

# **PWN Retreat: Evaluation Report**

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PWN Retreat Evaluation Report

## I. Executive Summary and Recommendations

Support for PWN's retreats is remarkable, among members, PWN staff and staff of other organizations that work with HIV+ women. There is universal support for their continuance; as well, suggestions were made for the development of additional, complementary formats, and several of these are included in our recommendations.

All respondents were asked to suggest ways to improve participation by 'first-timers' and also ways to minimize last-minute 'no-shows'; a number of their suggestions are included among this report's recommendations.

PWN has so far run two retreats specifically for Aboriginal HIV+ women; planning and programming for those retreats is still being developed. A number of recommendations are made in this area.

### Recommendations:

We have divided the recommendations into five sections, each dealing with a separate aspect of improving retreat planning, promotion and programming.

#### Promotion

Although almost all members are aware of the retreats, many have only a vague sense of what going to a retreat will actually be like and some have inaccurate interpretations of critical information, (reimbursement for child care and for travel expenses, the permitted use of medicinal marijuana, etc.). We feel strongly that using more graphic materials; highlighting information on issues that people worry about; and putting more emphasis on working with staff of other agencies to support attendance at the retreats would go far to increasing registrations in general and encouraging participation by first-timers in particular. Specific suggestions are:

- Make invitations to the retreat more colourful, and include photographs that show the setting, the accommodations, women participating in activities, etc. Consider *highlighting* issues that have been noted in phone interviews/focus groups to ensure that people are aware of information on subsidies, travel arrangements, medicinal marijuana, accommodation arrangements etc.
- Produce invitational posters, and provide them to other agencies (the Downtown Women's Centre, Oak Tree, AVI, for example) together with application forms and background information sheets for staff.

- Continue to work with other agencies to promote their capacity to refer women to the retreats (for example AVI, which made several referrals for May 2006 retreat) and to get them 'on board.' It would be worth phoning appropriate staff at perhaps half a dozen agencies to update them on what's planned for the next retreat, and to remind them of the process that's involved in applying for the retreat, the need for help with medical forms, etc. Staff turnover may mean that some people have little or no familiarity with the retreats.
- Arrange for previous participants to write articles for the PWN newsletter about the retreats: 'My first time at a retreat,' 'How I surprised everyone (including myself) when I led a workshop at a retreat,' etc. The intent would be to demystify the experience from the point of view of participants.
- Offer an incentive to new participants: a first-timer's gift package, that would be distributed to each new participants at the end of the retreat

### Pre-retreat arrangements

It is apparent from the number of last minute 'no-shows' that many members find themselves in a push-pull situation with respect to attending retreats: they want to go, they register to go - but in the end a variety of unspoken and unresolved fears keeps them from attending. We feel that a number of approaches are available that would minimize the drop out rate.

- PWN could arrange for a *pre-retreat information session*, at which people who are thinking of registering for the retreat could be 'walked through' what actually happens there: how to get to the retreat, what people should bring with them, how many people are likely to be there, what happens when people first arrive at the site, what programs and opportunities will be available each day, who to go to if there's a problem, and so on. A member who has already attended retreats could make a brief presentation, and could answer questions from a participant's point of view.
- Prior to a retreat, a buddy-system could be set up to link a person who had attended one or more retreats and someone who had never been to one. This would allow for conversations (by phone or e-mail) about what to expect at the retreats and help to allay fears. The buddy system might also extend to buddy-teams traveling to PWN together - but people made it quite clear that it should *not* extend to requiring a member to look after the first-timer during the retreat.
- PWN staff often knows intuitively that a particular woman is likely to be a 'no show.' It would be worth the time and effort to follow up one-on-

one with that woman to help her voice both the positive and negative feelings she has about attending, to support her decision to attend, and to allow for some pre-retreat discussion about her goals in attending.

- It would also be useful to have regular conversations (pre-retreat) with all first-time registrants who seem at all hesitant about participating.

### Retreat Arrangements

- Never organize a retreat on the Friday after a cheque day
- Schedule enticing and exciting programming (workshops/activities) for Sunday mornings. Better programming might prevent women from leaving early on the last day of the retreat
- Consider having member-led workshops on issues around sexual orientation
- Offer other agencies the opportunity to send staff or students to attend the retreat; the retreats provide a unique learning experience in a situation in which people are not seen as being in formal roles.
- For many women, the issue of child care is a serious barrier to attendance; quite apart from the costs of care. For example, women who have been sexually abused don't trust anyone to stay overnight with their children; isolated women simply don't know anyone who can offer child care; women who have children with disabilities can't get care-givers with the required special skills; etc. There is a need to understand the situations facing many members, and to look into possible ways to eliminate the barriers to participation they represent.
- Review meals- there were some comments about the inadequate size of meal portions at retreats and one member stated that food was removed so quickly after meals that 'slow eaters' were unable to finish their dinners.
- PWN improve communication arrangements for members who go to pick up others for the retreat, in case people don't show up, etc.

### Alternative' retreats

It's clear that there are some women who are not able to attend a three-day retreat, for a variety of reasons; for them, a one-day retreat would provide at least some of the value provided by the weekend retreats. As well, members indicated that they would like to have more frequent retreats - but cost implications make this an unlikely option.

Further, PWN is always aware of the difficulty the organization faces in providing services to members who live outside the Lower Mainland. Although a

transportation subsidy is provided to members from outlying areas so they can attend a retreat, this not only significantly increases the costs of holding retreats, it also means that people from other areas are less likely to maintain contacts with fellow-participants (one of the frequently-mentioned benefits of attending).

The following proposals are designed to help resolve each of these issues.

- consider holding one-day 'mini-retreats' - in addition to the regular ones. This would allow women who can't (or aren't ready to) attend a weekend retreat to derive some of the retreat benefits, and also perhaps to overcome some of the barriers that prevent them from attending a weekend retreat.
- undertake a pilot retreat for another region of British Columbia, which would be jointly run by a local ASO and PWN. The ASO would also commit to running at least one additional retreat, with only limited (phone, e-mail) support from PWN. The goals would be: to test-run the Retreat Tool Kit; to enable staff at the ASO to provide the benefits of the retreats to women in their area - perhaps on a long-term basis; to strengthen the relationship between PWN and the other ASO; and, if successful, to use the model for future work with other ASO's across the province. It was recognized that there are certainly problematic aspects to this proposal: developing a working relationship with an appropriate ASO, the difficulties of maintaining confidentiality in smaller communities, availability of suitable sites, transportation in rural areas, etc. However, it was felt that there are enough positive aspects to this proposal to justify further exploration.

### Aboriginal Retreats

So far, PWN has run only two retreats specifically for Aboriginal women; programming and planning for them is still a work-in-progress. The focus groups indicated that there is continuing support for such retreats, and provided some suggestions for future arrangements, particularly with respect to programming.

However, over the last seven years, PWN's regular retreats have averaged 20 participants, while the two Aboriginal retreats have averaged only nine members. 'No shows' were responsible for a greater than 50% 'loss' in attendance at these retreats. Clearly, from both a cost perspective and in terms of the number of people who could benefit, participation in Aboriginal retreats must be increased.

- PWN should plan more activities and workshops that introduce Aboriginal cultural elements.
- Aboriginal women in particular expressed a desire to have their children attend retreats with them; however, the idea was not unanimously supported. An option might be to prepare a short list of items to be considered (minimum or maximum ages of children who should attend, what programs should be available for them, sleeping arrangements, etc.) and then set up a group of Aboriginal members who would discuss child care issues and agree on program details. Perhaps PWN could designate one Aboriginal retreat as member-only, the next one as member-and-child(ren). Results should be documented and evaluated, and a determination made as to future directions.
- Aboriginal retreats should be planned so as to draw as many participants as the regular retreats do. Methods to achieve that goal:
  - increased promotion and pre-retreat support should be extended to Aboriginal members;
  - Aboriginal retreats should be 'overbooked' (to ~30 participants) with the expectation that 20 people will actually attend; and
  - if that number is not reached, the retreat should be postponed to a date at which at least 20 people are able to attend.

## II. Background

PWN has organized weekend retreats for HIV+ members for over ten years. A PWN retreat offers members an opportunity to connect with other HIV+ women; a chance to break out of the isolation and the stigma that often surround women living with HIV; a time to rest and enjoy being in a nurturing situation; the opportunity to lead workshops; and a chance to connect more closely with PWN staff.

The retreats are highly valued by the PWN membership. However, PWN staff considered that after ten years, it was time to have a fresh look at how the retreats are run and what they deliver. It was felt that changes in the social environment, in membership demographics and in members' program needs indicate the need for a review of the program.

Specifically PWN staff wanted to look at:

- how to attract participation by women who have never attended a retreat
- what might be done to reduce the number of women who are last minute 'no shows'

### III. Process

The consultants, Susan Dann and Susan Berlin, developed the following process to assess the retreats:

- a review of documentation from previous retreats, including evaluations, agendas, application and medical forms and retreat reports
- phone interviews with:
  - PWN staff involved in the retreats in any capacity
  - staff of outside agencies who refer clients to the retreat
  - a PWN member who has participated in retreats
  - a PWN member who has never participated in a retreat
- two focus groups with PWN members (one with members who attend retreats and one with members who have not as yet attended a retreat)

The survey questions appear in the appendices, as do the (slightly modified) questions that were used in meeting with the focus groups.

### IV. What we heard in the phone surveys

The retreats garnered extraordinary commendation from all involved. Most people, when asked, offered suggestions for general improvements to the program; and when PWN's specific concerns about the retreats were mentioned by the interviewers, many people offered ideas for dealing with them.

The following summary of the information collected is presented in the order of the questions asked.

#### 1. Role: How have you been involved in the PWN retreats?

We interviewed all PWN staff members who have attended any of the retreats, including the Executive Director; two people who have acted as Retreat Coordinators; the organizer of the two Aboriginal retreats held so far; people who work with HIV+ women at other organizations (including one who was the nurse at four of the retreats); one PWN member who has attended many retreats; and one member who is aware of the retreats, but has never attended.

As well, two focus groups were held - one for PWN members who have attended retreats (7 members) the other for members who have not (6 members).

The same survey questions were used in all interviews and - with a few modifications - in the conduct of both focus groups.

2. Expectations: *Before you attended a retreat, what were your expectations of what it would be like? Were those expectations met?*

Most respondents - even those who had never attended a retreat - appeared to have had at least some ideas about what the retreats have to offer. They mentioned 'being looked after,' 'being in a safe place,' access to body-work, making connections with other HIV+ women, and '...having a break from daily life, stigma, and dealing with illness in isolation.' Most - but not all - were aware that PWN provided a child care subsidy, and paid the cost of transportation for out-of-area members.

3. Benefits: *How do women benefit from participation in the retreat? While at the retreat? Short-term? Long-term?*

Every person interviewed felt that the retreats offer a positive experience to participants; a long list of specific benefits was offered.

'Magic happens' was the phrase used to encapsulate the experience of being in a situation so supportive that people were able to step outside their ordinary defences, talk to others openly, and deal with personal feelings as they could nowhere else. People described being at the retreat as a 'life-altering experience,' in a situation in which people are not placed in a role, but are free to be whole persons. ('I got to be myself.') Overall, the retreats offer a safe and supportive learning environment that people can't find anywhere else

In particular, the retreats were seen as offering a valuable experience for people who have recently been diagnosed: attendance at the retreat allows them to see that other HIV+ women are managing their lives successfully. One newly-diagnosed member who attended a retreat said, 'I looked around at everyone else and decided I could live to be 80.'

4. Suggested improvements (general): *From your perspective, how could the retreats be improved? (prompts: administration; locations; screening process; length of the retreats)*

Many of the suggestions for improvement to the retreats actually had to do with the *pre-retreat* preparations; relatively few had to do with the retreats themselves.



5. Improvements to program: Do you have any specific ideas about adapting/improving the content of the retreats?

Few people could think of any desired improvements to the existing retreat programs. Staff, however, expressed the desire to reach more women - including women from outside the Lower Mainland - and to eliminate any barriers to participation that might exist for some members. They also were aware of the cost of running the retreats, and wondered about ways in which those costs could be reduced, or could be made to benefit a larger number of women.

6. Barriers to participation: What do you think keeps women from attending retreats?

When asked about the barriers people have to overcome in order to attend the retreats, several themes were touched on repeatedly:

- *fear of the unfamiliar* - how will I get there, what kind of people will be there, what if no one wants to talk to me, what if I get sick, , what if there's a problem at home while I'm gone...
- *child care issues* - it's much harder to find trustworthy overnight child care than day-time child care. Women who are socially isolated simply don't know anyone who could look after their children. As well, some people (especially those with small children) don't like to leave their kids at all.
- *drug concerns* - the retreats are drug-free, and sometimes people aren't sure they can remain clean for the whole period they'd be away.

As well, one person commented that for people from outside the Lower Mainland, having to travel through Vancouver can provide a 'trigger' for getting back to the life they've walked away from. A retreat either on Vancouver Island, or in an outlying area, would provide fewer barriers for those women.

7. Attracting new participants: Do you have any suggestions for how to attract women who know about the retreats, but have never attended one?

Generally, the response to this question was that people needed to be 'walked through' their anxieties about attending - and most specifically, those anxieties that they are uncomfortable about expressing.

Several methods for doing this were proposed:

- members who have never attended a retreat could be invited to a 'Retreat Information' evening, where retreat details are explored: what expenses are covered by PWN, how to get to the retreat, what people should bring with them, how many people are likely to be there, what happens when people first arrive at the site, what programs and opportunities will be available each day, who to go to if there's a problem, and so on.
- As well, a buddy-system was suggested. This would link a person who had attended one or more retreats and someone who had never been to one, and allow them to talk about what to expect (by phone or e-mail). The buddy system might extend to people traveling to PWN together - but people made it quite clear that it should *not* extend to an expectation that the experienced participant would look after the first-timer during the retreat.

8. Preventing 'No-Shows': How can women who have expressed interest in attending a retreat, but changed their mind at the last minute, be supported so that they actually go?

When people were asked what caused members to be last-minute 'no-shows' they listed a combination of real-life difficulties and overwhelming anxieties as underlying issues. For example, children *do* get sick at inconvenient times, and baby-sitter arrangements *do* fall through at the last moment. However, that kind of practical problem can also be offered as an acceptable 'cover' for generalized last-minute panic about going away from home, concern about staying clean for three days, fear of exposure, fear of stigma, or other (un-stated) concerns.

The consensus was that if a real-life problem was the cause of last-minute withdrawal from the retreat, there was nothing that could or should be done about it. On the other hand, if the underlying cause for backing out was anxiety, then the same approaches that were suggested to attract more first-time participants (pre-retreat discussions, a buddy-system) could be useful in preventing no-shows as well.

9. Continuation of the program: After so many years of holding the retreats, do you think that PWN should continue to organize them? Is there a better way to achieve the same benefits for members?

The universal response to the questions of continuing to hold the retreats was an emphatic 'Yes!' However, when the issue was probed a bit, suggestions for *additional* elements and approaches were forthcoming.

- Despite the fact that retreat evaluation forms often ask for longer retreats, that idea was not widely supported in the interviews. Instead, people suggested more follow-up meetings, in the form of dinners or occasional 'workshop/spa days' for groups of retreat alumnae. These suggestions were seen as providing on-going support, but it was recognized that such day programs would be available only to members from the Lower Mainland.
- Another suggestion was designed to deal with the needs of members from outlying areas - and also with the cost limitations on how many retreats PWN can run. The proposal was that PWN could contract with an ASO from another part of BC to undertake a pilot local-area retreat, which would be jointly run by that ASO and PWN. The ASO would also commit to running at least one additional retreat, with only limited (phone, e-mail) support from PWN.

The goals would be: to test-run the Retreat Tool Kit; to enable staff at the ASO to provide the benefits of the retreats to women in their area - perhaps on a long-term basis; to strengthen the relationship between PWN and the other ASO; and, if successful, to use the project as a model for future work with other ASO's across the province.

It was recognized that there are certainly problematic aspects to this proposal: developing a working relationship with an appropriate ASO, the difficulties of maintaining confidentiality within home areas, availability of suitable sites, transportation in rural areas, etc. However, it was felt that the positive aspects of the scenario were sufficient to mandate further exploration of this idea.

10. Staff role: what role do PWN staff members play at the retreat? Follow-up?

Staff who attend the retreat are generally there to offer support: to be a listening ear, to be available if people raise particular questions or express specific needs.

However, one person expressed an interesting perspective: she said that the retreats provide a great learning opportunity *for staff, including staff from other agencies*, as well as for participants. She felt that because roles are not as clearly defined at the retreats as they are in a clinical setting, the women who go there feel more free to speak about what is happening in their lives, and how they are changing their lives. 'Health care professionals could learn a lot by listening to women in that kind of environment.'

## V. What we heard in the focus groups

The focus groups were extremely valuable sources of information, because the participants came from a range of cultures and personal backgrounds. Of the thirteen people (in both groups) who attended, about half were Aboriginal; two were Black (one from Africa); and several were lesbian or trans-gendered. Some were street-involved, others were not.

In many respects, the issues raised by the focus group members were identical to those mentioned in the phone interviews; there is no need to repeat those comments here. However, people at the focus groups raised some additional issues - chiefly relating to barriers to participation, and how to overcome them - and those are detailed here.

### *Barriers to participation in retreats*

1. *Child care support*: some members were under the impression that no child care support for the retreats would be paid for children over the age of 12, and several voiced concern about leaving teenaged children home alone while they attended a retreat. In general, worry about leaving children of *any* age was of particular importance to women who had themselves been sexually abused, and also to women who had recently moved to Vancouver and were as yet without a support network.

In actuality, PWN's child care subsidy policy provides for child care support during retreats, without any cut-off age for the support. However, the way the policy is worded can easily be misinterpreted, and obviously this has happened in at least a few cases.

2. *Cultural prohibitions*: Women from Africa face particular difficulties in deciding whether or not to attend a retreat. For one thing, we were told that African women simply do not talk about sex, or about drug use - so that the atmosphere of a retreat makes them extremely uncomfortable.

For another, African women are under especially strong cultural pressure to keep their HIV+ status hidden from their fellow nationals - and this makes it almost impossible for them to commit to a retreat.

Participation in retreats does not seem to be a viable option for these women; consequently, no suggestions for meeting their needs are included among the retreat-related recommendations in this report. However, we would like to stress that PWN should consider what alternative methods might be developed to provide HIV+ African women with some of the benefits that other women gain from the retreats.

3. *Drug issues:* Several women in the focus groups simply said that they could not have attended the retreats when they were using drugs. As well, not all members understood that the use of medically-prescribed marijuana at retreats would be possible. Finally, some members need to take large quantities of methadone, which has to be picked up, on prescription, by a health professional. Though this problem can no doubt be overcome, an opportunity to discuss the issue must be provided if a solution is to be found.
4. *Dread:* Some women - including some of those who have already participated in retreats - expressed reluctance to attend because they were afraid of seeing health deterioration among their peers.

#### *Suggestions for improvements to retreats*

1. *Cultural strengthening:* aboriginal women were in favour of PWN holding Aboriginal-only retreats. They wanted to learn more about their own culture, especially in a natural setting.
2. *Children:* Aboriginal women were also those who most strongly wanted to have their children attend retreats with them; several said that the need to leave their children at home was the chief reason they could not attend the retreats.

They felt that day-long retreats (a day-spa plus one or two workshops) in Vancouver would address a lot of their concerns about child care, since they wouldn't have to leave children overnight. They viewed such day retreats as additions to the weekend retreats, not substitutes for them.



## IV. Appendices

### A. Retreat Interview Questions

1. How are/were you involved in the PWN retreats?  
*(Prompt: attended, organized, referred women)*
2. What were your expectations for the retreat? Were they met?
3. How do women benefit from participation at the retreat? At the retreat/short-term? After the retreat/long-term?
4. From your perspective, how could the retreat be improved?  
*(Prompt: administratively, content/agenda, locations, member participation, screening process, length of the retreat)*
5. Do you have any specific ideas about adapting/improving the content of the retreat?
6. How do you suggest attracting new members to attend?
7. What keeps women from attending retreats?
8. How can women who show interest in attending a retreat, but haven't attended one, be supported to actually go? For staff: Is there a way to prevent "no shows" at the retreat?
9. For PWN staff: After so many years of having retreats, do you think that PWN should still continue with retreats? Is there a better way to achieve the same benefits for members?
10. For PWN staff: What roles does PWN staff fulfill at the retreats? Then post retreat-follow-up?

### B. Questions for Focus Group 1 - PWN members who have attended retreats

1. How did you first hear about the PWN retreats?

2. When you were deciding whether to go, what attracted you about going?  
Have you heard other women talk about what attracted them about going?
3. When you were deciding whether to go, what made you uneasy about going?  
Have you heard other women talk about what made them uneasy about going?
4. What are your strongest memories of the first retreat you went to?
5. Did any of you ever have to cancel going to a retreat at the last minute? If yes, what was the reason you had to cancel?
6. When people have had to cancel, here are some of the reasons they've given us. What do you think could be done to make it easier for women to come?
  - shyness about going off with a group of strangers
  - child care issues
  - sickness
  - staying in a drug-free place for several days
7. Do you think more women would come to the PWN retreats if there were:
  - easier ways to deal with the medical form
  - a 'buddy system' for *pre-retreat* recruitment and support
  - retreats outside the Lower Mainland for women living in rural areas
  - day-long (no overnight) retreats (spa-workshops)
  - support for staying in touch after the retreats
  - other?
8. Any other thoughts or suggestions?

*C. Questions for Focus Group 2 - PWN members who have not attended retreats*

1. How did you first hear about the PWN retreats?
2. When you were deciding whether or not to go, what attracted you about going? Have you heard other women talk about what attracted them about going?
3. When you were deciding whether or not to go, what made you uneasy about going? Have you heard other women talk about what made them uneasy about going?



4. What was the most important thing that finally made you decide *not* to go?
5. Here are some of the reasons other people have given for why they decided not to go:
  - shyness about going off with a group of strangers
  - child care issues
  - sickness
  - staying in a drug-free place for several days
6. Do you think more women would come to the PWN retreats if there were:
  - easier ways to deal with the medical form
  - a 'buddy system' for *pre-retreat* recruitment and support
  - retreats outside the Lower Mainland for women living in rural areas
  - day-long (no overnight) retreats (spa-workshops)
  - support for staying in touch after the retreats
  - other?
7. Any other thoughts or suggestions?