my collection of tips and strategies on the following pages. It is easy to say "try to keep a positive attitude" or "try to focus on the good", which are both reasonable suggestions. For me though, it is the concrete and conscious changes and actions that make this "positive attitude" possible. In many ways, the key is to take control of those expectations – to pick and choose what you need and want from the holidays. You set the agenda; you set your limits, and you determine the shape that the season will take for you. Hopefully, with the help of the suggestions here, we will all do less pulling our hair out and more relaxing and celebrating this season.

Holiday Survival Strategy #1 Plan ahead

Planning ahead does not have to be Martha Stewart-style, unless that's what you're into. It can mean just taking a moment a month or two in advance to answer a few questions about your expectations. By setting your priorities and sharing them with others early on, you're giving family and friends a chance to consider your needs in their holiday planning and you save them the embarrassment and disappointment of planning something that doesn't work for you.

- **What** are your expectations of the holidays? What are the things that would be really meaningful to you this year? Is it rest, family, entertaining, indulging, getting away? You may need to prioritize.
- If you really put your own needs and desires first, **Where** would you spend your holidays? It might be somewhere far away, at a big family gathering, or even in front of the TV in your own home.
- Perhaps one of the most important questions - **Who** do you want to spend the holiday season with? Who will help you feel positive, energized and optimistic? If you have commitments to see people that do not necessarily make you feel positive, can you also schedule a time to re-energize with somebody else or on your own?

Golden Lily Wallpaper, by William Morris, Victoria & Albert Museum, <http://www.vam.ac.uk>



Holiday Survival Strategy #2 Pick & choose

This holiday season, allow yourself to really pick and choose not only who you are going to celebrate with, but how you are going to celebrate. There is no reason why you have to do things "the way they've always been done" or the way they are done on TV. You can pick and choose your traditions and even invent your own. Maybe your tradition will be watching a movie over Chinese take-out and sleeping in the next morning. Maybe it will be getting up early, hiking with a group of your favourite girl friends and then doing the polar bear swim ... the possibilities are endless. You pick and choose.



Make your own traditions

Holiday Survival Strategy #3 Be creative with gifts and spending

For many people, the biggest burden during the holidays is financial. Definitely try to plan ahead – decide how much you can spend and how you might divide it up. Be realistic about how much you can spend and don't be afraid to ask for support.

- Suggest a homemade holiday, gift spending limit or gift exchange (where everybody draws a name from a hat and gets just one gift for that person). There are likely friends or family members who will be thankful, even if they don't express it.
- Dollar stores have an amazing selection of party and seasonal decorations, as well as cards, craft supplies and gift wrap.
- If you live near a major centre, Craigslist (www.craigslist.org) is an excellent place to find great deals on gifts for people you want to treat with something special.
- You can also do a lot with a small amount of money and a bit of creativity. Make cookies or buy candy in bulk at the grocery store, then divide up the treats into plastic baggies tied with a ribbon and a little gift tag.
- See if you qualify to receive donated holiday food hampers or children's gifts from an organization in your community.

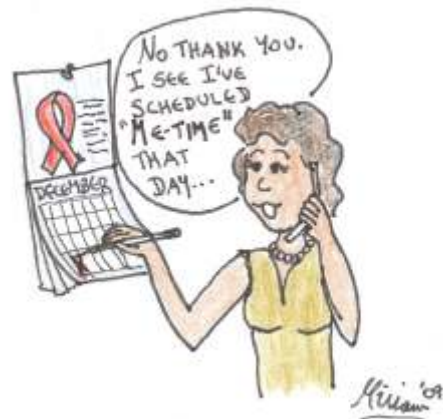
If the gifts, meals and frills of the holidays are important to you, then finding creative ways to make them happen on a budget will relieve a great deal of stress.

Holiday Survival Strategy #4 **Say “No, thanks”**

If you choose to celebrate the holidays in the way that is best for you, then you will likely have to say “No”. There is nothing wrong with responding to an invitation by saying “No, thank you”, with or without explanation. For potentially difficult Holiday gatherings you do attend, have an escape plan. If things get tough, take a breather in the bathroom or tell the hosts you are feeling unwell and need to leave early.

Holiday Survival Strategy #5 **Find support**

Try to spend time with people who make you feel comfortable and give you energy rather than draining it. Do some research to find out what groups and services exist to support people and families over the holidays. This is especially important if you are going to be alone. Whenever possible, try to be open and honest about your needs, limits and expectations, so that people know how best to support you. Planning ahead will help make this easier.



Say “No, thanks”

Holiday Survival Strategy #6 **Take care of yourself**

One of the smallest things that we can do for ourselves to keep sane during the holidays is to set aside a little bit of alone time each day. Just 30 minutes spent reading, day-dreaming or watching a favourite television show will make a big difference most days. Eating well and finding time for physical activity will also keep you feeling well and help you fend off the blues. Go easy on yourself; treat yourself; let yourself be you.



Improve well-being! Get Pampered! Learn about Complementary Therapies

What?

A complementary therapy is any practice, therapy or product that is not considered conventional medicine. Complementary therapies can be used for easing symptoms and improving your overall health and feeling of well-being. For example, acupuncture, meditation, aromatherapy, Chinese medicine, dance therapy, music therapy, massage, herbalism, therapeutic touch, yoga, naturopathy...

When?

During "hot lunch" Tuesdays (12:00-2:00pm) this fall 2009.

Where?

In the PWN drop-in, Suite 614, 1033 Davie St. Vancouver, BC.

Practitioners and educators involved in different types of complementary therapies are visiting PWN on the dates below:

Tuesday, October 20th

Get a Reiki session! Reiki is a Japanese technique for stress reduction and relaxation that also promotes healing. It is administered by "laying on hands" and is based on the idea that an unseen "life force energy" flows through us and is what causes us to be alive.



Tuesday, November 3rd

BC Compassion Club Society will be here to talk about using cannabis and other natural therapies for people living with HIV/AIDS.

Tuesdays, November 17th & 24th

Get a Reiki session! (What's Reiki? See October 20th, above.)

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

Thanks to our AIDS Walk Fundraisers!

PWN would like to acknowledge the support, work and dedication of our AIDS Walk sponsors. A special thank you goes out to our top five fundraisers – Patti Telford, Melissa Medjuck, Kath Webster, Kendra Loewen and Helenka Jedrzejowski. We would also like to thank and recognize the successful fundraising efforts of Ariane Alimenti, Louanna Atkinson, Monique Desroches, Jack Forbes, Damir Moric, and Magdalena Sweetgrass. Thank you to everybody who came out to walk; it was a lovely day.

Thank You Evelyn!

Thanks so much to Evelyn Maan, Research Program Manager at the Oak Tree Clinic, for her very informative presentation on “Hepatitis C and HIV Together”. Evelyn came to our Tuesday drop-in lunch on September 22nd, and was able to answer our questions and provide us with up-to-date information on this complex topic. We so appreciate Evelyn’s ability to summarize and present information in a way that is accessible to all. Thanks also to Anna Machala of Tibotec, who provided staff and members with a wonderful lunch at the event. If anyone would like copies of Evelyn’s handouts on HepC/HIV Co-infection, please contact Bronwyn at 604-692-3008.

What’s up in the Grocery?

The PWN Grocery will be open 12:00-2:00pm on the following Tuesdays:

- October 6th and 13th
- November 3rd and 10th
- December 1st, 8th and 15th

Special Dates to Note:

- December 1st – World AIDS Day, special programming in the drop-in 12:00-2:00pm.
- December 15th – Holiday Grocery

PAN and OAN Training Leaders

This fall, four members of Positive Women’s Network participated in a training initiative hosted by the Pacific AIDS Network in partnership with the Ontario AIDS Network. These women attended an intensive Level I PHA Leadership Development Training course from September 25th to 28th at Loon Lake, BC. The Level I course dealt with the question “Who am I as a Leader?” and guided participants in identifying their personal values and philosophy, developing leadership skills and practices, and gaining community knowledge and awareness. We hope that this will be the first of many training courses and just one step toward developing a strong network of PHA leaders in BC. Congratulations to our member graduates of Level I!



Events and Program Information

Free HEAL TeleWorkshop

The BC Coalition of People with Disabilities is offering a series of TeleWorkshops for people living with HIV/AIDS. The workshops are called HEAL (Health Education, Advocacy, and Leadership) and are designed to show how health education, advocacy and leadership can help you live a more fulfilling life. The next workshop will take place for five **Thursdays, October 15th to November 12th, 4:00-5:00pm**. To register or for more information, call Shelley Hourston at 604-875-0188 or email wdi@bccpd.bc.ca. You can also learn more at www.bccpd.bc.ca/healworkshop.htm. Spaces are limited, so register early.

October Retreat

A big Thank You goes out to all the sponsors of our October 2009 retreat on Bowen Island:

- Book Warehouse on Davie St.
- Capers/Whole Foods on 4th Ave.
- Lush Handmade Cosmetics
- MAC Cosmetics
- Shoppers Drug Mart on Davie St.
- Tibotec, a division of Janssen-Ortho Inc.
- Vancouver Pride Society

It's your support that makes our retreats such a success. Thank you!

PWN Support Group

Come connect with other members at the PWN support group. A chance to laugh and learn, and have something yummy to eat.

Thursdays 5:30-7:30, November 5th to December 3rd in Room 103, 1033 Davie St. For more information, call Sangam at 604-692-3006.

BCPWA Focus Group

PWN will be co-hosting a focus group with BCPWA for PWN members. Last spring, the British Columbia Persons with AIDS Society Treatment Information Program (TIP) commissioned a study to investigate the reasons why access to its peer treatment information program is declining. To investigate these reasons, information was collected by an online survey. Despite the success of the study, women were unrepresented, so BCPWA would like to do a focus group with women at PWN. An incentive for participants and snacks will be provided. Please contact Bronwyn at 604-692-3008 if you are interested. Date and time to be confirmed.

International AIDS Society Symposium

The Fall HIV/Antiretroviral Update hosted by the BC Centre for Excellence in HIV/AIDS will be a Special International AIDS Society Symposium, with invited speakers from the Governing Council of the International AIDS Society. The Symposium will take place on **Monday, November 16th, 8:00am-5:00pm** at the Sheraton Wall Centre Hotel (across the street from St. Paul's Hospital) in Vancouver. This is the place to hear about the latest global developments in antiretroviral treatment, research and management of the disease. Visit <http://cfenet.ubc.ca/hivupdate/registration.html> to register.

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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.



BC Hydrex for keeping our drop-in well-furnished.



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 Health Enhancement Program



Vancouver Foundation for sponsoring Leadership, Engagement, Action and Dialogue (LEAD).



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

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