The Positive Side

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CONFERENCE UPDATE
Running around at CAHR

Janet Madsen

Thanks to support from the CARMA research team, fifteen members and three staff from Positive Women's Network attended the Canadian Association for HIV Research (CAHR) conference in Vancouver from April 11 to 14. Hundreds of people attended this conference, and I can offer only limited reporting. For other coverage, I suggest you check out PositiveLite.com, PositiveLivingBC.org, and CATIE.ca.

Women in Research

For some of the PWN women, CAHR started with a pre-conference event to develop priorities in Canadian HIV research for women, trans people, and girls. These groups face multiple and often similar issues, which put them at greater risk for becoming infected with HIV and being lost to care. We need a deeper gender lens and greater involvement of women in HIV research.

One of the things that PWN support worker Melissa mentioned about this event was the talk about disclosure. She said there was discussion about the stricter disclosure laws that came into effect in the fall of 2012. Women who may have felt comfortable speaking about their status publicly don't want to do that anymore because of what they feel is increased stigma. Disclosure was one of the priorities identified by the group as a whole.

This is part of the official press release from the event: "Research priorities for women, trans people and girls highlighted at the ancillary session included legal implications of HIV non-disclosure, inclusion in clinical trials, and policy research that meet the needs of these diverse populations."

The acknowledgement that important populations are missing in research continued throughout the conference. There was a lot of discussion about the need for greater involvement of people living with HIV and vulnerable communities that don't see themselves at risk. Women and aboriginal people in particular are at great risk for HIV, yet their voices are often missing.

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Photo by Sangam

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Risk Awareness

In the conference's official opening lecture, Dr. Liviana Calzavara from the University of Toronto talked about the "unspoken forces" that shape HIV research, including policies, programs, academic funding structures, and societal norms. She says health and health research has focused too much on individuals and not enough on the social determinants of health that affect groups of people. We need to know more about the social influences of the HIV epidemic.

This is so true for women and aboriginal communities, who are particularly influenced by issues beyond personal decisions and power. Violence, poverty, limited education, substance use, and inability to negotiate safer sex are just a few of the things frequently beyond an individual's control in managing HIV risk.

On Saturday morning, Dr. Jeanne Marrazzo from the University of Washington looked at biomedical prevention methods for women: treatments (using HIV medications to prevent infection, known as PrEP) and medical procedures (male circumcision, for example). Studies on using HIV drugs to prevent women from getting infected can run into the problem of perception—if women don't see themselves at risk, they may not take the drugs as instructed.

In one study, 95% of the women said they were taking the medication, and according to pill counts in follow-up visits, 86% to 89% were supposedly taking it. Yet blood tests showed that only 26% of them had the drug in their bloodstream. Marrazzo said 70% of women involved considered themselves low risk for HIV, so they may not have had the motivation or support to use the drugs. Marrazzo mentioned partners being suspicious and sisters unsupportive of women's roles in the study, and of course this would be a factor. She also said male circumcision shouldn't be considered a prevention tool for women. Often men don't wait the required six weeks post surgery, and they won't wear condoms. Both increase women's risk of getting HIV.

The perception of risk came up again when Dr. Charmaine Williams from the University of Toronto presented information about black women in Toronto who are originally from African and Caribbean countries. She said that women coming from countries with high rates of HIV are used to seeing HIV prevention information in public spaces—it's normal. In Canada, they don't see it at all. They can be having unprotected sex with people from their communities of origin, where HIV is high incidence, but they don't see it as risky in Canada because of the lack of emphasis on HIV awareness. Married women think monogamy will protect them, even though they live in a community where multiple partners are the norm.

> "It's not risky to be an Aboriginal woman, yet that's often how it's framed"

So we have to figure how to approach this perception of risk. It's so important in figuring out how to reach people with prevention information. This came up again and again in presentations on women, heterosexual men and men who have sex with men, and youth.

Dear Doctor: Criminalization in the Community

HIV criminalization and disclosure are ongoing, difficult issues. Why should one feel like a criminal for having a virus? Unfortunately Canadian law can make people feel that way. Telling sex partners you have HIV before you have sex is the best way to protect yourself under the law, because if you don't you could face criminal charges. In the fall of 2012 the Supreme Court of Canada ruled on two cases of HIV non-disclosure, making disclosure even more essential.

To build a case in court, lawyers need to have expert advisors and witnesses that argue for (prosecution) or against (defence) charges laid against people with HIV. Dr. Robert Remis, an epidemiologist, has worked in support of the prosecution of cases. On Saturday a group of activists took to the stage behind him in protest. They also distributed a letter that called on doctors:

Use your title and platform to promote science, reason, and social justice. Advocate for universal access to HIV education, testing, and treatment, and say NO to the criminal prosecution of people living with HIV!
(Complete letter available at PositiveLite.com)

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Criminalization is not the best way to reduce the HIV epidemic. Public health campaigns making all people aware of HIV risks and responsibilities are the way to go. It's not *just* people with HIV who need to take responsibility.

The Impact of HIV in Aboriginal Communities

On Friday, the first full day of the conference, Dr. Clive Aspin from the University of Sydney spoke powerfully about the effects of HIV on indigenous people worldwide. Prevention efforts have largely failed for indigenous people, who are cut off from their roots and each other because of the extended effects of colonialism. Western religions have suppressed traditional social structures and belief systems, resulting in broken communities.

Aboriginal people are over represented in HIV+ populations in Canada, New Zealand, and Australia. Aspin suggested that indigenous people lack the political and social power to make governmental change. He said we need a holistic approach, recognizing family and community relationships as well as indigenous leadership. Collaboration between community and policy makers must happen if the future is to change for indigenous people.

Aboriginal women can't see change too soon. Information from the Public Health Agency of Canada says that 49% of HIV infections in Aboriginal people are women. Aboriginal people make up 4% of the Canadian population, yet 8% of HIV cases. Saskatchewan, in particular, has seen a significant rise in HIV cases in Aboriginal women in the past few years.

Jessica Danforth did a great presentation for the Native Youth Sexual Health Network about a prevention project aimed at Métis youth and women. PWN's support coordinator Bronwyn said, "I so appreciated her focus and language." In particular, Jessica said it's not risky to *be* an Aboriginal woman, yet that's often how it's framed. So true—it's actually environmental and social issues that can make things risky. Aboriginal women are often more affected by issues that put them at risk than non-Aboriginal women. It was wonderful when Jessica turned the focus to the beauty and pride in women's bodies, and the multi-generational work of the project. Yes!

The Cure—Are We There Yet?

There's been a lot of buzz in the last couple of months about the HIV "functional cure" in children, and it was addressed on Sunday morning in a special plenary presentation.

What is a functional cure? A child would be considered functionally cured if trace amounts of HIV were in the body, but not replicating. This is true for a toddler in the southern US, and also true for some kids here in Canada, with a huge difference—the child in the US isn't on HIV treatment anymore, but the kids in Canada remain on treatment.

The child in the US was born to a mom who received no prenatal care and tested positive in labour—a health care failure in itself. Her baby was given highly sensitive HIV tests and found to be positive too. Within 30 hours of birth, the baby was given intensive combination HIV treatment. This isn't normally done, as there's still too much we don't know about dosing and toxicities to give these drugs to all newborns exposed to HIV during pregnancy.

The child was on treatment for 18 months, and then disappeared from health care for 5 months. When brought back, the child had been off HIV meds for 5 months, but doctors couldn't find evidence of active HIV in the body.

The kids in Canada who have been treated with HIV medication since birth don't have any replicating virus either. They remain on their treatment and will stay on it. The girl in the US went off treatment because she disappeared from care, not because her doctors advised it—it's too big a risk that HIV could rebound and take hold of the body. The conclusion presented is that it may be possible to achieve a functional cure of HIV in babies who get treatment before the virus can establish reservoirs in the body where HIV "rests" until it springs into replication. We still have lots to learn.

Until Next Year

As usual, CAHR was great. As Bronwyn pointed out, it is great to see a shift towards more community-centred conversation and contribution. Medical and community representation is balancing out, as we continue to learn about HIV's effects on body and spirit.

"What's going on with my body?"

HIV & Menopause

By popular demand, Positive Women's Network held a session on HIV and menopause on April 18. Menopause, the participants agreed, was a topic that "nobody's talking about," so information is very needed.

Dietitian Jenn Messina, from St. Paul's Hospital, talked about healthy foods for older women (as participants enjoyed a lunch designed to meet her nutritional recommendations), and Oak Tree Clinic's Dr. Mary Kestler presented medical information.

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Hangin' with Dr. Kestler

Janet Madsen

Aging and HIV—It's not just you

Dr. Mary confirmed what we see within Positive Women's Network membership. Within five years, more than a third of women with HIV in Canada will be over 50 years old. Aging means women could be dealing with body changes on three levels: HIV treatment, HIV-related conditions, and aging itself.

The two most important hormones in our reproductive systems are estrogen and progesterone. As we age, hormone levels change. For some women that means big changes and discomforts, and for others it's not a big deal. Changes can include the following:

- Changes in menstrual bleeding (lighter or heavier) and less often than your usual pattern
- Sleep disturbances
- Mood changes—from very cranky to depressed (not unusual in the same hour!)
- Changes in sex drive
- Discomfort during sex
- Hot flashes
- Forgetfulness
- Urinary incontinence (estrogen plays a part in bladder control)

After menopause, hormones level out, and symptoms generally lessen.

"Do symptoms mean I'm heading into menopause?"

"Excellent question!" said Mary. Not having a period for twelve months can mean you've reached menopause, but there are other things that can also halt your period:

- Methadone or heroin use
- Stress
- Very low body weight (estrogen needs fat to work properly)
- Certain medications
- Serious illness

Women with HIV are three times more likely to miss periods (unrelated to menopause) than women without HIV. Always check with your doctor to assess your situation.

"Do women with HIV start menopause younger?"

A study of thousands of women found that the average age for menopause among all women is 47. One study gave the average age as 51, but included only middle- to upper-class white women—definitely not representative of everyone! As for whether HIV brings menopause sooner, it's thought that HIV doesn't play a big part. What does influence menopause greatly are smoking, low body weight, number of pregnancies (the fewer you've had, the earlier you'll reach menopause), and stress.

"Will women with HIV have more symptoms?"

Mary said women with HIV can have more symptoms. This is especially true for women taking efavirenz (Sustiva, Atripla). Depression, smoking, and stress can worsen symptoms. Mood changes and variations can be normal, but if they're interfering with your life, talk to your doctor. Counselling or anti-depressants may be something to consider. Mary admitted she's not big on anti-depressants alone—they can have side effects, so she prefers short-term use with counselling. Cocaine use decreases estrogen levels, so that could play a part in symptoms for some women.

Health issues after menopause

Mary focussed on three health issues after menopause: bone health, heart health, and cancer. All women lose bone density after menopause, and for women with HIV it's worse. HIV medication also adds to bone loss risk.

Eat calcium-rich food, and quit smoking and drinking, or at least reduce your use. Ask your doctor for a baseline bone scan so you know if there's any damage and to monitor further loss over time. If there is a concern, over-the-counter supplements or prescription medication can help.

Heart disease risk increases after age 42. High blood pressure, smoking, LDL cholesterol, low CD4 counts, and diabetes can contribute to heart health or illness. Talk to your doctor about your risks and what you can do.

Cancer risks increase after menopause for all women. Schedule mammograms as suggested by your doctor and report any vaginal bleeding. Once you're truly post-menopausal, you shouldn't start bleeding again. If you do, it could be something serious like uterine cancer.

I'm happy to report that when Mary spotted our recently released *Pocket Guide on Aging for Women Living with HIV*, she said, "That's a great resource!" (Thanks, doc!) The pocket guide includes the information above and also has sections on HIV basics for women over 40, mental and spiritual health, sexual well-being, abusive relationships, and more. Contact Erin, our resource coordinator, if you'd like a copy: erins@pwn.bc.ca or 604-692-3011.

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Lunchin' with Jenn Messina

Erin Seatter

Many women at the workshop said they had trouble digesting dairy products. Lactose intolerance is an issue for many people not of European descent, and also for anyone who stopped consuming dairy products and then tried to restart later in life, because of a lack of enzymes to break down the lactose. Yet industry and government push dairy products into food guides and grocery stories, and it can be hard to find other options in a dairy-oriented market. Milk is harder to digest than yogurt and cheese, Jenn said, so people who have trouble with milk may be able to eat the latter products. And other options are increasingly available, including soy.

Studies indicate that soy can help alleviate menopause symptoms because it mimics estrogen, explained Jenn. Some women said they found tofu easy to incorporate into meals; because of its neutral taste, it can be flavoured with different sauces and added to any dish. Other women said they haven't gotten used to the texture of tofu yet. Jenn suggested that dessert tofu can be blended into a smoothie—women were excited upon hearing this delicious and simple way to consume tofu!

JENN'S QUIZ ON MENOPAUSE & HEALTHY EATING

1 **TRUE OR FALSE: AFTER MENOPAUSE YOUR NEED FOR CALCIUM AND VITAMIN D INCREASES.**

2 **WHICH FOODS ARE GOOD SOURCES OF CALCIUM AND VITAMIN D?**

a. fortified tofu
b. salmon with the bones
c. cream soup
d. fortified almond milk
e. all of the above

3 **TRUE OR FALSE: MIND AND BODY PRACTICES SUCH AS YOGA, TAI CHI, AND ACUPUNCTURE MAY HELP REDUCE THE SEVERITY OF MENOPAUSAL SYMPTOMS.**

4 **KEEPING YOUR HEART HEALTHY IS ESPECIALLY IMPORTANT AFTER MENOPAUSE. TRY TO EAT MORE:**

a. fruits, vegetables, whole grains
b. beef, pork, lamb
c. butter, margarine, creams
d. meals out

5 **REGULAR ACTIVITY SUCH AS WALKING, SWIMMING, GARDENING, ETC. WILL HELP:**

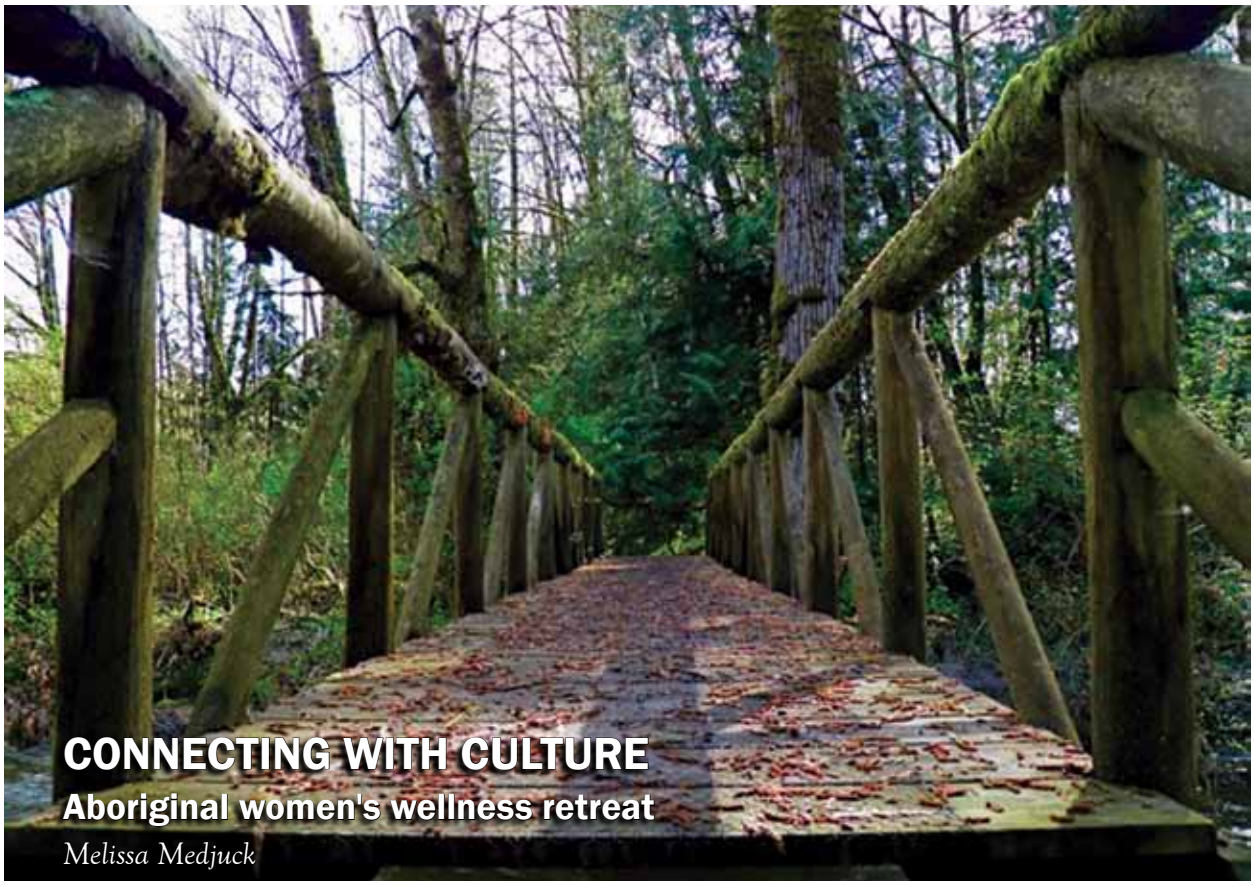
a. keep your heart healthy
b. keep your bones strong
c. improve your sleep
d. help you achieve/maintain a healthy weight
e. all of the above

What are whole grains? When Jenn posed this question, one woman immediately said, "Things that don't taste good," and others agreed. "Do you like oatmeal?" asked Jenn, who then revealed that oatmeal contains whole grains. Turns out whole grains don't taste so bad after all! Wild rice or basmati is a better choice than plain white rice, and quinoa is an excellent choice, said Jenn.

Guess what? Pork is NOT "the other white meat." Some women were surprised to learn that pork is not a healthy option. And it's easier to meet our daily protein needs than we think—small servings of protein sources such as eggs, meat, tofu, beans, and yogurt throughout the day will do it.

At the workshop, women got a taste of Jenn Messina's dietary recommendations for perimenopausal and menopausal women. The menu consisted of green salad, whole wheat wraps containing veggies and chicken, fruit, and a dip made of avocado and edamame beans—a creative way to eat soy. Soy milk was offered as a beverage. After lunch, women helped themselves to Greek yogurt, and everyone received a package of dessert tofu to take home.

ANSWERS
1 TRUE
2 E
3 TRUE
4 A
5 E



CONNECTING WITH CULTURE

Aboriginal women's wellness retreat

Melissa Medjuck

Photo by Sangam

"HIV is what it is. We got it. We deal with it. We are women with HIV. We support each other."

Positive Women Network's fourth Aboriginal Women's Wellness Retreat Weekend was held April 5 to 7, following retreats in 2006, 2008 and 2010. These retreats are open to any woman living with HIV in British Columbia who self-identifies as having Aboriginal ancestry.

HIV has a significant impact on indigenous women in Canada, as reflected in the large proportion of PWN members who identify as Aboriginal. Aboriginal women continue to experience the devastating impacts of colonization and ongoing racism. At an Aboriginal Women's Wellness Retreat, women feel welcome and safe, and can learn about or reconnect with traditional practices. The retreat can help foster resilience and promote healing through support, sharing, learning, and spirituality.

This year's retreat was held at Springbrooke Retreat Centre in Langley. A third of the women hadn't attended a PWN wellness retreat before. Another third live outside the Lower Mainland. All participants reported on their evaluations and in follow-up phone calls that they made connections with other women.

The retreat had one workshop that was mandatory (a workshop focusing on HIV, disclosure, and colonization facilitated by Bambie Tait from AIDS Vancouver). The opening and closing circles were also mandatory. These mandatory activities encourage women to connect.

"The best thing about the retreat was being myself. Letting go. Not being judged. Being understood. Learning about myself and culture with other positive women."

The Aboriginal Women's Wellness Retreat Weekend helps women from all over BC to form new connections and to create new informal support networks in their immediate area. One member commented, "The best thing about this weekend was meeting new sisters. I made lifelong friends and it will continue after the retreat." These feelings were echoed by several members.

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Several members said they felt more confident after attending the retreat: "This weekend made me make changes in my thinking. I am going to try to become more open." Upon reflecting on the weekend, another member said, "I know I am a loving caring person and I deserve a life. No more self sabotage. I am a great mom."

In follow-up calls, several members expressed the wish to facilitate a workshop at the next retreat weekend and shared workshop ideas with the retreat coordinator. Since the Aboriginal Women's Wellness Retreat Weekend, there has been a surge of interest in leadership opportunities, peer engagement, and community involvement. Several members who attended the retreat requested applications for various trainings and events.

Some of the weekend workshops incorporated sharing stories about HIV and the effects on individuals' lives. Members reported learning something new about HIV. A few members committed to trying to quit smoking after gaining information at the retreat; several members committed to taking their HIV medications regularly and engaging in regular self-care. Many members expressed learning more about Aboriginal medicines and HIV, as well as aging and HIV, from the various retreat workshops.

Photo by Sangam

"I learned so much about Native culture and actually got to participate in ceremonies."

We were thrilled to have additional staff beyond the PWN support team at the retreat. Verl Ferguson (Morning Star) is a Cree/Beaver elder, reflexologist, and grandmother. She attended the whole weekend and provided cultural teachings as well as facilitated a beading workshop. Christina Chant, nurse educator at the Downtown Community Health Clinic, attended as the retreat nurse.

We were honoured to have Roy Parcels, keeper of the Springbrooke sweat lodge, lead women through a sweat lodge ceremony on Saturday. Eleven women participated in the sweat lodge ceremony, and several women who did not enter the sweat lodge helped make prayer ties and offered support to women inside the lodge. One member commented, "The best thing about the weekend was the sweat. It was powerful and I found a tremendous release and healing has begun." In addition to the sweat lodge ceremony, women were offered cedar brushings throughout the weekend by a PWN member who is an Aboriginal elder. During opening circle, women were led through a smudge ceremony by Verl, the elder.

A dynamic and energetic group of women explored their potential and strengthened their peer connections and connections to their Aboriginal roots. Positive Women's Network plans to offer another Aboriginal women's retreat in the near future.

SCHEDULED RETREAT PROGRAM

Opening circle
HIV and disclosure (Bambie Tait, AIDS Vancouver)
Beading (Verl, elder)
Sweat lodge ceremony (Lodge keeper Roy Parcels)
Healing the spirit: Learning about traditional Aboriginal medicines (member-led workshop)
HIV, women & aging - What you need to know & what you can do (Evelyn, Oak Tree Clinic)
Healing through ceremonies: Learning about traditional Aboriginal ceremonies (member-led workshop)
Partner yoga (member-led workshop)
Essential U: Learning about essential oils (member-led workshop)
Water rock ceremony (member-led workshop)
Closing circle

ON TRACK *with* EVELYN MANN *at*

OAK TREE CLINIC

Janet Madsen

If you're a patient at Oak Tree Clinic, or you've been to any PWN health education events, you've probably met Evelyn Maan. And if you haven't met her in person, you've probably been touched by her work, because as I discovered, she's the hub of lots of things up at Oak Tree Clinic.

Oak Tree Clinic is one of Canada's leading centres providing HIV health care to women and their families. It opened in March 1994 in response to increasing cases of women and children with HIV in BC, and the recognition that women experienced HIV differently than men. It wasn't just the health and medical aspects that were different for women, but emotional and social ones too. That remains true today, and Oak Tree offers comprehensive care in response.

Research on women and HIV was scant when Oak Tree opened. Very few women were involved in research trials, and then as now, there were worries that women might become pregnant while part of studies of drugs that might have negative effects on developing babies.

While knowledge from research using men can be used when caring for women, more women-specific research is needed. We need to know more about how HIV affects women's systems, hormones, and reproductive health.

The Oak Tree Clinic team takes that gap in knowledge seriously—they've been involved in women-focused research for many years.

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Rolling Out Research Studies

Evelyn is the Research Program Manager at the clinic. I asked her what a typical day looks like, and she said there really isn't one. Once she explained the details, I got it.

If you think of a research study as a movie being filmed, Evelyn is the producer behind the scenes making sure that everything is in place so the movie can roll. She makes sure the script is ready—the research proposal is designed, reviewed, and approved. She also makes sure it has the funding it needs to get going. She gives funders reports on how the projects are going at different points in the process. She also figures out what staff will be needed during different stages of the project and decides how the workload should be assigned.

She coordinates the actors—research staff, clinical staff, students, trainees, and study participants. "Keeping people connected and on task is a huge part of my job," she said. Knowing the schedule and people involved in each stage of a project is vital, as it can be years in length.

Evelyn is also in charge of the cameras, or systems for gathering information. They must be well designed and maintained to make sure data are recorded consistently throughout the research. This is essential for researchers to present their final conclusions. See why there's no typical day?

Sharing Research News

Another part of Evelyn's job is community health education. She has come to PWN lunches and retreats many times to give women the latest research news. Her background is in nursing, so she knows all the technical terms of research and medical information. Yet she's conscious that's not the case for everyone and that information can be confusing. She has a way of making complicated information easy to understand and always reassures her audiences that no question is stupid.

At the Canadian Association for HIV Research (CAHR) conference, Evelyn was on the CATIE Learning Institute team, helping to develop the wrap-up summary sessions for all conference attendees. I asked her about the work. She said, "I know it's going to sound lame but I actually enjoy the constant learning." And supporting women to get a better sense of their health is so key. "I love the women," said Evelyn. "They inspire me and keep me reminded why the work is so important."

Just a few of Oak Tree's current studies....

Canadian Pediatric HIV Surveillance Program – Canadian surveillance

Oak Tree Clinic Perinatal Database – BC surveillance

Identifying Unique Risks to Pregnancy in Perinatally Infected HIV+ Women – 23 centre chart review, based in South Carolina

Update on Evaluation of an Emergency Prophylaxis for Prevention of Mother to Child HIV Transmission in BC – program review

A study of an HPV VLP vaccine in HIV+ girls and women – Open label vaccine trial, 20+ CDN centres, CTN study

Vaginal Microbiome Group Initiative, Study 1B – master's student project

Prospective Cohort of HIV and Hepatitis C Coinfected Patients – expansion to cross-Canada study: "If HCV is an OI Why Has HAART Not Improved Liver Disease?" – Montreal-based CTN study

Valacyclovir in Delaying Antiretroviral Treatment Entry – Toronto-based CTN study

Experimental HIV Monitoring Program – CfE-based study

Text Messaging to Support Patients with HIV in BC – Oak Tree texting intervention study

Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) – ON & BC co-based project

HIV & Cancer – chart review with OTC, SPH, & BCCA assessing cancer rates

The new CARMA – cellular aging and HIV co-morbidities in women and children

CARMA-1 – prospective look at HIV+ pregnancies (continuation from "old" CARMA)

CARMA-2 – mitochondrial & telomere studies in a prospective cohort (continuation from "old" CARMA)

§ CARMA OSTEO – prospective observational Oak Tree studies looking longitudinally & cross-sectionally at bone health in HIV+ women

§ CARMA ENDO – prospective observational Oak Tree study looking at prevalence and predictors or endocrinopathies in HIV+ women

CARMA-4B – A provincial database review of long-term health outcomes of HIV-uninfected children born to HIV-infected mothers – BC database review

CARMA-7 – Bone and renal outcomes in HIV-exposed, uninfected infants with perinatal exposure to Tenofovir – prospective observational study

Members' Retreat to Bowen Island

Connect with other HIV+ women! **RELAX!** **Have Fun!** **Be Pampered!**

FRIDAY, SEPTEMBER 20 to SUNDAY, SEPTEMBER 22, 2013

This retreat is open to all HIV+ women living in British Columbia.

It's FREE!
PWN covers all retreat & transportation costs.

Applications will be available in June.
Space is limited so apply early.
Deadline to apply is Friday, July 19, 2013.

For more information, contact us

Positive Women's Network

Email: pwn@pwn.bc.ca

Thanks to our funders ACAP/PHAC and PHSA and our exclusive pharmaceutical sponsor GILEAD

Thank you

Thanks to CARMA, whose support allowed fifteen members and three staff from PWN to attend the Canadian Association of HIV Research conference.

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Challenging HIV.
Changing women's lives.

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