

# ICW NEWS



## HIV Positive Women Building Strength and Visibility in the Asia Pacific Region...



...Special focus on the amazing work being done by positive women's networks and on the voices of women activists in the region.

**inside:** Working together: ICW and WAPN+; Positive poetry; HIV in marriage; Network news and stories from India, Indonesia, Pakistan, Cambodia, Papua New Guinea, Pacific Islands, Thailand and Nepal...



# Exclusive! What's Happening in the Asia Pacific Region

ICW Collaborating with Regional Networks. News and stories from India, Cambodia, Nepal, Indonesia, Pakistan, Thailand the Pacific Islands and Papua New Guinea

**Anandi Yuvaraj**, ICW's first Asia Pacific regional coordinator, has been in post for a relatively short time. But in that time she has accomplished an amazing amount. Emma Bell went to Thailand to work with Anandi to build up ICW's presence in the region. This is a positive and challenging development for ICW and one which is greatly assisted by forming partnerships with strong regional and national HIV positive women's groups such as WAPN+.

## A Message from Anandi

It is wonderful to greet ICW members through this special issue. I strongly believe that it will increase our visibility in the region and strengthen ICW's global links. As the first Asia Pacific Regional Coordinator, one of my key tasks is to build up ICW as a strong advocacy platform here. My job is to evaluate what ICW's work should be and to make recommendations on future developments. This is very much in line with our Global ICW strategic vision towards regional autonomy.

Already we have initiated a number of informal and formal engagements with a range of stakeholders. A number of these conversations are represented here; they describe the incredible work being done by HIV positive women's networks in the region and illustrate their major concerns.

## Meeting inspirational positive women

A three-day Think Tank was organised by ICW and WAPN+ in early October 2008 with the financial support of UNIFEM's South East Asia Office. There, women underlined the importance for ICW to ensure that ISC representatives from the region are selected in a way which achieves full accountability and transparency for members.\* There were also recommendations to increase the visibility of ICW in the region. See page 3.

As a follow up to the Think Tank, meetings were planned with the Cambodian Positive Women's Group in Phnom Penh, the Thai Positive Women's Network, the Positive Women's Network in India, the Indonesian Positive Women's Network and other ICW members throughout the region. These visits were inspiring and motivated us to further our work.

## Developing our strategy for the region

We also engaged the help of a consultant based in Bangkok to develop an ICW Asia Pacific Strategic Plan for 2009-2011. The preliminary report will be available at the end of April. It will

- explore the priority areas for ICW in the region including research and capacity building for advocacy and policy work
- identify priority countries, and strategies for resource mobilisation, and for partnerships with various regional players.

Copies will be sent to all members in the region.

## Training workshop in Kathmandu

ICW had a strong role in facilitating the Asia Pacific Women's Leadership in HIV/AIDS training workshop, held in Nepal from 16 March - 3 April 2009 (programme partners are: CEDPA, ICRW, ICW, NMAC, GCWA/UNAIDS). Beri Hull, our Global Advocacy Officer and I represented ICW and helped design and facilitate sessions on sexual and reproductive rights and on the greater involvement of people living with HIV (GIPA) with invaluable support from members, Ekta, Sita, Maura and Svelta. We also held an informal networking meeting and were delighted that many women became ICW members on the spot. We look forward to continuing working with them and other wonderful HIV positive women from the region in the upcoming months.

## Meeting regional friends

I have met with regional players such as AusAID, the AIDS Alliance, UNIFEM-South Asia, UNAIDS, 7-Sisters Coalition, APCASO, Help Age India and Save the Children UK, to ensure that organisations working on HIV in the region are fully supportive of programmes and networks that promote HIV positive women's rights.

ICW News 44 provides readers with snapshots of some of the experiences and great work being done by HIV positive women in the region. It was wonderful to work with Emma Bell, then ICW's Communication and Research Offices, to capture some of this for the newsletter. ♥

*Please keep sending your articles for future issues of the newsletter.*

\*UPDATE! See announcement on the ISC elections on page 15.

“According to a United Nations Development Programme study in India (2006), an estimated 40 per cent of widows leave their in-laws' homes after their husbands' deaths due to AIDS, and 80 per cent of those women are deprived of their property and inheritance rights.”

Quoted in Commission on AIDS in Asia's report "Redefining AIDS in Asia, 2008".

# Working with **WAPN+**

## Asia Pacific's Pioneering Positive Women's Group

**Frika Chia** and **Susan Paxton** of the Women's Working Group of the Asia Pacific Network of People Living with HIV (WAPN+) explain its role and the beginnings of a collaboration with ICW.

WAPN+ operates throughout four sub-regions - South Asia, South East Asia, East Asia and the Pacific and is part of APN+. A key focus of WAPN+ has been on training in the areas of capacity building, treatment literacy and research on treatment access for women and children living with HIV.

In October 2008, members of WAPN+ and ICW representing nine countries throughout the Asia Pacific region attended the ICW Think Tank meeting in Bangkok. Our main objective was to map the needs of women living with HIV throughout the region and to identify ways that ICW and WAPN+ can work collaboratively to meet these needs.

Participants representing ICW and WAPN+ agreed that the following are key priority areas for women living with HIV throughout the region and the ways ICW can aid in their development:

- **Income generation**

HIV-related stigma and gender inequalities prevent many HIV positive women from accessing employment opportunities or developing their business skills and they struggle to cover the costs of their family and themselves accessing appropriate treatment and support.

WAPN+ is going to produce an inventory of successful women's income-generation programmes in 2009. ICW can ensure that support for these activities, the development of women's business skills and promoting property rights, is put firmly on the donor agenda.

- **Women's rights**

HIV positive women are often not aware of their rights relating to inheritance, custody of children and their sexual and reproductive lives.

WAPN+ will produce a pamphlet on positive women's sexual and reproductive health and rights this year. ICW can train HIV positive women on their rights, support women to document and report their experiences and advocate for improved services that enable HIV positive women to make informed choices about sexual and reproductive issues.

- **Access to treatment**

HIV positive women lack access to treatment for opportunistic infections, sexually transmitted infections (STIs) and to pap smears. Access to ARVs is not universal and women face problems securing time and money to travel to treatment centres. There is almost no free HIV and treatment monitoring tests and access to second line treatments. Health care professionals are often insensitive and judgmental of HIV positive women.

WAPN+ carried out a peer research project on women's access to HIV treatment and services in six countries and is now disseminating study findings. ICW can use this research to advocate for universal access to good quality treatment and for monitoring. ICW can also advocate for stronger linkages between HIV treatment and sexual and reproductive health services and for more health specialists for HIV positive women.

- **Capacity skills**

As previously mentioned under income generation, HIV positive women's low level of education and skills lead to a lack of confidence and dependency on their husbands and partners. This, as well as gender inequalities in political arenas and the ties of domestic duties, limits women's meaningful involvement in decision-making processes at local/regional/global levels.



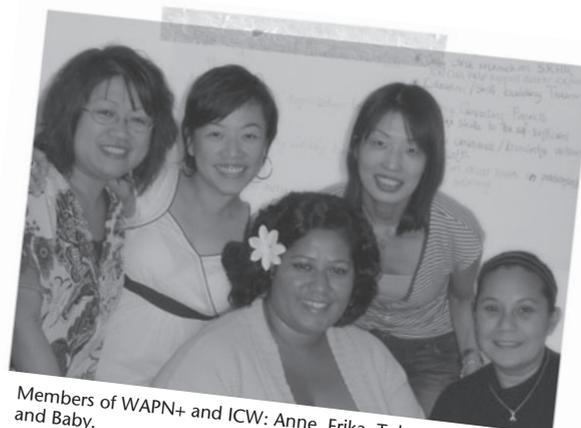
Susan Paxton from WAPN+

WAPN+ will continue to respond to the capacity building needs of HIV positive women at a regional level. ICW can run capacity building workshops at country or sub-regional level. ICW can also advocate for the meaningful involvement of HIV positive women in policymaking processes at different levels and for sustainable core funding for positive women's groups.

Identifying how ICW and WAPN+ can work collaboratively throughout the region generated much discussion. It was recognised that ICW can be used as a platform to advocate on regional and country issues at a global level and can provide support to strengthen HIV positive women's networks. WAPN+ has an important role to play in actively mobilising positive women, working with networks, and providing support, advocacy and training at regional level.

## A positive first stage

The ICW Think Tank meeting marked the first stage in the process of developing a working relationship between ICW and WAPN+. What is clear is that we are on the same page around the key issues affecting women living with HIV in our region and our commitment in addressing these needs. ♥



Members of WAPN+ and ICW: Anne, Frika, Tuberi, Naoko and Baby.

# Building Incredibly Beautiful Lives Enthusiastically in the Pacific Islands

The Pacific Islands AIDS Foundation (PIAF) is the only regional organisation for people living with HIV in the Pacific Islands. It was founded in 2002 by Maire Bopp, a young Tahitian woman who was one of the first Pacific Islanders to go public with her HIV status. Today, PIAF operates a number of programmes to better the lives of PLHIV.



Maire Bopp, the CEO of PIAF and one of the first women in the Pacific to publicly disclose her HIV positive status, with Joave Nadaubale, a BIBLE participant and AIDS Ambassador trainee on PIAF's staff.

The poems below were written by participants in the B.I.B.L.E. (Building Incredibly Beautiful Lives Enthusiastically) programme, a life-skills programme for PLWHIV that builds skills in English and computer literacy while also helping PLHIV learn how to cope with HIV. Some B.I.B.L.E. participants choose to continue on into PIAF's AIDS Ambassadors programme, which trains PLHIV to become public community advocates.

Poems were written by women attending the most recent B.I.B.L.E. programme in Fiji in December 2008; participants came from Samoa, Kiribati, Solomon Islands and Fiji. For many of them, B.I.B.L.E. is the first time they have been able to meet with other HIV positive Pacific Islanders and express

their feelings. We hope that these poems help to shed light on these women's experiences of living with HIV in the Pacific. Because many of the participants have not yet disclosed their status publicly, their names have been removed to let their words speak for themselves. ♥

## MOTHERLY LOVE

I am a mother  
 I live in a village surrounded by trees  
 and beautiful rivers  
 I have a lot of friends who always  
 support me when I'm down  
 I can hear the echoes of my daughter's  
 voice inside my heart  
 I can see a brighter future for my  
 friends whom I'm with during this two-  
 week workshop  
 My heart is overflowing with joy  
 I am a mother.  
 I wish I could have a good husband and  
 a beautiful baby girl in the future  
 I remember the last time I saw my  
 daughter's face in the hospital before  
 she died  
 I hope that I have learned a lot from  
 this workshop and for the best for all  
 my friends  
 I am a mother.

## THE LEAVES AND ME

Sitting on cold breeze of mountain  
 I could hear birds whistling and sing to and fro  
 In month of March I went to see my  
 counselor in the hospital  
 Before I went inside the room I look  
 Outside and saw a tree, its leaves  
 Turn golden brown and starts to fall  
 I thought, the leaves is dying just like me  
 Months passed new day came  
 I could hear people mumbling around our house  
 Not knowing that I'm inside the room  
 I was helpless and hopeless  
 The only thing I saw is a leafy wall  
 And I thought, Lord! you going to take  
 me out  
 Sunset gone and sunrise came  
 It's new day again, I heard voice says  
 It's not end you protected by seal  
 around you  
 And make use of the talent that  
 I've given you and to be an example  
 Where you going to found a joy of happiness in  
 your life

# PWN+ Network Activism in India

The National Consultation Meeting held in December 2008 in Delhi brought together over 100 HIV positive women from across India to discuss women's issues and to highlight the incredible work of the **Positive Women's Network (PWN+)**. The following article is a condensed version of a much longer report by **Anandi Yuvaraj**.

During our days of meeting, illuminating discussions brought to the fore our areas of concern. For instance, there is an absence of programmes or services for women prisoners, trafficked women, and for injecting drug users. The specific vulnerabilities of contracting HIV faced by married women and of seeking help and services were highlighted. Women also described the heartache of disclosing to their children.

Since their inception in 1999 PWN+ has set up many support groups and projects. Yet there is limited encouragement at the national level for treatment, support and prevention programmes for women. There is also little recognition of the importance of involving HIV positive women in the response to HIV despite the Commission on AIDS in Asia's report saying that if women aren't included the infection rate will further increase.

## Urgently needed improvements

PWN+ recommendations for improving HIV positive women's involvement in the national response to HIV included the recognition that criteria for involvement should not be related only to educational qualifications. Work and life experience are important! But on-going training and capacity building, including policy analysis and women's rights, would strengthen our involvement. An exclusive space for women living with HIV within the National Program is needed. As well, the National AIDS Control Organisation (NACO) reports need to include qualitative research and documentation from every district level. HIV positive people's networks should be drawn in to the recording of this information. Finally, forming and strengthening more women's groups needs to be specifically supported by NACO and State AIDS Cells at every level. ♥



India's PWN+ launching a prevention campaign which aims to collect 1 million signatures.

“Work and life experience are as important as educational qualifications.”

## Action Projects

### Launch of signature campaign – 1 million signatures target

PWN+ launched a HIV awareness and prevention campaign on World AIDS Day 2008. The event was inaugurated and signed onto by the Union Minister of Labour, Shri Oscar Fernandes. PWN+ and ICW members took the campaign out to NACO officials and other stakeholders who had gathered at a national level event.

### Strengthening PWN+ in advocacy and service delivery

Through this project PWN+ improved representation of women living with HIV in Tamil Nadu and Kerala, developed an annual advocacy plan for the network and a position paper on stigma and discrimination faced by women and children living with and affected by AIDS in health care settings. The paper was presented at the National public hearing meetings.

### Public Hearing as an advocacy strategy

This project documents case studies of discrimination faced by women and children in health care settings. The gathered testimonies were shared with panelists from the National Commission for Women, NACO and representatives of the National Human Rights Commission. The issues presented in these meetings include poor access to accurate knowledge and information, services for women, the stigma and discrimination faced by women, and weak health systems.

### Violence campaign

Twenty HIV positive women were trained to address questions around gender, violence and HIV/AIDS.

### Social Light Communications

This PWN+ income generation project is a design and printing company run by women living with HIV. Any surpluses are invested back into PWN+ and other community based organisations working for women and children living with HIV & AIDS.

# Unwanted Pregnancies: I Can't Bear This Anymore!

'He keeps saying, 'You have HIV because you are not spiritual.'"

'Again I delivered at home but the baby was stillborn.'"

**K** is a 29 year old Indian woman who has been married for ten years. She is second wife to her husband. She has one daughter of eight and one son of five. She was diagnosed HIV positive in 2003. Her husband is a Hindu pandit who performs pujas at homes for income.

**M**y husband's first wife committed suicide after giving birth to two daughters who are now 16 and 14. I look after them along with my kids. My second pregnancy was confirmed when I was seven months pregnant. I had regular monthly periods and did not have any morning sickness so I didn't know. I started feeling movements within my womb and decided to consult the doctor. They asked me to have an ultra scan to confirm the pregnancy and they also tested for HIV without informing me. I was then referred to the local hospital but not given a written referral.

## Hospital discrimination

At the hospital I had to wait until 70 other patients were seen. When I raised my voice about why they took so long, the response was, 'If I touch you first and then conduct a delivery with other women, the virus will be transmitted to them. I do not care about what you go through, you will have to wait until I see everyone else.'

I did not have money to go to a private hospital so I delivered my baby at home with the help of a dai. We asked for a prescription of ARV tablets from the government hospital but the doctors in charge said no, ARVs were only available if you were being treated there. I couldn't buy them over the counter either.

## My husband is in denial

My husband was also tested for HIV but he never showed the results to anyone. He is in denial. He keeps saying, 'You have HIV because you are not spiritual. Nothing will happen to me because I am a pandit and I do puja every day.' He abuses me verbally and physically. Because of his behavior his first wife burnt herself alive. My parents are supporting me financially. I wanted to get sterilised so I asked the hospital and I was advised to use the female condom instead but they're too expensive.

I became pregnant again because my husband did not use condoms consistently. I was not aware of my pregnancy until the third month. I went to a private hospital and paid for an abortion. I did not tell my husband for fear of getting beat up. When he asked why I was so weak, I lied to him saying 'Ohhh... I was lifting some heavy things and I started bleeding. I think it is not there anymore.' The fourth time I was pregnant we went to the hospital but they refused to conduct the delivery. Again I delivered at home but the baby was stillborn.

I do not think I can bear this anymore and I want a sterilisation. I have asked the local network to support me and the staff of the Delhi Network have assured me that they will help.

"Our biggest challenge is in regards to language."

## Indonesian Network – Empowering Women

Santi sent ICW News a report on IPPI.

**T**he name of our organisation/network is Indonesian Positive Women's Network (IPPI – Ikatan Perempuan Positif Indonesia). Our responsibility and mandate is to voice out the needs of infected and affected women in Indonesia, as well as to empower them through various capacity building programmes. Our organisational scope is national. Our vision is to enable HIV infected and affected women in Indonesia to be empowered, possess high quality of life and equality in health, social, education and economic aspects.

IPPI will join in the women's programme to voice the women's issues, especially those who are living with HIV and the affected ones in Asia Pacific region and specifically Indonesia. The strategy taken by IPPI is through information dissemination to the mailing list. Also by making efforts to involve the members in abstract writing workshops.

## Taking part: ICAAP9 in BALI

The priority advocacy topics that will be addressed during ICAAP9 are PMTCT, women's multi burdens and women-friendly health services. One of the plans is to get actively involved in all the ICAAP9 conference sessions in order to address the issues of women living with HIV, attempt to have our members as speakers and to have our members addressing women's needs in every session.

We will be attending the pre-congress in capacity building, and satellite sessions, symposia and the Asia Pacific Village.

The biggest challenge that IPPI faces is in regards to language. Only a few of the members are English literate. This situation had caused very low active involvement from the members in welcoming ICAAP9. This also relates to abstract writing.

Our members need information, support and capacity building. We are planning to mobilise between 200 to 300 women in the Women's Forum, apart from the Women's Court. The Women's Forum is aimed at women in general, while the Women's Court is specifically for women living with HIV. ♥

IPPI members in a meeting



# Pak Plus Society

## Equipping Women with Courage

Shukria Gul reports from Pak Plus Society (PPS) in Pakistan

There are around 5,000 HIV and AIDS patients in Pakistan registered in different public hospitals. UNAIDS estimates that the number of expected HIV and AIDS patients is over 80,000. According to Pakistani virologists, women account for nearly 13 per cent of the total HIV and AIDS population in Pakistan.

### Issues affecting HIV/AIDS Positive Women in Pakistan

- Gender inequalities have played a pivotal role in the spread of HIV in Pakistan. According to the Federal Education Ministry, the overall literacy rate is 46 per cent. But only 26 per cent of the women are literate. It is not only difficult to reach women with information on how they can protect themselves from HIV infection, but also restrictions on mobility often make it difficult for them to access health and social services.
- There is a lack of awareness or knowledge about the disease; those who know by chance mostly do not know where to go or whom to share with. This is especially true in the case of women. In Pakistan there is a culture of silence that surrounds sex which dictates that 'good' women are expected to be ignorant about sex and passive in sexual interactions. This makes it difficult for women to be informed about risk reduction or, even when informed, difficult for them to be proactive in negotiating.
- Disclosure of an HIV status is a very difficult emotional task creating opportunities for both

support and rejection. HIV is a social stigma and a taboo in this hostile society. Mostly people do not accept HIV positive woman.

- Poverty and lack of economic opportunities increase Pakistani women's vulnerability to the disease.
- Women are specifically vulnerable to HIV because of socioeconomic factors such as poor hygiene, low literacy rates, limited mobility and access to health facilities, and the lack of decision-making powers.

### Role of Pak Plus Society for HIV positive woman

Pak Plus Society plays an important role in empowering HIV positive women, because the Director of the society is also an HIV positive woman. She has faced all these social and biological issues, and so she feels the sufferings of every single HIV positive woman and she is standing alone for their care and support. PPS is trying to equip these women with the courage and support to stand against social stigmas and discriminations. PPS is committed to improving the quality of life of HIV positive woman by giving them the parental and life skills based education to maintain a healthy and positive way of living. ♥

"Gender inequalities have played a pivotal role in the spread of HIV in Pakistan."

"Disclosing an HIV status is a very difficult emotional task."

"The director of Pak Plus Society is also an HIV positive woman."

## Wedding of an HIV Positive Couple

The 1st of March 2009 was a very happy day for Pak Plus Society.

PPS had tried to organise this event for one year and finally we were able to manage the marriage ceremony of two of our HIV positive members. Mr S is a migrant worker who got infected four years ago. Miss J was infected by her husband who died three years ago. They are both on ARVs.

The PPS Team arrived at the bride's home to find the other guests already there. The bride and groom were beautifully dressed and looking very attractive. The ceremony started with the formal greetings and introduction of the guests. After the introduction the local Imam offered the Nikkah of the couple. A PPS staff member was the witness for the bride's side. After the Nikkah everyone congratulated and presented gifts to the newly married couple. Then we all had a delicious wedding lunch.

### Optimistic about the future

The new couple seemed very happy and appreciated the PPS team for managing the entire event. The bride looked quite relaxed after the marriage. She was widowed three years ago and she had a tough time during that period, with no one to take care of her. She paid special thanks to the PPS staff member for her kind efforts to solve her problem.

The couple was quite optimistic and hopeful about their future life. At that moment the PPS team had a session with the couple individually and then together to provide them with all the necessary information and materials regarding HIV and AIDS, and also to make sure they realised their responsibilities being a married HIV positive couple. ♥

# Cambodian Positive Women: Connecting, Networking, Supporting

In December 2008 Mony Pen, ICW member from the Cambodian Community of Women Living with HIV/AIDS (CCW) welcomed a visit from Anandi Yuvaraj and Emma Bell. She devised a packed schedule of meetings which produced a rich array of material for the newsletter, so much that we can only give you a taste.

## Why We Formed CCW

The Cambodian Community of Women Living with HIV/AIDS (CCW) was formed with the support of UNAIDS and UNIFEM when some HIV positive women separated from the Cambodian People Living with HIV/AIDS Network (CPN+) because their voices were not being heard. Now we concentrate on issues like PMTCT, income generation, leadership, advocacy and coordination among networks. We want to sit together with community people, service providers, and policy makers in order to work together and learn from each other.

There are now 54 self-help groups in three districts. More women than men join but often men don't want their wives or partners to get involved.

"People don't know much about the drugs they are taking."

## What we do

The groups' activities are many and various, including advocacy around human rights and the daily needs of HIV positive people. Some of the groups have formed a partnership with Buddhist monks and are trying to overcome hurdles to getting people involved. People cannot afford transportation and many poor and jobless people form mobile populations that drop out of health care. Knowledge about treatment and opportunistic infections is poor. People don't know much about the drugs they are taking – only the shape and colour of the tablets - and nothing is known about side effects. There is much to accomplish and very little money to assist our tasks.

Members of the CCW



## Sexual and Reproductive Health: What It's Like for Us

Members of CCW who met with Anandi were keen to describe their lives.

**M**ost of us are housewives. In our meeting today only five have husbands who are alive. When our husbands pass away we don't know what to do.

Many of us have children. If we get pregnant by chance and want an abortion we are not always able to disclose our status. The medication provided if we have an abortion may interact with ARVs.

Our fear is that if we disclose we will be discriminated against. Most of the doctors don't encourage positive women to get pregnant. They tell us to use condoms. In one hospital they have a policy that if you get pregnant by mistake you have to go with your husband to get an abortion. If you go on your own you get refused. When we get refused we use traditional

healers who give women papaya tree root. That makes blood come out and you just keep bleeding.

*Anandi – When I was diagnosed in 1997 there were no PMTCT services. I decided not to have a child. Now we have medications which make it safe, but I'm 45, so it's too late for me. However, young women now have options. How do we make sure they can use those options? Why talk about improving rights if we cannot access them?*

Family members don't encourage us to get remarried. They say they will fire you from the house. Some women say they don't want to use their vaginas any more – burn them!

*Anandi – we should be proud of our vaginas!*

In Cambodian culture it's not good to remarry. Even if the

other person is HIV positive you shouldn't have lots of sex.

*Anandi – do you believe if you have lots of sex, it affects your health?*

Some people believe this. Before, people believed that if you were HIV positive and had sex, your health would get poorer. Now with training we have learned this is not the case. But most of us here are widows and we are heads of households. We are very tired and are not in the mood to think about love and sex. ♥

## Sex Worker Union

**While we were in Phnom Penh, Mony took Anandi and Emma to meet 15 members of the Sex Worker Union. Seven of the women are HIV positive, five use drugs, ten are married or have partners. Four of the women had been gang-raped.**

**Our Union advocates for the rights of sex workers and to reduce stigma and discrimination.**

We encourage sex workers to go for regular health check-ups and HIV testing and we educate women to use condoms with clients and partners. We also refer women to the clinic for treatment and do follow up to make sure they are taking their medications regularly. HIV positive sex workers have access to treatment through a specific programme for them. Our union also follows up on cases of discrimination by police and health staff.

**One woman told about discrimination from a neighbour.**

The neighbour called me a prostitute and said I deserved to be infected with HIV. She claimed I would die soon and that 'no one will come to your funeral'.

**Other women described the harassment they face.**

Every night policemen disturb and bully us. They even threaten to shoot us with their slingshots. My leg is bruised from a police beating.

Drug gangsters attack us and take money from our clients. Then our clients hit us because they think we are working with the gangsters. Four days ago I got black and blue eyes from a client. Most of us go along the riverside at night. It's not safe but some clients go there.

**Of the 15 women at the meeting, 5 had been beaten by a client because they asked them to use a condom and the client didn't want to.**

In the last few days one man took me to a guesthouse and agreed to give me \$1 after sex. Afterwards he took me by the throat and forced me to give him my money.

**Gang rape is a big issue.**

We try and help each other but sometimes we can't. Ten days ago eight men took me and raped me – they didn't give me money. Sometimes one man comes to pick up a girl and we think she's safe but when they reach the guesthouse there are five or ten men. Last week one of us was gang-raped by 15 men.

Sex work is illegal. For us, the anti-trafficking law has made things worse. This is because sex work and trafficking are treated as the same thing. This law also makes women afraid to carry condoms.



Cambodian Sex Workers Union members

**We can't always go back to our villages.**

Some of us go back to the villages if we are infected. But community chiefs have expelled women from their villages. My friend went back and told her family about her status. The mother accepted it but the father kicked her out. Her younger brother told everyone in the village. Now she is dead.

**Nine of us have children.**

I am seven months pregnant with the child of a client. We used a condom but he removed it. Women might get an abortion if they could afford it but some of us are too poor and keep the baby.

It's complicated. We don't necessarily use condoms with our husband or partner. Maybe the partner does not want to. Maybe they think you have somebody else. My husband wants to have sex with me everyday. If you say you are too tired it can lead to domestic violence. Not all of us are open about our status. Some of us have told but sometimes the partners don't care.

I went with a pregnant member of the Union to the hospital for a health check-up. The health workers said, 'What are you doing getting pregnant? You are a sex worker'. They blame us. Most of the women don't want to get pregnant but it happens by chance.

**The Sex Worker Union tries to follow-up with authorities when the women are discriminated against. ♥**

There wasn't room for all our Cambodian material so in the next newsletter we will carry a moving interview with women, all widows, in a support group in a remote village in Kampong Cham Province. These women emphasised the difficulties they had in obtaining medications.

# Passionately for HIV Positive People in Papua New Guinea

Maura Elaripe Mea is a member of ICW's International Steering Committee, having been elected to that position through the Asia Pacific Network of People Living with HIV/AIDS (APN+). Here she tells us about her work in Papua New Guinea (PNG) and her personal story of a forced sterilisation.

I was diagnosed HIV positive in June 1997 when I was tested without my knowledge at the ante natal clinic. My HIV work started in 2001 when I was introduced to the care and counseling advisor of AusAID, an Australian agency which provides support to projects in PNG.

I disclosed my status during 2001 at a public gathering. In 2003, I was among 20 other people living with HIV and AIDS who with funding from UNDP started our national network, now known as IGAT Hope Inc.

I am passionate for HIV positive people to have quality lives and access to services. In 2006 I was elected as the country rep to APN+ and served for two years on the steering committee. In 2007 I was appointed by WAPN+ to represent them on ICW's International Steering Committee as a member from Asia Pacific. In November 2007, together with WAPN+, we organised a workshop on facilitation skills for positive women in PNG and out of this workshop the Positive Women's Network was formed which is now known as 'Wabha PNG' (meaning women affected by HIV and AIDS in PNG). I am now employed by AusAID's HIV programme in PNG as a GIPA advocacy officer to work for and with PLHIV groups, NGOs and government.



Maura Elaripe Mea from PNG and an ICW International Steering Committee member.

“We must not give up nor give in.”

## My Experience of Forced Sterilisation

We didn't have any information or services available at the time I was tested in 1997. I wasn't counselled and for three years I went into hiding and locked myself away from the world, expecting to die any day. After three years, I thought this is not right, I'm not dead yet. I learned about HIV and met AusAID people who asked if I had received counselling.

I said, 'I don't know what you mean. I haven't had counselling since day one of my diagnosis. In fact, up til now I tend to counsel other people.' I find that very weird and interesting.

During that time, I lost two of my babies. They didn't die because they had HIV. The first one died because she was stigmatised. They said I was HIV positive and they refused to treat her. They didn't find out the cause of her fast breathing. My second baby died because they administered an oral polio vaccine and he instantly developed polio and died.

Then in 1999 they forced me to have sterilisation. They said I was stupid to become pregnant and had no right to be pregnant. Afterwards they told me 'it's for your own good'. Now I totally regret it because I didn't have information about my right as an HIV positive woman to sexual and reproductive health. Forced sterilisation is cruel. Every person has the right to marry and have children. ♥

This is an edited version of an interview Maura gave to Irin/Plus News in Mexico during the AIDS conference in 2008.

“During that time I lost two of my babies.”

# Striving for Voice and Choice in Thailand

In January ICW and WAPN+ met with Nat, Too, Chompoo and Chai who are involved with the Thai Positive Women's Network. Emma Bell listened to these women describe the exciting work they are doing to promote HIV positive women's reproductive and sexual health and rights in Thailand.

One of the projects we are working on is gathering information from HIV positive women to find out who we are. We have sent out a 1000 questionnaires asking such questions as:

- How old are we?
- Are we on treatment?
- Are we married or not or in a relationship?
- Who is the income earner of the house?
- Do we want a baby? Does our partner want a baby?
- Do we disclose our status?

We are now analysing the data. Some of the issues that are coming out are the difficulties of discussions with partners and children and also the shyness women feel when seeking health services from a doctor. We are involved in a campaign to promote pap smears among HIV positive women of a certain age because of the connection between HIV and cervical cancer. We have found that women feel very shy when they go to the doctor but government services are not sensitive to this and the campaign does not address it. They just think a pap smear is good for you and it is free of cost. We see this as a gender issue but government officials, health workers and others we talk to see it as a cultural issue. They are reluctant to talk about the lack of power women have and their rights in the context of women's health.

We are also concerned about migrant women's access to ARVs. Treatment is free but if you don't have a work permit to work in Thailand you cannot get them. We found out this is a problem during some earlier research on treatment we conducted for WAPN+.

## The right to full information on pregnancy

We also want information to be given to HIV positive women who want to get pregnant. But health officials say that the information is just experimental. The attitude seems to be that if women know they can get pregnant when their CD4 count is low and don't have any opportunistic infections, they will run and get pregnant. They don't think that women have the right to have the information and make their own choice. The Government's HIV surveillance of women is done through statistics gathered at antenatal centres (ANC). If the ANC statistics are low then the general statistics for HIV are low. Therefore the recommendation to HIV positive women is to not have children. The government claims they don't do this any more but there is a view that still exists in hospitals.

## Information meetings in hospitals

We asked positive women about the problems they face and based on this information we have developed five one-hour curriculums. Every month we meet with HIV positive women and men in the hospital while they are waiting for their monthly medications or waiting for check ups. There are more women than men at these meetings but if men come we involve them. Our curriculums are more accessible and less complicated than those produced by the Ministry of Public Health, because ours are developed by women.

The five curriculums are:

1. Disclosure to a partner.
2. Communication with a partner for prevention.
3. Safe sex – for example, we discuss methods like the withdrawal method. Men say lets use this method - you can't get HIV, STIs or pregnant. This is a myth but women do not have information and control over the method used.
4. Pleasurable sex - because we believe that promoting safe sex is not enough.
5. Planned pregnancy.

We have 100 trainers in nearly 50 different hospitals in four regions of Thailand. We invite women from the groups we talk to in hospitals to become trainers and invite them to be part of the network. Our members are also members of the Thai Network of Positive People. We work closely with them but they do not pay enough attention to the reproductive health issues of HIV positive women.

We also feel that we need to understand men and that is why we have a project on men. What are their beliefs and ways of thinking? Let's try to talk together productively. ♥

"They don't think that women have the right to make their own choice."

"We invite women from the groups we talk to in hospitals to become trainers."



ICW and WAPN+ meet the Thai Positive Women's Network.

# Ekta's Story of Motherhood, Drug Use and HIV

Last year in November Emma Bell interviewed Ekta Thapa Mahat, assistant programme officer for the National Association of PLHA in Nepal (NAP+N) that gives direct help to more than 150 support groups across Nepal as well as residential and care homes for positive people and their children. Ekta talks about her experiences of motherhood, HIV and drug use.

In 2003 I gave birth in a gallery where drug users go to inject. I did not know I was going to give birth. It was a very unwanted pregnancy. When I gave birth I was in pain. I thought I had overdosed

**I gave birth in a gallery where drug users go to inject**

on heroin and that made me feel so sick. When I woke up street cleaning women were around me – they cut the cord. After 19 hours the baby was still alive.

When I saw my baby I thought I was the only mother to feel strange. I didn't love him. When I saw him crying I feel a little love for him. Some NGO people bring milk in a glass and I used a swab for filtering heroin to put milk in and then into his mouth so he could suck. At first I had no idea about breast feeding.

## Going into rehab

Finally I decided to go to a rehab centre. They took care of my baby very well and he was taken to hospital and immunised. After one month I was fine. And I feel love for my child and I decide to leave and stop using drugs. I stay for two years in the centre and volunteered and counselled other users. I had 1000 rupees per month to cover food and some things for the baby. I had a new life. I became famous because I have a god-gifted quality - I can speak and I am not scared to speak in front of people. Eventually I said to a counselor, I am getting bored staying inside these four walls. I want to go outside and see the streets.

I went to a workshop about drug use and they were talking about women drug users and I was the only woman participating there. They did not know that I was a woman drug user. They were all men and HIV experts and some from ministries at director level. I said, I can present on women drug users. I had so much inside of me. I was very new. I went in front and kept on and on talking about the problems and the consequences. They were listening and they give a big clap. I felt a little light – I came back to rehab and the next day several organisations offered me a job. I joined a harm reduction programme and helped with a big project. I am a founder member of the national network of drug users. It is a very big network now. I am 25 now and I was 18 then.

## Earning well and going back on drugs

I earned so much money I could afford an apartment with a maid for the baby so I could work – too many people to help me, empower me. I was the only young woman speaking out about drug use. Others were too old and about to die and they had been using heroin for 30 or 40 years. I became very famous. I earn good money and I went back to drugs. I thought I could use once and I

**When I saw my baby I thought I was the only mother to feel strange.**

was free from rehab centre. I was so alone. I found a friend, a drug user friend, a guy – he was very good to me. I had no good sex experience until then and I felt sexually attracted but he was not. He was following me for the money. And he was still using drugs and he said why don't we use once and I said OK. But then you want to use again and again.

Previously when I was with the father of my child my experience with sex was very bad and painful. I did not get any pleasure. I felt I am doing naughty things which I should not do and I had fear in my head. What will I do if someone knows? He was my drug using partner and he was very good to me. He said we can't study any more so let's get married and sell drugs. He ran away when I got pregnant.

## Boyfriends

I know what guys are like. They just want to have sex with you once. I have gone through a lot of struggles. It is difficult to rent a room when you have a child they ask where is your husband? I say I don't have a husband. I don't want to lie and say that my husband is in Canada – it can happen to any young woman.

Now I have a boyfriend that really loves me but I am still not satisfied with him because he doesn't work. He does not contribute to my survival. But he loves me at least and I don't go with a lot of guys these days. Everyone knows that I love him and he loves me and it's a social security. Before when I did not have permanent boyfriend everyone offered me sex. When I was 20, 21, 22, I did not know anything. Sometimes I feel like making love with them, sometimes I hate them, but now I can decide to what limit I should love one and expend my money for someone.

IDU women are more vulnerable to harm than men. Women always need men for security. When I was dealing drugs I need a man because if three men come and start to rob me there is nothing I can do. You can be harassed and threatened'. Drugs are illegal but if you have a man and give him drugs or have sex with him he will save you. Women can't go around at night but men can sleep anywhere. Women are afraid of getting raped, attacked. We

written on your head. You can see drug users from miles away - your activity, your thinking, working, your living, your clothes always dirty. For HIV positive people if you have info about treatment and positive living it is easier. Drugs can kill you instantly - if you can't handle it you can overdose.

never imagine that it happens like this in rural areas. Nearly every house in some villages there is someone infected. If men don't migrate to India people look down on them. Lots of people go to Bombay. The Nepalese men are labourers there and in the weekend they go for sex - no other entertainment.

In 2002 the WHO and the Nepal government estimated that the number of people living with HIV is 72,000 and

“He was following me for the money.”

sleep near temples but there are many guys. If you go to a hotel and say you have no place to sleep they want some benefit out of it - sex. Or sometimes they don't give you because junkies look dirty.

### Drugs and HIV

I was diagnosed with HIV in 2005. Drug use is more difficult to live with than HIV. With HIV you can work. I can bear HIV - I can work and live with HIV. It is not

### Drug use and HIV in rural Nepal

There are 40 women to every 60 men have HIV in Nepal but the number is increasing. When it started we are all drug users - we did not know about other ways. We find out about the borders and then when we went there we see the situation is even worse for women than for IDUs in Kathmandu. The people at the borders come to Kathmandu at very late stage - so we go there and give them transportation and encourage them to get tested. If late it is difficult. Not easy work to go and say where is your husband - is he a seasonal worker? We have to get to know the community, so we campaigned for two years. So many people came out HIV positive, lots of women coming - more women than men. They don't have a husband. Their children are infected. We

“Drug use is more difficult to live with than HIV.”

they have not re-estimated since. In 2008 there were 19,020 reported cases and 16,000 people on ARVs, with more women than men accessing ARVs. The problem is the government and donors say we have access, they have pills on the shelves but one has to go there to take ARVs and there are too many difficulties to get there. People are very poor and don't have transportation and there are no viral load machines. ♥

Sita and Ekta. An interview with Sita will feature in ICW News 45



# What Do We Mean by HIV in Marriage?

**Anandi, Frika** and **Cathy Kolokitas** discuss the specific situation of women contracting HIV in marriage or long-term relationships. They ask if we should be addressing HIV in marriage in the Asia Pacific region

The AIDS Commission in Asia (2007) estimated that at least 75 million men buy sex regularly from about 10 million women, and 20 million men have sex with men and/or inject drugs in the region and are also possibly married or have girlfriends.

develop an evidence-informed HIV prevention and access to care, treatment and support strategy for married women.

“We must understand the diversity among women.”

As a result several million women a year may be exposed to HIV during sex with a husband or partner who is already infected. Over 2 million women have HIV in the region and 80% of them got HIV from their partners (husbands or long-term partners). Married women make up the greatest number of new infections in countries with mature epidemic such as Thailand and Cambodia.

Successful efforts to curb the epidemic among female sex workers and their clients in these countries have resulted in general declines; however more new infections are taking place in the home between husbands and wives, and in intimate relationships with partners. There are relatively few targeted interventions that focus on protecting married women from HIV, or that reach HIV positive women who are married, and there are insufficient interventions focused on clients of female sex workers.

Based on the evidence documented in the AIDS Commission report (2008), many women do not perceive their risk or if they do they can't do anything about it due to unequal power dynamics within their relationships, rigid gender roles and stigma in acknowledging that your husband injects drugs, visits sex workers or has sex with men. For those women who are HIV positive, many do not know their status or if they do know, don't know how to seek care, treatment and support.

To address the critical gap in HIV interventions the UNAIDS Regional Support Team (RST) and partner organisations including UNDP, UNIFEM, UNFPA, ICW and APN+ joined together to lead a joint programme initiative to assist countries in the Asia Region to

## One approach won't fit all

ICW and APN+ staff (including WAPN+) raised their concerns with the initial title of the programme – ie 'spousal transmission'. The partnership decided that the term 'HIV in marriage' would be more appropriate than 'spousal transmission'. It is broader; therefore it can encapsulate HIV positive women's experiences as well as prevention efforts. Moreover, ICW and APN+ felt that the term 'spousal transmission' is stigmatising because of the focus on who gave who HIV. Whereas 'HIV in marriage' is not blaming either husband or wife and puts emphasis on the relationship of two people bound together by marriage. By marriage we are not just referring to the legal definition, in other words documentation at a registry, but also to marriage in a cultural sense. For example, the tea ceremony in China or, for instance, in Burma, where once seven households situated in four directions from your house say that you are married, it means that you are married.

Interventions targeting married women should be different from interventions aimed at women not in married relationships, or interventions aimed at female drug users, or female sex workers. But steps must be taken to ensure that any intervention does not inadvertently label married women as 'good girls' and unmarried sexually-active women as 'bad girls', and to be mindful that sex workers and drug users may also be married women. We must understand the diversity among women and the numerous identities women may have in order to achieve our goal of universal access to HIV prevention, treatment and care services for women. One approach will not fit all. ♥



So Lonely! Vietnamese HIV pamphlet ignores the sexual and reproductive lives of PLWH



## Asia-Pacific AIDS Congress in Bali, 2009

500 Delegates and 50 Countries expected at important HIV/AIDS Conference. Bali will play host to the 9th International Congress on AIDS in Asia and the Pacific (ICAAP) scheduled to be held August 9-13.

The theme adopted for the Bali conference is: "Empowering the People, Reinforcing Networks." The theme aims to enhance cooperation in the 20 year struggle to eradicate AIDS.

ICW has submitted a skills building session on Gender and Harm Reduction. We also hope to help run a support office for PLWH in the community space with the 7 Sisters Coalition and WAPN+. Materials and information about ICW can be found at the 7 Sisters booth. Please visit us!

**For more information about the conference go to [www.icaap9.org](http://www.icaap9.org)**

## Au revoir to Luisa and Emma

ICW is losing two of its long-term staff members. **Luisa Orza** and **Emma Bell** have each contributed much to ICW. In a departure from our usual thanks and goodbyes, the newsletter asked the two friends to write farewells for each other. **Jeni Gatsi**, who has worked closely with both Luisa and Emma sent a warm tribute. Thanks Emma and Luisa for all your creative and productive ICW work over the years.

### Jeni for Emma and Luisa

When I saw your resignations, I was filled with a sense of sadness. I guess you had to let your wings fly, It is us (ICW and myself) who will be losing such treasured diamonds. It was because of the two of you that my work in Namibia prospered to such high levels. Your support and mentorship has been wonderful. Every time I worked with you I felt appreciated and that motivated me to do so much. I want to thank you once again for all the support and encouragement you provided me and our women in Namibia. May you have more kudos and greater things in your future endeavours. Love you both and big kisses and hugs.

### Luisa for Emma

Emma has been there through some of my darkest and brightest ICW moments, from breaking down on a motorway on a dark rainy night in Durban to working with positive women to develop really strong tools and advocacy agendas; from having to fight with the CEO of Swazi-Air to get to a workshop on time, to hearing how the young women's dialogue has changed the lives of ICW members. Through all of these events Emma has astounded me with her humour and humility, her ability to focus on the most important issue and her complete commitment to the vision and values of ICW. Emma - I know our friendship will continue and I look forward to opportunities to work with you again.

### Emma for Luisa

Luisa and I joined the staff of ICW within a day of each other back in February 2004 and left within a few weeks of each other in 2009. Not wholly a coincidence as I don't know how I could continue my ICW work without her wisdom, warmth, generosity and support. Among the wonderful experiences for me of working with ICW over the last five years has been developing a strong working relationship and friendship with Luisa. She always makes time to help with any problem whether with work or at home and everyone at ICW would also say she is great fun. I wish her loads of best wishes for her life after ICW and know that I will continue to benefit hugely from our friendship. ♥

Luisa and Emma: colleagues and friends



## Get the Newsletter by Email

The newsletter is available on email. Please get in touch with Carmen [carmen@icw.org](mailto:carmen@icw.org) if you would like to receive your copy of the newsletter by email or by post.

## Recent Sad News

It is with a heavy heart that we report the death of Lynde Francis. Lynde was an ICW member for many years and served first as an ICW regional representative and then as a member of the International Steering Committee from Zimbabwe. We send our condolences to her loved ones and to her legions of devoted friends and admirers around the world. ICW has lost a brave and true activist.

We will carry a longer tribute to Lynde in the next issue. ♥

## New ISC Members Elected from Cambodia, Canada, and USA

Bev Greet and Dorothy Onyango are happy to announce the results of recent elections to the International Steering Committee. From Asia Pacific we have Mony Pen and for North America, Louise Binder and Jessica Whitbread. Bertha Chete joins from ICW Latina, Siphwiwe Hlophe from Southern Africa and Mpendwa Abinery from East Africa. Congratulations! More on these women in the next issue of ICW News.

## Thank You!

Thank You to all contributors to this issue including: Katy Proctor, MariJo Vazquez, Franck Pertois, Susan Paxton, Frika Chia, Anandi Yuvaraj, Jeni Gatsi, and all the women who took part in creating the material in this issue. Special thanks to Emma Bell who was my expert co-editor for this issue.

## ICW NEWS ISSUE 44

Sue O'Sullivan: editor  
dsprint and redesign:  
design and print



**Issue Number 45**  
**Deadline: June 15 2009**

**Focus: The language we use – reflections and meanings of the words we use when talking about HIV & AIDS.** Do you have strong feelings on this subject? Send to Sue and Katy Proctor at the ICW London office, or email to: [sue@icw.org](mailto:sue@icw.org) and [kproctor@icw.org](mailto:kproctor@icw.org)

**Issue Number 46**  
**Deadline: September 15 2009**

Please send all material to Sue at the ICW London office, or email Sue and Katy: [sue@icw.org](mailto:sue@icw.org); [kproctor@icw.org](mailto:kproctor@icw.org)

**Cover photo:** PWN+ members light the candles to celebrate and observe the lives of women who have contributed in the fight against AIDS on World AIDS Day 2008

# ICW Staff and International Steering Committee Contact Information

## The International Community of Women Living with HIV/AIDS (ICW)

ICW is the only international network run for and by HIV positive women. It was founded in response to the desperate lack of support, information and services available to positive women worldwide and their need for influence and input on policy development. ICW is a registered UK charity.

### Patron: Mary Robinson

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\*All ISC places are voluntary and unpaid.

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## ICW members

### ICW Members Receive the Newsletter Free

#### ICW welcomes HIV positive women around the world as members.

- ICW membership is open, free and confidential to all women living with HIV/AIDS. All members receive free copies of the newsletter and other ICW publications.
- If you wish to become a member please fill in this form and send to Carmen Tarrades at the London International Support Office. You then will be sent a longer application for membership.
- If you are already a member and wish to update your contact information or ask something about your membership, please tick the appropriate box below and also send to Carmen at the same address. If you have not been receiving your newsletter, we can correct this error if you send us this form and indicate the newsletter language you want.

I want to become an ICW member. Please send me a membership form

I am already an ICW member and I would like to receive the newsletter in:

English  Spanish  French

NAME

ADDRESS

POSTCODE

COUNTRY

**Send this form to:** Carmen Tarrades, ICW International Support Office, Unit 6, Canonbury Yard, 190a New North Road, London N1 7BJ, UK Email: [carmen@icw.org](mailto:carmen@icw.org)

**Note:** ICW is happy to arrange to send small bulk orders of the newsletter for free to the networks and groups of HIV positive people. Please contact Carmen if you want to organise this.

## ICW needs

### your support

#### ICW friends\* and supporters

ICW's vision is that information must be accessible to all HIV positive women.

All ICW publications, including the newsletter, are distributed for free in English, Spanish and French to all HIV positive women members and beyond. It reflects their visibility, voices and visions.

If you want to support our work, you can simply make a donation. Just **£20 (or \$US30 or €30)** for instance, helps send the quarterly newsletter to 20 HIV positive women.

We welcome donations of any size, and you can make a secure, on-line donation in GBP, Euros, or US dollars at [www.icw.org](http://www.icw.org) and click **Donate Now**.

Or send your donation by post to Corinne Miele – ICW Donations, Unit 6, Canonbury Yard, 190a New North Road, London N1 7BJ, UK (cheques made payable to 'ICW'). Please include your contact details so we can keep in touch and tell you about ICW's latest news. If you have any questions about donations, please contact Corinne at: [corinne@icw.org](mailto:corinne@icw.org)

\* Friends: our growing list of friends support us but are not themselves HIV positive.