

The Positive Side

A NEWSLETTER FROM POSITIVE WOMEN'S NETWORK | VOLUME 23 NUMBER 2 | MAY-AUGUST 2015

ON THE BIG SCREEN



Heidi and Joella after their win.

by Erin Seatter

Leaf of Faith, a short video produced through a partnership between Positive Women's Network and film maker Joella Cabalu, won the Play it Forward competition on March 21.

Cineworks organizes the contest to bring together creative and non-profit communities in Metro Vancouver. Ten film makers and ten non-profits were paired to make a video intended to capture the spirit of each organization. The videos were screened at the Cinematheque, where audience members voted for their favourite.

Challenging perceptions

When talking to support worker Bronwyn Barrett at a Cineworks meet-and-greet event, Joella learned about the impact of HIV on women and became interested in working with PWN.

"I think a common perception is that HIV-positive people are gay men, sex workers, and drug addicts," says Joella. "I was surprised to learn that women were also a vulnerable population."

Continued on page 2

Contents

HIV & ME	
Twenty years of choices	4
Beauty Night	7
A HOT TOPIC	
Menopause and HIV	8
Microbicide research shows care and support gaps	9
RUBY AND KELSEY SAY GOOD-BYE	
What I learned from my practicum	10
Events and announcements	11



Heidi and Carrie at the screening

“In that first meeting, my own perceptions were challenged, I learned more deeply about the issue, and I wanted to share that challenge with viewers. Hence, the aim of the video was to challenge people’s perceptions of HIV and reflect on the stigma associated with it.”

Leap of Faith features Heidi, a PWN member who learned she had HIV at the age of 24. The video opens with footage of her bungee jumping almost two decades ago after her diagnosis.

“When someone tells you you’re not going to live or you have a limited amount of time left in your life, for myself, I end up pushing things to the limit, to the edge,” she explains in the video. “Because I kind of feel you have nothing to lose.”

Heidi describes coming to terms with having HIV, connecting with other women living with HIV through PWN, and finally opening up about her status in an email to family and friends last year. “I

got showered in love and support and blessings from people that made up for all the stigma and rejection I came across in my past,” she says tearfully.

Re-creating safe space on set

Carrie is a PWN member who met Heidi at a wellness retreat, where the two became fast friends. She appears alongside Heidi in the video.

“PWN is a place for all HIV+ women. This is where I met Heidi,” says Carrie. “It has been a real honour just to be asked to be a part of Heidi’s journey and the *Leap of Faith* film.”

“For approximately 20 years I have been one of the lucky ones and benefitted from this wonderful organization. PWN is the one and only group to provide a safe women’s space for luncheons and

retreats for positive women. These are only a couple of the things PWN does for HIV+ women.”

Joella understood the importance of mirroring PWN’s safe space when making the video.

“I felt honoured to be the conduit in sharing Heidi’s powerful story. With this responsibility entrusted to me, I endeavoured to create a safe space for Heidi when we filmed her interview by having an all-women crew on set.”

“The experience in making *Leap of Faith* with PWN and Heidi was collaborative and meaningful,” says Joella.

For Bronwyn, working on the film “was a departure from what I usually do in my day-to-day work at PWN and an amazing learning experience.”

“This is a memory I will never ever forget,” says Carrie. “Thank you Heidi for taking the leap. You handled this with such class, dignity and grace. “

Continued on page 3

Reaching hearts

When Heidi attended the screening, she didn't expect the video to win. "I was so touched by and surprised that we came in first place," she says. "I'm pleased the piece was so well received by the audience to bring awareness and attention to a very important organization, Positive Women's Network, and Joella, the director, and her many talents."

"One of the main reasons for doing this was to bring attention to the stigma that still surrounds HIV. Looks like we hit it bang on!"

Carrie echoed this sentiment, saying her hope is that "such an important project" will "educate people on the subject of HIV."

It looks like the video is already doing its work. According to Joella, "one of the most touching comments from a viewer is that they connected with Heidi on a human level, when she talks about her struggle about disclosing her status and the tough negotiations associated with it."

PWN and others will be able to use the video to help support other women living with HIV. Commending Carrie and Heidi for their bravery, Bronwyn notes that she "was so impressed with Heidi's grace and strength in answering such difficult questions in front of the camera. Taking this leap will surely inspire others who are struggling with their own issues of stigma and disclosure."

She added that "it's wonderful for PWN to have this little gem of a film to share with the larger community, potential funders, and newly diagnosed HIV+ women in particular."

The experience also had an impact for Heidi. "I have experienced rejection firsthand numerous times because of my HIV status, so taking this leap has been scary at times but I felt I was ready. It has been well worth all the rewards I've encountered."

She decided to follow up on her HIV disclosure email by sending a second one to friends and family about the video. "I wished to share with them all how their support helped me be able to come forward to do this clip."

Thank you to those who helped make the film!

JOELLA CABALU director

ANGELINA CANTADA cinematographer & sound

BRONWYN BARRETT production coordinator

CLAIRE INGLIS production assistant

SHANNAN LOUIS editor

MARC STOCKLE composer

CINEWORKS executive producer

TELUS funder of the Play it Forward campaign

**And most of all
CARRIE and HEIDI for their courage**

People responded with excitement and stories of sharing the video with others.

"I didn't realize that people would be passing it on to their friends and family," says Heidi. "It's the ripple effect."

"Another dear friend, the brother I never had, shared it with his kids and spoke of the friendship we've had for the last 19 years, me being the sister he never had, and explained how me having HIV doesn't mean he loves me any less."

"I took this opportunity and ran with it and I'm so pleased that I did. I've helped create awareness for all of us HIV+ women and put another perspective into the minds of the mainstream, following in the footsteps of many women before me who have helped me build my courage."

You can view Leap of Faith on the PWN website: pwn.bc.ca/hiv-community/hiv-me/leap-of-faith

20 YEARS OF CHOICES

by Tracy

This reflection was written on January 19, 2015.



Twenty years ago today, January 19, 1995, I was diagnosed with full-blown AIDS. It was a life-changing event.

Well more like an earth-shattering time. One second I was a normal, active 31-year-old business owner, and the next second I was thrown into a whole new world, so sick and expected to die within a year, unable to continue my horse training career.

It had been quite the emotional and health roller coaster for many years after that fateful day, on many different levels. Dealing with a diagnosis I never saw coming and the physical health issues was one aspect. Another aspect was the stigma

around HIV/AIDS, which led me to shutting down my social circles and withdrawing from society except for family and my closest and most trusted friends. The emotional aspect was huge, especially the significant decrease to my self-confidence and esteem. How I felt about myself was at an all-time low and stayed that way for many years.

Presently, my health is stable and I love my life! I have gone from a CD4 count of 31 upon diagnosis, with 11 being my lowest count, to between 400

Continued on page 5

and 600 on average, with a new high record of 749 last year. To put it in perspective, a normal healthy person has a CD4 count of between 1,000 and 1,500. I have gone from having a permanent chest tube to being "tubeless" over the years. Even though the capacity of my left lung is about 10%, I choose to still be active, dancing, riding, and pushing my endurance limits.

I have gone from being so weak that a shower wore me out, only being able to bench press 3 pounds, and needing a mounting block to mount a horse to now being much stronger and building a house, mounting a horse from the ground, and being able to walk all around Cross Iron Mills Mall and still go home and do other activities. The line "You have come a long way, baby" comes to mind! When I look back and reflect on the past 20 years, I have come to realize that choices are really the central theme.

This includes the choice I made to not use condoms because I was on the birth control pill when engaged to the man who infected me. All I worried about at the time was getting pregnant. Getting HIV didn't cross my mind. The choice was mine to not be more informed and protected.

Then all the choices I made after my diagnosis—first, accepting the diagnosis, especially with being so unlikely to have been infected. Then choosing to live or die, to fight or give up. As you know, I did choose to live and fight, despite being sent home on palliative orders after my second year in the hospital. I did choose to never give up, no matter how bleak and dark the days were.

I chose to never miss a dose of my 20+ pills per day. Even when one of those medications was available only in a liquid form and tasted so awful. I called it the "vile, liquid, putrid shit." I used to mix it with orange juice to get the crap down, and to this day I can't drink orange juice.

I had to choose who to tell about my condition. With the stigma I perceived and fear of rejection I felt, it was a difficult choice every time I considered informing someone. I have no regrets informing the people in my life and have only ever been rejected once. The list of people I've disclosed to remains relatively short to this day, a choice I may change in the future.

I did choose to open my heart and love again.

With new research and improved medication, combined with my choices, I slowly improved and got stronger. Then, the course of HIV changed due to many breakthroughs, and it was no longer a death sentence. I would live. I would live longer than first anticipated. I may actually live to my full life expectancy. Now I had to choose how I was going to live.

I slowly got myself involved with people and other groups, including HIV support groups. I even founded and facilitated a support group for heterosexuals living with HIV and was able to help others out. I became a board member for AIDS Calgary, again contributing but also slowly increasing my self-confidence.

With the change to my health, my marriage also changed. After much deliberation, I finally chose to divorce my husband, and embarked on another chapter. I entered the workforce again, made new friends, and became more socially involved.

I did choose to open my heart and love again. I had felt that HIV prevented me from being loved again, and Alan worked hard to prove it otherwise. I have remarried and feel so lucky to love and be loved by Alan. He is such a good man, who is so supportive and has brought much to my life!

Continued on page 6

I will continue to live my life with choices at the forefront of my mind.

I remember how devastating the loss of a country lifestyle was to me 20 years ago, but I had chosen to accept what I couldn't change and adapted to city life. With my new life with Alan, we both chose to buy property in the country and build our dream life. A life of sustainability filled with animals, including horses, dogs, cats, chickens, and other livestock planned for the future.

We chose to do the building ourselves. This is a huge project and seems never ending at times, but the sense of accomplishment makes all the choices so worthwhile. I have increased my strength, plus expanded my knowledge and skills, including how to use many power tools, my favourites now being the chop saw and most recently a router.

I remember being so devastated at having to close my thriving business as a horse trainer and instructor. I felt cheated in many ways, but I had to remind myself of my choices all those years before. Now, I made the choice to utilize our property and operate a small horse-boarding facility with some lessons and horse training added in plus my judging.

I also develop websites, a skill I developed when left so weak after numerous serious health issues. I chose that watching daytime TV was not for me but I could be useful and contribute to society using computers so I learned HTML. I have since expanded my knowledge and skills, joined various networking groups, and now have a thriving business!

I know I am disgusted by my body image, caused by lipodystrophy. This is a fat redistribution condition caused by certain HIV medications. It has stripped the fat off of my face, arms, and legs and put it all on my trunk. I have "cheek envy," having lost the fat pads of my cheeks now. I also hate this huge belly, which makes me look like I have had six kids. Then I remind myself that no matter how I look, I am alive and I choose to be grateful for that!

I am the healthiest, strongest, and happiest I've been since that fateful day 20 years ago. Twenty years of choices—some that I would do differently if given the opportunity, but most have been good choices, some even great choices, and I choose to have no regrets.

I will continue to live my life with choices at the forefront of my mind. How will I live today? What will be my attitude today? What will I do with my time today? How will I make the most of the time I have? How will I contribute? What will I do to make a difference?

So many choices, but one important lesson is that there is always a choice, no matter how dark and devastating life seems to be. My hands are firmly on the steering wheel of my life, and it is certainly my choices that will continue to drive the direction my life takes, and how everything unfolds as I continue down this road.

To many years of more choices, and continuing good health and happiness!



by Ruby Bissett and Kelsey Haerberle

On the evening of April 8, Positive Women's Network hosted a Beauty Night for members. Women came together, kicked back, and practised self-care in a safe and supportive environment.

Organized by practicum students Kelsey and Ruby, the evening was conceptualized in the spirit of PWN's famous wellness retreats, as a way for women to take a break from their often hectic and stressful lives and indulge in a little tender loving care.

Sixteen women in attendance (plus volunteers and staff) got to choose to have massages, manicures, pedicures, and haircuts, as well as do some card making and art therapy. The massages were especially popular.

The feedback from attendees was overwhelmingly positive, with women expressing how much a night like this helped with their self-esteem and feelings of belonging in community. Much of the feedback we received showed that many of the women who attended realized that they do not spend enough time on self-care, but that when they do it greatly helps with their mental health and sense of well-being.

The women who attended beauty night enjoyed the fun times, feeling of unity and camaraderie,

and the calming atmosphere. The main suggestion for improvement was to have longer sessions. All suggestions received from the evaluations will be taken into consideration for the next beauty event.

We would like to extend our sincerest thanks to Beauty Night Society for helping us out with this event; the six wonderful volunteers who came to lend a hand; Melissa and Sangam for staffing the event; and last but not least, the women who participated in Beauty Night. We can't wait for next time!

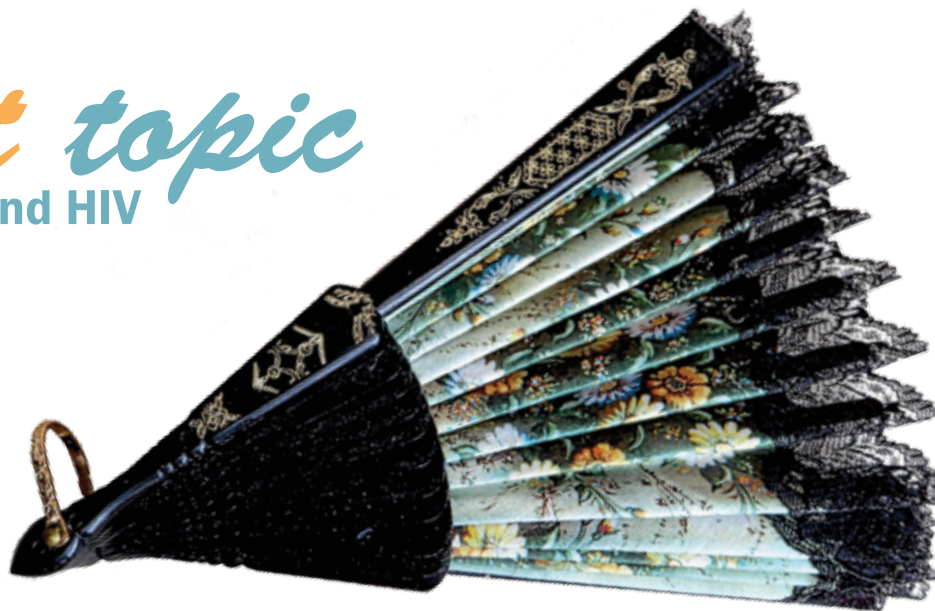
What women had to say

- **It helped me get out of my apartment and relax in a safe place with ladies I know.**
- **I got to reconnect with other women.**
- **It is OK to be myself and grow in a community.**
- **It was nice to take a "me" break. I need to do this more often because I deserve it.**
- **It reminded me to be kind to myself and that I am beautiful.**

a hot topic

Menopause and HIV

by Kelsey Haeberle



In the afternoon of March 11, Positive Women's Network hosted a workshop on menopause, facilitated by a few of the energetic and passionate staff of Oak Tree Clinic. Many beautiful PWN members attended the workshop. All were interested and eager to learn more about HIV and menopause.

Menopausal changes begin when the ovaries (reproductive organs containing eggs) naturally begin to slow down the production of sex hormones, including estrogen and progesterone.

The workshop covered different subjects related to the overall well-being of women living with HIV and experiencing menopause. These included early onset menopause and the use of complementary therapies to alleviate symptoms.

Due to widespread use of highly active antiretroviral therapy, women with HIV are living longer and healthier lives, which means they are reaching menopause.

Dr. Mary Kestler of Oak Tree Clinic answered the question, "Will I go through menopause at a younger age because of my HIV?" She explained that menstrual bleeding does generally end sooner for women living with HIV; however, it may not actually be the onset of menopause that stops the

Some symptoms of menopause

- hot flashes
- night sweats
- mood swings
- increasingly irregular periods
- fatigue (extreme tiredness)

bleeding. Many other life factors play a role, such as addictions and eating habits.

Dr. Kestler conveyed that the average age a woman goes through menopause is around 51. The average age for women living with HIV is around 47.

Complementary therapies aim to treat the whole person and not just the symptoms of a disease. Yoga, reiki, and meditation can treat menopausal symptoms. It is important to remember to consult with your doctor about what treatments you are trying. Some therapies may have unwanted side effects or interact with HIV drugs, such as traditional Chinese medicine (acupuncture, Chinese herbs) and herbal supplements (ginseng, St. John's wort).

Overall, the workshop was informative and sparked great conversations on healthy living and menopause.

MICROBICIDE RESEARCH SHOWS CARE AND SUPPORT GAPS



by Ruby Bissett

A new form of HIV prevention is making waves in the world of HIV treatment and prevention, but not entirely for the reasons one might hope.

Microbicides are substances that can be inserted vaginally to reduce the transmission of various sexually transmitted infections, including HIV.

In one study, microbicides containing the antiretroviral Tenofovir were found to be 39% effective in preventing HIV transmission, when used in an “event-based” manner, that is, used before intercourse. Two other studies, known as VOICE and FACTS, didn’t produce the results researchers were hoping for; they were not able to conclusively report on whether the microbicide was effective.

Why the difference?

The major factor found in all studies that accounted for the disappointing results was adherence levels. The majority of participants seemed to want to be part of the studies, but didn’t actually use the microbicides as directed.

In the VOICE study, the major difference between actual adherence and reported adherence was due to a desire to stay in the study for the benefits

provided, such as pregnancy and HIV testing, medical monitoring, and the honoraria money. This certainly points to a need for greater access to reproductive health services for women in the areas this study was conducted.

But what is more concerning is that some women reported that they were hesitant to use the microbicide because it would associate them with HIV.

How to increase adherence?

In the recent FACTS study, there was a marginal improvement in the disparity between women’s self-reports that they were using the microbicide and the actual levels of Tenofovir detected in their bodies.

This improvement has been attributed to greater support and education efforts for participants. As a result many participants who did adhere to the instructions reported that they felt like they were doing something that mattered.

The general takeaway from these studies is that for microbicides to be effective, participants should be provided with education and support. Otherwise they will likely feel wary of the microbicide’s usefulness or afraid of being stigmatized for being associated with HIV.

WHAT I LEARNED FROM MY PRACTICUM

by Ruby Bissett

“I want to thank all the members at PWN for being so welcoming to me over the past seven months.”

As some of you know (but many of you likely don't) I'm a third-year social work student at the University of British Columbia, and for the past seven months I have been doing my practicum at PWN.

From day one of social work school, the major lesson our professors, colleagues, and mentors drill into us is that in social work, relationships are the foundation of everything.

I could be the most well-intentioned, intelligent, and forward-thinking social worker, but without a solid relationship based on trust and mutual respect with the people I'm working with, there's no way I will be effective.

This has always made sense to me, but I was never entirely clear on how it would play out until I spent a few months at PWN. Now, if you ask me what the best part of my practicum has been, I will enthusiastically say that the best part is you—the members.

Getting to know the women who come to PWN has been an amazing experience for me. I feel so fortunate that you have trusted me and shared your lives with me. Not only have I made some wonderful connections, but the women at PWN have taught me great lessons that I will carry forward into my career for years to come—lessons that no professor or textbook could ever hope to teach me.

I have learned, above all, to have patience and compassion, not only for others, but for myself.

I want to thank all the members at PWN for being so welcoming to me over the past seven months. To the staff at PWN, thank you for being patient with me, supporting me, and sharing your expertise with me. To Kelsey (my counterpart), thanks for always being on the same page as me (and not being afraid to tell me when you're not!)

Certainly not least, to Melissa, thank you for facilitating my learning and my growth as a student and social worker, and for always being supportive and receptive to my concerns and needs while never coddling me or allowing me to do any less than my full potential. I am so humbled and so grateful, and will carry this experience with me for the rest of my life.

by Kelsey Haeberle

I came into PWN not knowing what to expect from my practicum since my knowledge of HIV was very limited. I was unsure of how HIV was transmitted and of the varying effects it has on individuals living with it.

The knowledge that I have gained from not only the staff, but also the members of PWN has allowed me to have open dialogue with family, friends, and acquaintances. We have discussed subjects that are not well known to the general public such as the transmission process, the challenges of living with HIV, and the resilience of the women who attend PWN.

I have thoroughly enjoyed coming in every week and seeing the smiling and friendly faces of the members and staff of PWN. The spirit of PWN is very uplifting and light, and the atmosphere is one

in which many can relax and feel safe.

This practicum experience has made me aware of how important it is for services to have a welcoming ambience for members to feel comfortable in. PWN has taught me the importance of feeling safe within a service agency and has reinforced the importance of building strong relationships with clients throughout my social work career.

PWN has given me many tools to establish what I believe to be a positive relationship with my clients and a strength-based approach by meeting individuals where they are at.

I honour the relationships that I have built through PWN and will assuredly miss each and every person that I have come in contact with during the course of my eight-month practicum.

Events and announcements

Kamloops: HIV and hepatitis C co-infection workshop for service providers

Both HIV and HCV are stigmatized illnesses with an overlap of populations that are infected and affected. HIV has a higher profile so there is a tendency to downplay the seriousness of HCV infection.

This workshop is intended to raise basic awareness of the hepatitis C virus (HCV) and HIV biology in the context of co-infection, including transmission, testing, disease progression and treatment. It will assist frontline service providers to help clients address dual diagnosis, dual stigma and maintenance of good health while living with co-infection.

Friday, May 8, 10 a.m. to 3 p.m.
Royal Inland Hospital, Conference Room 1
311 Columbia Street, Kamloops, BC

Presented by staff from CATIE and Positive Women's Network.

To register for this event, please email lisa.deol-rollo@interiorhealth.ca

SpringBoard conference

SpringBoard is an intimate half-day event that includes lunch and sessions related to the lives of women with HIV.

Thursday, May 21, 11 a.m. to 3 p.m.
Blue Horizon Hotel
1225 Robson Street, Vancouver, BC

- Elle Pea and Evelyn Maan will present on growing up with HIV. Elle has had HIV since she was a kid, and she now has a child of her own. Evelyn works at Oak Tree Clinic and will share some of the research on adults who were exposed to antiretrovirals and HIV in utero.
- Marnie Goldenberg (the Sexplainer) covers the topics the kids in our lives need: sexuality, health, and sex-positive relationships. Need some tips on talking with kids? Marnie will have them!
- Jessica St. Jean and Sarah Chown from YouthCO will talk about decolonizing work in the HIV and sexual health sectors, so we can build spaces and narratives that support and value indigenous youth experiences.

Please contact us to register for this free event. A limited number of travel subsidies are available for out-of-town members.

2015 PEER SUPPORT GROUP DATES

PWN (for Aboriginal women) 11:30 a.m. - 1:30 pm	Vancouver Women's Health Collective 5-7 pm	Oak Tree Clinic 11-1 pm	Positive Haven 1:30-3:30 pm
May 15	May 20	May 22	May 25
June 5	June 17	June 19	June 22
July 17	July 22	July 24	July 27
Aug. 14	Aug. 19	Aug. 21	Aug. 24
Sep. 11	Sep. 16	Sep. 18	Sep. 21

All group meetings include lunch or dinner.

For child care or more information, call Jane Cameron at Oak Tree Clinic: 604-875-3755.

Positive Women’s Network

address 614-1033 Davie Street
Vancouver, BC V6E 1M7


phone 604.692.3000
toll-free in BC 1.866.692.3001

email pwn@pwn.bc.ca

hours office Monday to Friday 9:00 to 4:00
drop-in Monday to Thursday 11:30 to 3:30

online www.pwn.bc.ca

 Positive Women’s Network
You Should Know

 @PWN_BC
@YouShouldKnowCA



Challenging HIV.

Changing women’s lives.

administration

Marcie Summers | Executive Director

Donna Tennant | Director of Development

Nancy Hoo | Bookkeeper

Aretha Munro & Monique Desroches |
Administrative Coordinators

health promotion

Janet Madsen | Communications Coordinator

Erin Seatter | Resource Coordinator

support

Bronwyn Barrett | Support Program Coordinator

Sangam | Support Worker/Educator


Melissa Medjuck | Support Worker/Retreat Coordinator

Valerie Van Cleef | Support and Outreach Worker


CONNECT WITH US


Thanks to our supporters!

The work of Positive Women’s Network is made possible through generous support from individual givers, in-kind donors, and grants from the Provincial Health Services Authority of BC, the Public Health Agency of Canada, and BC Gaming, as well as the following supporters.


 **abbvie** The exclusive pharmaceutical sponsor of SpringBoard.


 **GILEAD** Supports educational workshops

 **janssen** Sponsors lunch learning opportunities.


 **MAC AIDS FUND** Contributes to our support and outreach programs.


 **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.

 **ViiV Healthcare** Funder for our women’s health carnival.

DISCLAIMER

The information herein cannot replace information provided by a medical or legal professional. In using this material, the user acknowledges these limitations and does not hold Positive Women’s Network or its funders liable for any damages, costs, or consequences that may result.