

# The Positive Side

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## What do PEER RESEARCHERS need to excel?

Janet Madsen

I recently went to a café scientifique (a panel of speakers and discussion) called “Employing Peer-Based Research Associates: Are We Providing Enough Support?” Five speakers presented their experiences on peer-based research projects. Three self-disclosed peer research associates – Chuck, Jonathan, and Shelly – and two lead investigators – Dr. Angela Kaida and Surita Parashar – were on the panel. The discussion covered a lot of ground, from individual motivation for peer-based work to policy and guideline development.

### Motivation

An HIV diagnosis means a shift in direction for most people. Even those who live in highly affected populations like the gay community have personal changes to absorb. Thankfully for those in the big city, there are good doctors and social service supports out there to help with the transition. (The speakers work in the city so didn’t address being a peer research associate in an outlying or less urban area, which I’m sure has additional challenges).

Once people have regained some balance in living with HIV, they often want to give back to the community that’s supported them. Chuck said this is why he wanted to get involved. He feels one of the strengths of community-based

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research is the many ways people can be involved. One person will thrive on an advisory committee, another as an interviewer or group facilitator, and still another at presenting the research results. There are lots of ways to give back and make a difference.

## Building a Project

Dr. Angela Kaida is one of the principal investigators in CHIWOS: the Canadian HIV Women's Sexual and Reproductive Health Cohort Study. CHIWOS is looking at how women with HIV in Canada access health care and social services and where improvements can be made. Angela said positive women play a central part in the work, for "women are underrepresented in research and women are underrepresented in leading research."

CHIWOS has a team of peer research associates to do one-on-one in-depth interviews. Angela spoke about barriers women face in even considering getting involved as a peer research associate, including how far a woman has disclosed her HIV status in her world, her level of job skills, whether she is actively using drugs, whether she has basic supports such as housing and food security to enable her to dedicate time to the work. For peer research associates in community-based research, Angela said the bulk of the work is in helping people learn to see themselves differently. She talked about the transition from individual with HIV to "steward of research."

Jonathan talked about how fast things can change when getting involved in peer research. He went from being a bartender to being a research associate in a year. He's learned some important lessons. Peer research associates "don't have to know everything," he pointed out, acknowledging they can feel that pressure. There's also a real need to develop standards of employment for peer research associates that address differences in what projects pay, how people get paid, and benefits of the job.

This changing of roles prompted a lot of discussion. When individuals shift from community members to community representatives in the role of peer research associate, they must become more aware of the impact of their actions, as people will see them differently. And if peer research associates are involved in various community projects, each requiring confidentiality, where do they go to debrief? Or

what happens if peer research associates talk about their personal viewpoints and possibly bias research or someone's access to care and support?

Everyone acknowledged there is fine-tuning to do. Straddling personal and professional lives is difficult. Peer research associates will hear other people's stories. Surita, who was the lead in a photo voice project called "The Way I See It," described the process of interviewing people with trauma like "pulling off scabs" for peers with their own histories. She stressed that researchers can't expect peers to absorb this as "just part of the job."

## Creating Support

All three peer research associates emphasized the need to build outside emotional support into projects. Chuck suggested knowing who to go to when you need an ear to listen before you start a project or job.

Shelly talked about challenges in figuring out the balance between personal and professional support and summed up with three points: support, boundaries, and peer crisis. She acknowledged her "personal lens," then talked about personal and professional differences. She said working in the HIV community as a paid staff person meant changes to her relationship to supports in the community. Figuring out how to get support when needed – and it will be needed – is part of the job.

If peer research associates are in crisis, they can't always be honest about it, because they feel they can't take off their "work hat." This is why it's so important to have stuff in place before a crisis hits. Shelly was very clear that peer research associates should be willing to work on themselves. "Going through mental health work is part of a peer research associate's responsibility. It's ethical," she said.

Everyone involved in peer research must be aware that all parts of it require a lot of thought. What do people need to do before, during, and after their involvement to stay healthy and get help when they need it? How do we support the work of peer researchers without asking unreasonable things of them? No one should be expected to be on call all the time, but it can feel that way for some. How do we create a balance between individual and worker? What kind of standards are needed to support the research and the researchers? Perfect answers aren't there yet. But as shown by the forum, the community is committed to finding them.



## NO SHAME, NO BLAME – JUST HELP

Janet Madsen

### **Tight. Closed. Trapped.**

Do any of those words describe you? What about shamed, blamed, or guilty? These can be painful and heavy sensations, and many women live with them. They might not be intense every day, but they play a part in how you see yourself. They influence the choices you make and what you think you deserve.

There are lots of reasons why women feel caught and cornered. Although we come from different communities, there is a common thread that runs through them; often we are blamed for our pain and troubles, as if simply being female is the reason women suffer. A woman who is sexually assaulted was wearing the “wrong” thing or was in the “wrong” place. A woman who is sexually abused somehow “made” her abuser do it because he couldn’t help himself. A woman who is bullied or beaten by her partner isn’t doing the “right” thing to keep her partner happy. A woman who speaks up about being harassed “doesn’t have a sense of humour.” A woman who turns to drugs or alcohol to ease her pain “isn’t strong enough.”

Too often, we absorb the blame as truth. It soaks into us, making us feel poisoned and poisonous. It makes us feel we aren’t worthy of caring friends or loving relationships.

But we are.

If these situations or feelings describe you, do you have somewhere to dump them when they get too heavy, or someone to talk to who can help lighten the load? You don’t need a heavy load on top of HIV, which is complicated enough. There’s a lot to learn about the virus and how it affects the body, about taking treatment and how to take it, about how and when to tell people you have HIV. Living with HIV shouldn’t add to shame, but for many women it does.

At Positive Women’s Network (PWN) we don’t want women to feel burdened with shame about their HIV status or other pieces of their lives that cause pain. Come in as you are—you’re welcome. When you connect with us, you can talk to a support worker about what you want and need. You may decide that it would help to talk with someone about what’s going on in your life.

One of the PWN support workers can meet with you if you are in a crisis situation. She can help you find medical care, a safe house, treatment possibilities, or help you decide on the next step. The support team can’t provide regular ongoing sessions though, and that’s where Jane comes in. Jane is a counsellor who works at Oak Tree Clinic. In a partnership between PWN and Oak Tree, she provides regular one-to-one counselling sessions to PWN members at our office. Jane specializes in addictions, trauma, and grief and loss.

It’s not surprising that addictions and trauma often go hand in hand with HIV. Grief and loss are frequent feelings women have because of trauma, whether it’s their own or something that has moved through their family and community for generations. Drugs or alcohol are common coping tools. It’s all connected.

Jane can help you understand the connections and deal with some of the stuff that gets in the way of feeling good. She sees members at PWN on Monday afternoons, and each session lasts about an hour. She sees a number of women who are dealing with painful stuff; no one is immune from it. And you don’t have to be alone with it.

Counselling can help you look at things that have happened and see how you can change or accept your response. It can help you learn how to live with things. And it can help you understand what would make you feel better.

To make an appointment with Jane, call 778-873-7586. Her voicemail is confidential. You may be interested in taking the step now, or thinking about it for the future. Either way, you deserve it.

# READING BETWEEN THE LINES

## Medication packaging and plain language

Janet Madsen

**Taking medications is part of life, from treating headaches to HIV. Whether liquids, pills, or capsules, they all have a set of instructions to make them work. If you've ever been confused by medication packages, join others who have been too. Ingredients and dosing information can be difficult to understand, and it's not just because of the teeny-tiny print.**

### Over-the-counter medications

Over-the-counter medications (often referred to as OTC medications) can look different from one another because of packaging and labelling, even if they're the same type. This means people can get mixed up on why and how to use them. Deborah Campbell, a compliance professional who works with pharmaceutical companies, reports that one in nine visits to emergency departments is due to medication errors. This is obviously a problem, and it's one that Health Canada is trying to fix.

Health Canada is introducing new guidelines under the Plain Language Labelling Initiative. The aim is to make labels easier to understand so medications are used properly. Health Canada is following the lead of the US, which uses Drug Facts Labelling modelled after nutrition information labels.

Drug Facts Labelling provides standardized information about over-the-counter medication. It explains what is in the medication that makes it work (the active ingredient), what it is used for, how often to use it, and what to do if symptoms get worse. It also includes information on other ingredients in a medication that aren't medicine, but can affect people with allergies.



Do you need to know about the over-the-counter drugs you're taking? This is where a pharmacist can help out. Pharmacists specialize in knowing all about OTC and prescription medications. They can listen to your symptoms and tell you what you might use to deal with them. Some medications don't offer a cure—cold medications are a good example. Nothing will cure a cold, because it's a virus, but some medicines can help you feel better.

Pharmacists can also look up any prescription or non-prescription drugs you are currently taking to see how any additions might interact; sometimes the action of one drug can cancel out the action of another. Pharmacists can check any HIV medications you are on against OTC medications and offer advice.

### Prescription medications

Prescription medications come with information too—what they are, what they are used for, how much to take, and how often to take it. Product inserts are often included to provide additional information about possible side effects, who should

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and shouldn't take the drug, etc. This information can be tough to understand. Deborah Campbell admits, "I have trouble reading these product inserts myself, and I work in the pharmaceutical industry."

Talk to your doctor about what you are being prescribed and why. Some women feel they should just take a prescription and go, but you can ask whatever you want to know, at any point that you're taking the medication. Even if drugs are approved for use, information about how they affect different people is valuable, especially if they produce an unwanted effect. Your doctor should help you learn about medications being suggested.

Just as with OTC medicines, you need to know how to manage what you are taking. What is the suggested dosage and what are the possible side effects? Is there a possibility of interactions with other medications? (This is why you need to tell your doctor everything you're taking, including alcohol or drugs.) Do you need to have follow-up appointments to see if the medication is working? Under what circumstances should you call the doctor?

We are lucky to have so many medications available to us, but we need to know how to use them. Talk to your local pharmacist and your doctor. Know when and why to consider medications so you can be as healthy as possible.

## Sources

Better, clearer drug labelling will save lives, Deborah Campbell, September 20, 2013. Retrieved November 24, 2013 [http://www.thestar.com/opinion/commentary/2013/09/20/better\\_clearer\\_drug\\_labelling\\_will\\_save\\_lives.html](http://www.thestar.com/opinion/commentary/2013/09/20/better_clearer_drug_labelling_will_save_lives.html)

Harper Government Launches Plain Language Labelling Initiative to Improve Drug Safety for Canadians - Proposed changes will make it easier for Canadians to read drug labels, June 14, 2013, Health Canada. Retrieved November 27, 2013 [http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/\\_2013/2013-82-eng.php](http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/_2013/2013-82-eng.php)

OTC Drug Facts Label, US food and Drug Administration, May 28, 2009. Retrieved November 27, 2013 <http://www.fda.gov/Drugs/ResourcesForYou/Consumers/ucm143551.htm>

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## GENERAL INFORMATION YOU WANT TO KNOW ABOUT

### Over-the-Counter Medications and Prescriptions

- 1 What is in the medication, and what are the symptoms or conditions it is designed to treat?**
- 2 What is the single or one-time dose?**
- 3 What is the daily dosage and the number of days you're advised to take the medication?**
- 4 What are the possible side effects? Are there any warnings about who should not take the medication? Everything has potential risk and benefit, including over-the-counter medications.**
- 5 What are the additional ingredients in the medication?**
- 6 When do you need to call the doctor? If your symptoms don't improve as promised, or if you take too much of a medication, when should you contact or see a doctor?**



**Project Overview**

Since 1991, PWN has provided a range of leadership, support, and health education to women living with HIV across BC. PWN is driven by a partnership of women living with and affected by HIV. This survey of our membership is

one way to hear how women are connecting and engaging with programs and services. PWN member Monique Desroches was hired to conduct and report on the member survey, which was written by HIV+ women and PWN staff.

**Data Sources\***

- 238 mailed surveys → 17 completed
- 63 emailed surveys → 3 completed
- 16 in-person surveys → 16 completed

Total = 36 completed surveys

12% survey return rate

\* Contact info available for 309 PWN members out of a total of 751 members

**“How I feel being a member”**



**Survey says:**

**Where members live**

- 75% Metro Vancouver
- 11% Vancouver Island
- 6% Prince George
- 5% Okanagan
- 3% Gulf Islands

**Ethnic/Cultural Identity**

- 57% Caucasian
- 24% First Nations
- 12% Métis
- 5% African
- 2% Chinese

**Ages: 30 – 72 years**

- 16% in their 30s
- 39% in their 40s
- 33% in their 50s
- 9% in their 60s
- 3% in their 70s

**Tested HCV+**

- 49% Yes
- 49% No
- 2% preferred to not answer

**How members connect with PWN**

Overall, survey participants said they connect through the drop-in, support groups, special events, and retreats. Many members live outside of Vancouver and stay connected through retreats, newsletters, emails, the websites, the blog, Twitter, and Facebook. A significant number stated it is other members who keep them connected.

“I entered PWN feeling alone and lost. Now 4 years later I’m a lot healthier and more educated on the sickness plus married now.”

**Programs and services accessed**

The top three programs are the various retreats, the Tuesday drop-in lunch, and the food bank. The retreats are often the only program out-of-town-members attend. Many members noted that receiving and providing peer support is a vital service at PWN.

“I believe after I became a member of PWN it opened up a door for me to acknowledge my illness. For a very long time I was hiding and avoiding my feelings. Until one time I get a chance to go to a retreat.”

## How long after diagnosis did you start coming into PWN?

≈ 1 Month 22%	≈ 1 Year 11%	≈ 5 Years 11%	≈ 10 Years 6%	≈ 15 Years 14%	≈ 25 years 3%	Not Sure 33%
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### Benefits of being a member

#### ☑ Meeting other HIV+ women

Witnessing a peer living well with HIV is oftentimes a revelation for a woman. The sense of solidarity in a shared experience is uplifting.

It is perhaps this capacity of holding space for positive women and thereby facilitating connection that is PWN's greatest strength.

#### ☑ Sense of belonging

At the Tuesday lunch and at the retreats members find a place where it is safe to be HIV+. For many, PWN is the only place they can reveal their status and relax with other women.

#### ☑ Resources

Members value the information they have received regarding pregnancy, aging, diabetes, treatment, nutrition, stigma, criminalization, housing, and mental health issues.

Many members visit Twitter and Facebook regularly for info about PWN.

#### ☑ Referral to other services

Members appreciate not only referrals to other services outside of PWN but the ongoing support they receive as they access outside services.

"As a member of PWN I have been able to embrace my diagnosis for the first time in 14 years! <3"

"Coming to PWN made my dreams come true. I was lonely and no family... I was inspired by the staff and got the love I needed as a person living with HIV."

"I am not alone in my illness and I know there is someone I can relate with and talk to."

"I can be a strong woman"

"I have a strong network of allies and peers and somewhere to turn if I require support."

"There are people out there who care and can and will help those who need it however that looks."

### Members want to see

#### ☐ GIPA & MIWA

Members stated quite clearly that it is other HIV+ women who make the most impact in their lives. Members who have participated in the Wellness Retreats and Skills Development reported increased feelings of confidence, a renewed sense of worth, and an acceptance of living with HIV.

Members want to see HIV+ women involved in a wide variety of activities at all levels of PWN, including the board, staff, and peer support.

#### ☐ Outreach

Living with HIV can be an isolating experience regardless of where one lives. However, members living beyond the reach of most ASOs feel particularly alone and sometimes uninformed.

Members want to see resources and services reach more areas of the province by having PWN partner with other agencies for women-specific programming and send print resources to communities beyond the urban centres.

## Have you referred other positive women to PWN?

69% Yes

31% No

"I think it is so important as a woman to look out for other women struggling with this disease."

"All women regardless of ethnicity, age will find something beneficial."

"I don't know any other positive women."

"I never discuss my status in public."

"Most I know are already involved."

# LEADERSHIP INTERESTS?

## The Board of Directors would like to meet you

Over its 22-year history, Positive Women's Network (PWN) has had a diverse Board of Directors made up of women living with HIV and their allies. It was the vision of the founding members of PWN that this would be our strength: women living with HIV and those affected working hand in hand to provide services, fight stigma, and give voice to communities of women. This partnership has served PWN well in its longstanding work as a leader on HIV women's issues in Canada.

This partnership runs through all levels of PWN: volunteers, staff, and the Board of Directors. As the recent membership survey shows, members want peer representation to continue. Right now, the Board of Directors is looking for positive women to join. The board is a real opportunity for people to develop as leaders for PWN in their own communities.

What does the Board of Directors do? The board looks at the "big picture" of PWN in three main areas: policy development, community development, and fundraising events. Board members may be strong in different areas, and many women discover unknown strengths as they go along!

Policies and guidelines provide a framework for the organization's work. They help make services consistent and professional. They provide guidance to help the people and programs of the organization succeed. Community development is another part of the board's work. Board members act as ambassadors for PWN at community and fundraising events as well as on committees with community partners. The board also supports the work of the Executive Director and contributes to decisions about fundraising events and funding applications.

PWN welcomes all women (we are trans-friendly), is non-judgmental, and believes all women's voices are valuable and essential. Some women who join the board have no previous experience, and those who have been on the board for a while help newcomers learn. Each board member is encouraged to bring her skills and perspectives to discussions.

The PWN Board of Directors is actively seeking women living with HIV to apply for board membership. New members are elected at our Annual General Meeting every June, and they may also be appointed by the board during the year.

## Some encouragement from PWN members who have served on the Board of Directors



“As someone who has previously sat on PWN's board as well as other boards within the AIDS movement, it gave me a sense of purpose. I saw myself as a catalyst for change and a voice for other PHAs. As a woman it empowered me to have my voice heard within a world grounded in patriarchal roots. It educated me on the gender differences of living with HIV, which helped me to better understand living with this disease as a woman. We, as women, have a lot to contribute to this movement.”

“No one can better understand the needs of positive women than positive women themselves! Please consider joining the PWN Board of Directors. Your input and unique perspective as a woman living with HIV is very valuable and will help guide and strengthen PWN.”

“I believe that it is important for HIV+ women in our community to take part in things, as they know more than anyone else what is really like being a woman living with HIV. We are experts on what is needed and/or wanted to make their lives better. It is also important to take part in things rather than to take on the feelings of "woe is me" and "the world owes me," which gets a person nowhere. It was a great honour to be on the board at PWN. I gained a chance to give back to PWN a little.”

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## Events and Program Information

### Beat the Blahs!



PWN members and volunteers are invited to our post-holiday, beat-the-blahs, celebrate-the-new-year lunch and volunteer appreciation at Beyond Restaurant in the Century Plaza Hotel (1015 Burrard Street, same place as last year).

Join us for a fabulous meal, fun company, and door prizes! No need to RSVP. Just show up at noon on Tuesday, January 21.

### Ready to dive in

Dr. Andrea Szewchuk will be the keynote speaker at our annual SpringBoard conference. The focus will be on trans women's health. Join us on May 8 at the Blue Horizon Hotel! More information to come on our website.

We have a small amount of funding to cover travel and accommodation costs for members outside the Lower Mainland. Contact us if you are interested in coming.

*Spring***BOARD**  
2014

### Build your skills

The next Skill Development Weekend is happening May 9 to 11 at Loon Lake. Applications will be available in March.

### CAHR heads to the Rock

CAHR 2014, the 23rd annual Canadian Conference on HIV/AIDS Research, will take place in St. John's, Newfoundland, May 1 to 4.



For more information, including how to apply for scholarships, visit <http://www.cahr-acrv.ca/conference/>

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**Challenging HIV.**

**Changing women's lives.**

### administration

**Marcie Summers** | Executive Director

**Donna Tennant** | Director of Development

**Nancy Hoo** | Bookkeeper

**Aretha Munro & Monique Desroches** |  
Clerical Assistants

### 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

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