

The Positive Side

A NEWSLETTER FROM POSITIVE WOMEN'S NETWORK | VOLUME 22 NUMBER 3 | SEP OCT NOV DEC 2014

“I AM HERE FOR YOU, AND I AM LISTENING” Women take peer support to the next level

by Melissa Medjuck

A group of women extended their peer support skills in a second level of training, facilitated by PWN support workers Sangam and Melissa from July 2 to 4, 2014.

“I have learned more about what I am capable of, big and small, and that I can be there for someone,” one woman said.

In 2010, PWN ran the first Peer Support Training, and it has been offered every year since. Over 35 women have taken the training. In response to member input, we now offer Peer Support Training Level 2.

Twelve members took the level 2 training - a dynamic and compassionate group of women who offer formal and informal support to other women living with HIV in their communities. With transportation, accommodation, and all other training-related expenses covered, four members who are geographically isolated from the Vancouver-based PWN support programs were able to participate.

Many topics were covered in the three-day training, including active listening, HIV stigma, criminalization of HIV nondisclosure, diet and nutrition, depression, grief and loss, and self-awareness. One participant noted that she “liked how the topics are mixed up but it all comes together for a learned experience.”

A topic that struck many participants was boundaries. After the training, one participant said, “I shared everything I learned about healthy boundaries with my family and plan on trying to follow what I learned in the training about having better boundaries.”

A special thanks to our guest speakers: Michael Vonn, a lawyer with the BC Civil Liberties Association; Jenn Messina, a clinical dietitian from the IDC Clinic at St Paul's Hospital, and Jane Cameron, a trauma counselor from Oak Tree Clinic. The training was generously funded through the Vancouver Foundation.



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WOMEN DEVELOP TIP SHEET ON STIGMA

by Erin Scatter

“I have learned more about taking care of myself and tips on how to cope with stigma.”

One issue tackled in July's peer support training sessions was stigma—“the way shame and blame takes away our honour, self-esteem, and respect as women living with HIV.”

Women said that HIV-related stigma feels like hatred. It makes them feel alone, isolated, and lonely; sad, tearful, and depressed; scared, hopeless, and lost; ashamed, dirty, yucky, and unwanted; and angry “like a volcano erupting.” They described feeling like they had done something wrong and experiencing physical pain, including in their hearts, and bodily shaking.

Based on their experiences, women offered tips on how to cope with stigma to help other women navigating life with HIV.



Tips For Coping With Stigma

Written by women living with HIV for women living with HIV

- **Breathe!** Take several deep inhales and exhales
- **Remember “it will pass”** — the feeling will pass
- **Call a friend, a support worker, a counsellor, or a peer** to talk about how you feel — be open and honest
- **Remember you are worthy of love and respect!** You deserve love and respect
- **Ask an ally** to talk to the person who made you feel stigmatized
- **Contact your local HIV service organization**
- **“Fake it till you make it!”** — Act how you want to feel (e.g., If you want to feel happy, act happy)
- **Educate yourself** about the topic that is making you feel stigmatized
- **Speak out against stigma** and help educate others by volunteering at your local HIV service organization
- **Be quiet and still**
- **Ask someone for a hug**
- **Eat good food**
- **Create a “zen place”** in the corner of your bedroom, and go there! This is a place for you — a sanctuary, a meditation altar, a comfortable place to sit, somewhere you might put a few special items you love (e.g., a stone, a shell, a book)
- **Squeeze a stress ball**
- **Hug a pillow**
- **Use traditional medicines** (e.g., medicinal marijuana, smudge, cedar brushing, sweat)
- **Do self-care and release your feelings** through activities — take a walk, swim, fish, camp, take a hot shower or bath, do beadwork, play a musical instrument, read, watch TV, go shopping, listen to music, take a nap, treat yourself, pamper yourself
- **Do some journalling**
- **Connect with your spirituality** — talk to your Creator, be in nature, pray, meditate
- **Challenge yourself** to do something new

Hoopla

a women's health carnival

Thursday, October 9
10:00 am – 4:00 pm

Heritage Hall
3102 Main Street
Coast Salish Territories
Vancouver, BC

Join us for the hoopla!

Explore interactive learning zones and resource sharing on an array of health-related topics. Also enjoy feature presentations, including Micheal Vonn from the BC Civil Liberties Association, who will talk about what happens to your personal information under BC's eHealth program.

This event is free and open to the public.
Children and all genders welcome.

For more information

www.pwn.bc.ca
pwn@pwn.bc.ca
604-692-3000

Presented by



In partnership with



Funding provided by



**We have funding to cover travel and accommodation costs for members coming from outside the Lower Mainland.
Please contact us if you are interested in attending!**

"WE ARE A SPECIAL FAMILY"

Women create stress-free environment at Skill Development Weekend

by Melissa Medjuck



A dynamic group of women strengthened their connection, communication, and leadership skills over a “stress-free” spring weekend at Loon Lake, British Columbia.

The fourth Skill Development Weekend organized by Positive Women’s Network was held from May 9 to 11, 2014.

The theme for the weekend was freedom from stress. This practice of remaining grounded and focused by repeating the mantra “stress free” became a ritual that the group did several times a day. Saying the words “stress free” in unison brought smiles, laughs, deep breaths, and a sense of calm.

The weekend included a few mandatory workshops, which encouraged engagement with peers and centred on HIV education, self-care, and self-awareness. PWN members facilitated six out of 13 workshops.

“The best thing about the weekend was that I facilitated a workshop, and it was successful. I gained the experience of doing a workshop, and I learned from it,” said one woman.

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Other women felt motivated to try leading a workshop in the future. “After seeing members facilitate workshops, my hope is to be able to do a workshop next time,” said one.

Women enjoyed the array of programming. As one woman put it, “The workshops were very insightful. I liked the helpful examples of setting our boundaries. I learned a lot about women, HIV, and health. The flamenco dance workshop spiced up everything, and the yoga calmed me down!”

All participants reported on the evaluations that they made connections with other women. The group was diverse and included ten participants who identified as having Aboriginal ancestry and seven participants who identified as having African ancestry. One member poignantly stated in her evaluation: “We are a special family.”

The Skill Development Weekend serves as a catalyst, enabling women from all over BC to create informal support networks in their immediate area. As one woman stated, “The weekend taught me that I am not alone. I have some women beside me. I learned that I am [and we are] much bigger than the one part of us that is HIV+.”

Several women also commented on the self-growth and feeling of wholeness they experienced. “The best part of the weekend was connecting to myself,” said one. Another woman said, “I take home with me the feelings of reinvigoration and self-confirmation that I am a worthy and loved individual.”

PWN support workers Melissa and Sangam, along with Yasmin Winsor, an outreach street nurse at the BC Centre for Disease Control, provided support to women throughout the weekend.

This Skill Development Weekend had a 77% attendance rate. Of the 30 members invited to attend, 23 women participated. Reasons for cancelling included work commitments, illness, intimate partner violence, and addiction relapse. Three participants (13%) were attending their first PWN retreat.

In addition, seven participants (30%) came from outside the Lower Mainland. By organizing and covering all the weekend-related expenses, more members who are geographically isolated from the Vancouver-based PWN support programs were able to participate in this memorable weekend.

Positive Women’s Network plans to offer another Skill Development Weekend in the near future.

Workshops

- **Women and HIV (CATIE)**
- **Roll your own beeswax candles (member-led workshop)**
- **Awesome sleep (member-led workshop)**
- **Canoeing and nature walk (Pinnacle Pursuits)**
- **Making memories and storytelling (member-led workshop)**
- **HIV, women, and aging (Nurse Evelyn from Oak Tree Clinic)**
- **Essential U: Aromatherapy oils (member-led workshop)**
- **Hep C treatment options (member-led workshop)**
- **Find your power: Boundary setting**
- **Duende! The spirit of flamenco**
- **Guided meditation (member-led workshop)**
- **Candlelight yoga**
- **Boundaries: The art of self-care**



AIDS CONFERENCE 2014

Issues from Down Under

by Janet Madsen

The 20th International AIDS Conference was held in Melbourne, Australia, from July 20 to 25, 2014. This piece touches on three things: Considering key populations, rethinking the cure, and reducing HIV globally.



Photo: International AIDS Society/Steve Forrest

Considering Key Populations

"If there was a phrase that defined the 20th International AIDS Conference," reported Gus Cairns of AIDS Map, it "was 'key affected populations.'" The World Health Organization's Consolidated Guidelines on HIV Prevention, Treatment and Care for Key Populations were released just before the conference and sparked debate.

Women aren't listed as one of the populations. Alice Welborn of Open Democracy said that there was little mention of women at all in the conference and barely any at the closing. She reported that young women activists spoke up about HIV, reproductive health, and gender inequalities, but she still had "doubts about how much the academics, politicians and policy makers really listened to their messages."

Cairns said that WHO has identified key populations as different from vulnerable populations. Key populations are at risk no matter where they are in the world because of high-risk behaviours. Women have varying levels of human rights in different countries. Yet if you look at the application of laws, social practices, and norms, women continue to have less power and say over

what happens to their bodies and their lives. In a world where sexist laws and societies reign, I'd say women are still at a disadvantage.

Silvia Petretti wrote about the WHO key populations as well: "I find it puzzling that women are excluded from this definition of key populations, as women in some parts of the world represent 60% of those diagnosed with HIV." Gender definitely matters when it comes to HIV prevention globally – the virus hits girls and young women particularly hard. Of the adolescents infected with HIV each day in the world, two-thirds are girls, according to Welborn. Research presented by Dr. Salim Abdool Karim showed that school-age girls in South Africa are becoming infected by older males, not their peers.

Thankfully, the key populations do include sex workers and transgender people. The WHO guidelines recognize that "legal issues, stigma, discrimination and violence pose barriers to HIV services for sex workers" (page 27) and the prevalence of HIV in trans women represents serious vulnerability. There is lots of work still ahead of us in ensuring equal rights and opportunities for girls and women in the fight against HIV risk.

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Read more

Gus Cairns: Of guidelines, targets and resources: the documents that defined the 2014 International AIDS Conference. <http://www.aidsmap.com/Of-guidelines-targets-and-resources-the-documents-that-defined-the-2014-International-AIDS-Conference/page/2895350/>

World Health Organization: Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations (landing page). <http://www.who.int/hiv/pub/guidelines/keypopulations/en/>

Alice Welborn: AIDS and adolescents: denying access to health. <https://www.opendemocracy.net/5050/alice-welbourn/aids-and-adolescents-denying-access-to-health>

Silvia-Petretti: Women who use drugs: resistance and resilience in the face of HIV. <https://www.opendemocracy.net/5050/silvia-petretti/women-who-use-drugs-resistance-and-resilience-in-face-of-hiv>

Notes on Trans women and Sex Workers- World Health Organization: Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations, page 27. http://apps.who.int/iris/bitstream/10665/128048/1/9789241507431_eng.pdf

Rethinking the Cure

Just before the conference began came the news that HIV has rebounded in “the Mississippi Baby,” as young girl in the US is known.

For those who aren’t familiar with her story, she was given intense antiretroviral treatment within 30 hours of birth, and then went off it when her mom lost connection with the health care system. (This is a statement on health care in the US).

When the mom and daughter reappeared in the system, the girl seemed to be free of HIV even though she wasn’t taking HIV drugs. Scientists were amazed, and they were also aware they couldn’t try to duplicate this experiment because it wouldn’t be

right to put anyone at risk of HIV progression.

They have watched her health carefully to see what can be learned. Sadly, HIV has bounced back in the girl and she’s on HIV treatment again.

The co-chairs of the AIDS 2014 conference say that we should be hopeful all the same. Her case, and those of others who are maintaining extremely low levels of the virus, are signs that we can win this war against HIV.

Discussions on the cure were a big part of the conference, and a pre-conference symposium was dedicated to the topic. At one time the idea of a cure was to eliminate HIV completely from the body. The new approach of extreme control may be enough to ensure long and healthy lives for people infected. The process could include a combination of treatment, gene therapy, and “kick and kill.”

Treatments to control the virus and prevent it from taking hold in people who aren’t positive (pre-exposure prophylaxis) are already in use. One of the challenges of treatment is it can’t reach all the HIV that lives in a person’s body. The “kick and kill” approach would activate “sleeping” (latent) HIV and kill it once it is circulating in the immune system.

Cairns described how gene therapy is being explored. If you think of genes as the “recipes” that manage our bodies, adding an ingredient to interact directly with HIV could be significant.

One therapy under consideration is use of an artificial gene to “make a protein fragment that anchors itself to the cell wall and acts as a fusion inhibitor” to HIV. In other words, HIV can’t attach to a cell in the first step of making more copies of itself. It would be different from medications that do this, as it wouldn’t have to be taken all the time but would be part of the body’s function.

In contrast, another gene therapy would aim to keep the latent HIV asleep. Both of these ideas are very early in research, so large clinical trials haven’t taken place. We shall keep our eyes on developments.

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Read more

Françoise Barré-Sinoussi and Sharon Lewin: A proof of concept for an HIV cure exists. Now even our setbacks are useful. <http://www.theguardian.com/commentisfree/2014/jul/21/a-proof-of-concept-for-an-hiv-cure-exists-now-even-our-setbacks-are-useful>

2014 Towards an HIV Cure Symposium 19 & 20 July 2014. <http://www.iasociety.org/Default.aspx?pageld=753>

Liz Highleyman: Setbacks and Progress in the Search for an HIV Cure. <http://betablog.org/setbacks-and-progress-toward-hiv-cure/>

Gus Cairns: Novel techniques probed in cure research. <http://www.aidsmap.com/page/2893348/>

Reducing HIV Around the World

Reducing new HIV infections is the global aim no matter where we live. Doing so relates to other health concerns too—sexual health, reproductive health, housing, financial security, food security and more. In parts of the world where mothers and their infants lack health care, effective birth control is a big concern.

The WHO supports the use of injectable birth control as an economical and functional method. However, there have been questions about whether it increases the risk of HIV transmission. Information presented at the conference suggests it can make women more susceptible to HIV infection. Researchers say couples should be advised to use internal or external condoms in addition to injectable birth control. The costs and access associated with this additional piece will challenge (and frustrate) some, yet putting women at further risk for HIV transmission isn't acceptable.

Dr. Salim Abdool Karim spoke about how to approach epidemic control. By reducing transmission, reducing community viral load levels, and using pre- and post-exposure prophylaxis (prevention), the epidemic can be significantly slowed. These tools already exist although there is no vaccine. To actually put the tools we have into use, there also need to be non-medical changes, such as continued work on stigma and discrimination.

The final word goes to numbers. Remember 3 by 5? That was the goal of getting 3 million people in key countries on HIV treatment by 2005. Well the new numbers are 90/ 90/ 90. That's the United Nation's aim: 90% of all people with HIV aware of their status, 90% of people on treatment, and 90% of those on treatment with lasting viral suppression by the year 2020. This is just one of the pieces that was highlighted in "Ten Things You Should Know From AIDS 2014," posted by AIDS-Free World. It features ten excellent issues that we can all take and run with, from women's reproductive rights to harm reduction. I highly recommend it.

Read more

Roger Pebody: New analysis suggests increased risk of HIV infection for women using contraceptive injections. <http://www.aidsmap.com/page/2894227/>

Keith Alcorn: What is needed to 'step up the pace' on HIV prevention and treatment? <http://www.aidsmap.com/What-is-needed-to-step-up-the-pace-on-HIV-prevention-and-treatment/page/2892723/>

The 3 By 5 Initiative. <http://www.who.int/3by5/publications/documents/isbn9241591129/en/>

Ending the AIDS epidemic: a new target for HIV treatment. <http://www.unaids.org/en/resources/presscentre/featurestories/2014/july/20140720treatment/>

Ten Things You Should Know From AIDS 2014. <http://aidsfreeworld.org/Publications-Multimedia/Articles/AIDS-2014.aspx>

But Wait! There's More

Conference bulletins Day by Day. <http://www.aidsmap.com/aids2014/Conference-bulletins/page/2867295/>

HIV Update on Key Research. <http://www.aidsmap.com/page/2898373/>

AIDS 2014 Coverage from The Body Pro. <http://www.thebodypro.com/content/74725/the-20th-international-aids-conference-aids-2014.html>

CAHR Conference 2014

Report from the Rock

by Janet Madsen

This year's Canadian Association for HIV Research (CAHR) conference was great, according to Bronwyn, PWN Support Program Coordinator. She went to “the Rock” – also known as Newfoundland – to present two PWN posters, one on leadership training and the other on member involvement at PWN. Here are a few highlights from the conference.



Women and Research

May 1 was the launch of the “National Consensus Statement on Women, Trans People and Girls and HIV Research.” The purpose is to influence researchers, decision makers, and policy makers to have a better understanding of women’s issues when approaching research and funding for women and HIV programs. Jaqueline Gahagan, one of the key authors, and other women who had been involved spoke about some of the recommendations. It was noted in the wrap-up to clinical science presentations that women are often underrepresented in studies. How should research focus on involving women in meaningful ways, not just in tokenistic ways, or as subjects?

Bronwyn said a wonderful part of the conference was when long-time advocate Darien Taylor received a Red Ribbon Award. Darien was one of the co-founders of Voices of Positive Women in Toronto and a director at CATIE. She gave a speech about being a research subject more than once and feeling “naked and afraid” in the room at CAHR. She talked about coming out publicly, when so few women could or did. She said it was difficult as an HIV+ woman, being exposed, especially in the room full of researchers, and what they know about her. She said she knows the research is so important, but being a subject still makes her vulnerable and uncomfortable. She has given so much of herself to the HIV community, and it is fantastic her bravery and commitment were recognized.

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Read the National Consensus Statement on Women, Trans People and Girls and HIV Research: <http://www.cfar.emory.edu/downloads/news/2014/NationalConsensusStatementEnglishV10.pdf>

Read about Darien's Red Ribbon Award" <http://www.cahr-acrv.ca/darien-taylor-2014-red-ribbon-award-winner/>

Science and Advocacy

In the opening plenary on May 1, Richard Elliott from the Canadian HIV/AIDS Legal Network spoke on "Evidence + Principle: Science and scientists as critical enablers of human rights and public health." He said it's vital that scientists work alongside advocates, and scientists work as advocates. He thinks that governmental policies may actually be making the epidemic worse, using criminalization, the war on drugs, and ongoing stigma as examples. He cited a stat from UNAIDS that "every hour 50 young women are newly infected with HIV".

The idea that the world is moving toward the "end of AIDS" is one he doesn't believe is true, but it can be used as justification to stop working against the roadblocks that still exist. HIV criminalization in Canada is contrary to international recommendations. There has been a huge failure in the war on drugs. Scientific research shows that harm reduction works, yet the federal government does not support it.

Dr. Mark Tyndall talked about the role of scientists in advocacy too. He was one of the authors of the Canadian consensus statement on HIV and its transmission in the context of criminal law, which was signed by over 70 scientists. The statement says that "HIV physicians and scientists have a professional and ethical responsibility to assist those in the criminal justice system to understand and interpret the science regarding HIV." In specific cases, the chance of HIV transmission is low to no possibility, depending on a person's viral load and treatment adherence. Tyndall and his fellow scientists recognize that this goes against the public health messaging of "safe sex for everyone at all times," but say that a courtroom trying one person's circumstances is very different than a safer sex message for a general audience we are trying to protect.

Read more about Richard's presentation: <http://www.cahr-acrv.ca/cahr2014-mark-wainberg-lecture-press-release/>

Read the Canadian consensus statement on HIV and its transmission in the context of criminal law <http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=3&atlKy=12838&isuKy=1160&isArt=t&romfold=In-Press>

Connecting Women

There was good interest in our posters. One presented the results of our 2013 membership survey on how positive women connect and engage with PWN, showing which programs were important for members and emphasizing the importance of peer support. The other poster described our positive women's leadership training, a project conducted in partnership with the Pacific AIDS Network and Status of Women Canada.

There was also great stuff on community-based research and involvement of peer research associates, which is happening more and more. Dr. Angela Kaida and Allie Carter presented on what's happening with the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS). The focus of CHIWOS is the social factors such as poverty, marginalization, violence, and gender inequity that limit how women with HIV are able to access care.

See the posters:

<http://pwn.bc.ca/wp-content/uploads/2014/05/CAHR-2014-poster-Positive-Womens-Leadership-Training-e-display.pdf>

<http://pwn.bc.ca/wp-content/uploads/2014/05/CAHR-2014-poster-Engaging-Positive-Womens-Voices-in-HIV-Services-member-engagement-survey-results-e-display.pdf>

Read about CHIWOS: <http://www.chiwos.ca/home/>

Next year's conference will hit Toronto April 30 to May 3. Learn more: <http://www.cahr-acrv.ca/conference/>

Events and Announcements



Change in the air at PWN

Long-term executive director of Positive Women's Network Marcie Summers will retire in May 2015 after providing leadership here and across the country for 22 years. PWN is one of the only women-specific HIV service organizations in the country and contributes to many national organizations. Marcie's work establishing the organization and making positive women's issues heard at national and international tables has been vital.

The PWN Board of Directors is establishing a Transition Committee to lead the search for a new executive director. There will be no changes to support services or health promotion programs during this time. The committee will include Marcie, two staff members, current and past PWN board members, and PWN member representatives, with possible representation from one or two partner organizations.

The Transition Committee will do the following:

- Commission an organizational assessment through an external consultant
- Review and post the job description
- Interview prospective candidates and hire the new executive director

The committee will start in September 2014. If you have any questions or would like further information, please contact the PWN board at pwnboard@pwn.bc.ca. Information will be available as we go through the process. Feel free to ask!

Lunch 'n' Learn

Tuesday, September 23

Dr. Mary Kestler from Oak Tree Clinic will talk about "Aging with Grace: What positive women need to know about menopause and beyond."

Tuesday, October 28

Evelyn Maan from Oak Tree Clinic will also do a presentation. Topic to be announced.

Sponsored by Merck.

Celebrate the 30th birthday of the AIDS Walk

Funds raised through the AIDS Walk enable Positive Women's Network to maintain two portable housing subsidies for PWN members. Last year we raised over \$14,000. We hope to match or increase last year's number through the efforts of our 2014 Team of Walkers.



This year, an overarching poverty relief program has been identified as a priority issue for women living with HIV. This program includes not only affordable housing, but also groceries, hot lunches, child care subsidies, toiletries, transportation, and other items that will help alleviate poverty.

If you'd like to walk with PWN, please contact our office for registration instructions to ensure you are part of our team: 604-692-3000 or pwn@pwn.bc.ca.

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 Positive Women's Network
You Should Know

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@YouShouldKnowCA



Challenging HIV.

Changing women's lives.

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support

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Sangam | Support Worker/Educator


Melissa Medjuck | Support Worker/Retreat Coordinator

Valerie Van Cleef | Support and Outreach Worker


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 **MERCK** Supports educational opportunities.

 **RBC** Sponsors our Peer Mentorship Training.

 **KINGSLY STREET FOUNDATION** Contributes to our portable housing subsidies and food program.

 **SHOPPERS DRUG MART** Funds our Empowerment Retreat.

 **vancouver foundation** Supports our Peer Mentorship Program.

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