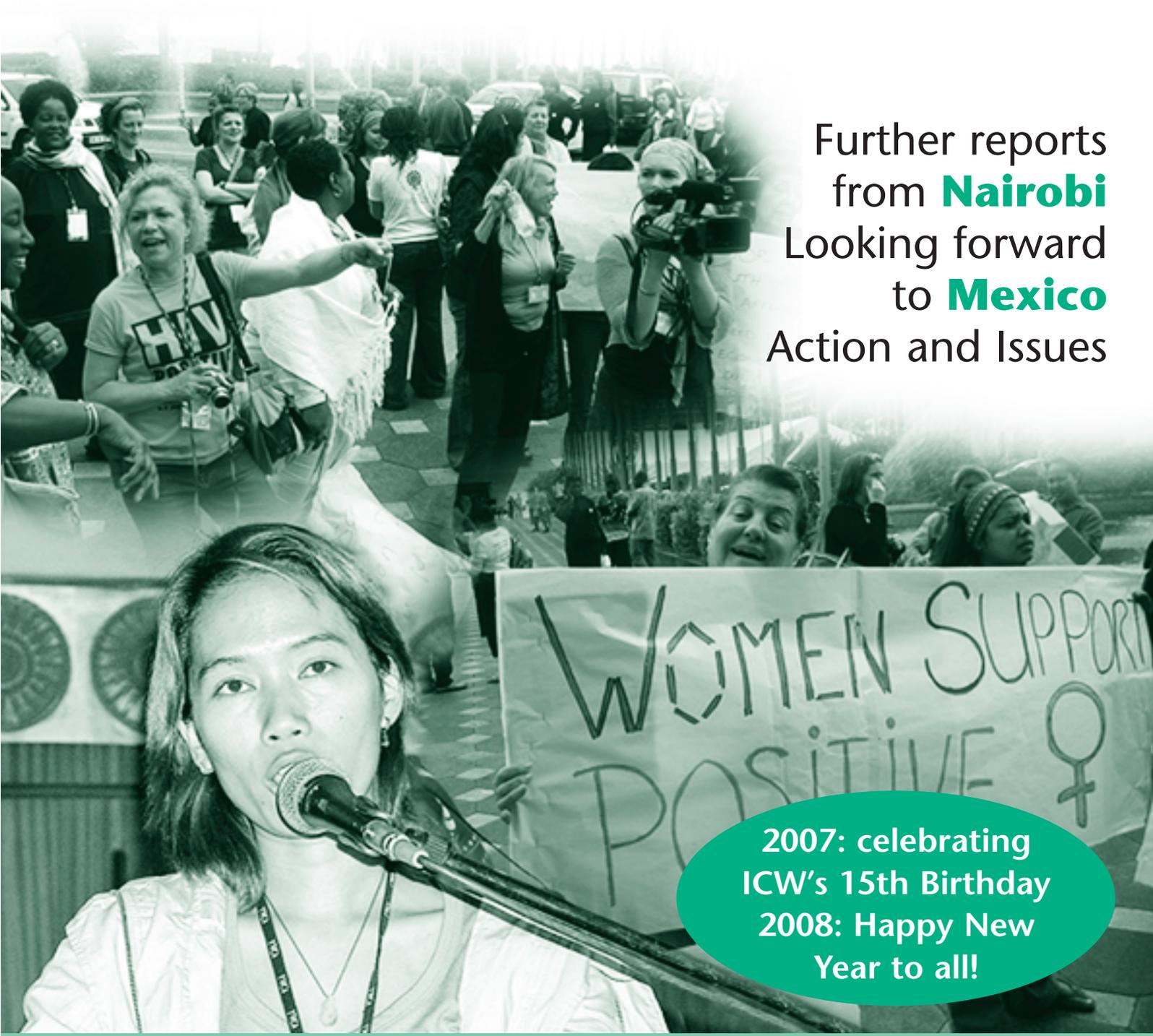


ICW NEWS



Further reports
from **Nairobi**
Looking forward
to **Mexico**
Action and Issues

2007: celebrating
ICW's 15th Birthday
2008: Happy New
Year to all!

Special Focus: Reflections on our work/planning for the future

inside:

Migrant women's lives; young HIV positive Australian's experiences; learning about the ISC; regional report cards; Muslim positive people in Kenya; and much more.



AIDS 2008: Rolling on to Mexico

The XVII International AIDS Conference will take place in Mexico City 3-8 August 2008. ICW will again be an official conference partner, albeit with a reduced voice in the organisation of the conference. For the first time, ICW and GNP+ (Global Network of People Living with HIV/AIDS) are sharing one seat on the conference organising committee. At this point, we are unsure exactly how this reduced power will affect ICW's presence at the conference.

Organisation of the AIDS Conference

AIDS 2008 is convened by the International AIDS Society (IAS). In Mexico local partners include the federal government of Mexico, the municipal government of Mexico City and local scientific and community leadership. Besides ICW and GNP+ international partners for AIDS 2008 include UNAIDS; ICASO; World YWCA; Asian Harm Reduction Network (AHRN).

Fiona Hale with her daughter Laura



ICW Members: Apply for a Scholarship to the AIDS 2008 Conference!

If you wish to attend the conference you must apply for a scholarship or register directly with AIDS 2008/IAS. The forms must be accessed, filled in, and submitted online.

AIDS 2008 Scholarships

The conference organisers have stated they are committed to making AIDS 2008 accessible 'to people from resource-constrained environments and to young scientists globally.' They will award scholarships for some delegates 'from developing countries, community groups, marginalized communities, people living with HIV and AIDS, youth and students to help them attend.'

A limited number of scholarships will be available for HIV and AIDS related media representatives from around the world.

Think about submitting an abstract

There are a limited number of scholarships for AIDS 2008. Having an abstract accepted is the best way to get to the conference. So think carefully in order to present yourself in the most advantageous way possible, bearing in mind what the IAS is prioritising.

Look on www.icw.org for some practical advice on how to submit an abstract.

Scholarship Information and Deadlines

If you are applying for a scholarship you must complete the online International Scholarship Application Form.

This form will be available through the conference website: www.Aids2008.org, from December 2007.

The deadline is 26 February 2008

For any questions concerning the International Scholarship Programme you can email:

internationalscholarship@aids2008.org

NOTE: ICW is putting together some practical tips on how to find sources of possible funding for AIDS 2008. We will be posting these on the ICW members email listing. If you aren't on that list, please get in touch with Emma or Carmen at the office by email. (Carmen@icw.org; emma@icw.org) ●

Au Revoir to Fiona Hale

Fiona Hale who recently returned after having her lovely daughter, Laura, to job share the International Network Manager position with Helen Kirkland, is leaving her post in the New Year. Fiona's family is living in Newcastle and with a young child, being away from home was simply not possible. Fiona will be missed by all. (And we all hope she'll continue to be involved with ICW in one way or another!) She has been a stalwart support and inspiration. In the next newsletter (No. 40) we'll carry messages to Fiona from members and staff. ●

From Toronto, Via Nairobi, On to Mexico

“The sharing of our stories is an important action in itself.”

Another gigantic AIDS conference is on the horizon. ICW wants to make links between the 2006 conference in Toronto and the one coming up in Mexico in 2008. The International Women’s Summit, which took place in Nairobi in 2007 forms a vital connection between the past and the future.

Sophie Dilmitis’s reflections on Nairobi highlight both its considerable successes and unmet goals. Can we learn from Nairobi how best to have a strong presence in Mexico, especially when thinking about getting our messages across to the tens of 1000s of delegates who are neither HIV positive or that interested in women’s issues!

Louise Binder tells us about Canadian positive women’s ‘report card’ project which they presented in Toronto in 2006 and which created a big stir among conference delegates and in the press. Could more report cards from around the world be used in Mexico?

Stephanie, bright as a spark, and 15-years-old, explains in an adaptation of her speech at Nairobi why HIV positive teenagers need empowerment and support and a presence at all international conferences in the future.

Positive Women Make an Impact in Nairobi

In *ICW News 38* we reported on the World YWCA and ICW co-convened global gathering of women living with HIV in Nairobi, Kenya, which took place in July. As part of the larger International Women’s Summit (IWS) on HIV and AIDS, The Positive Women’s Forum brought together 281 diverse HIV positive women from every region of the world. Here one of the main organisers, YWCA, ICW ISC member, **Sophie Dilmitis**, reflects on the meeting’s successes and challenges.

and discrimination; human rights, including sexual and reproductive health and rights; advocacy around gender inequality; access to affordable treatment, care and support.

The Forum was an integral part of the Summit, designed from the outset to provide a safe space for HIV positive women to address issues of concern and to strategise for the broader Summit in a closed environment.

What the Forum achieved

- **Inspired positive women to promote and internalise positive women’s leadership, gaining the confidence to become leaders themselves.** Many times, leadership is perceived to come from a person at the decision making table or the one delivering a powerful statement. Yet many HIV positive women leaders have achieved success as a result of their passion and commitment to

meet the urgent needs of the community and not necessarily because they are highly articulate or well educated. One participant, who was asked to moderate a session at the last minute, reported afterwards:

I want to thank you for giving me this opportunity. It is only through these kinds of experiences that I can develop my speaking skills. When you asked me to do this, I was terrified that I could not do it but I have done it and I enjoyed it, so thank you.



Musimbi Kanyoro who stood down as General secretary of the World YWCA during the Nairobi conference

In the lead up to the Forum, a global consultation with over 2000 HIV positive women identified five key challenges to be addressed through the event. These challenges formed the basis of the agenda for the Forum and included: Women’s leadership and economic empowerment; stigma



Inviolata Mbwavi, Kenyan ICW member, speaking Nairobi Town Hall meeting

opportunity to come together to discuss their lives and issues. Some may ask, where are the actions? Where are the next steps coming out of this forum? But it's important to recognise that the sharing of our stories is an important action in and of itself, and the first step toward actions and recommendations.

HIV positive women's voices were heard throughout the Forum and the Summit, raising awareness of our issues among a broad audience of policy makers, leaders and activists. HIV positive women also provided leadership in all panels and sessions, not just in the Forum. It was important that all participants had the opportunity to learn about the issues facing women living with HIV. A YWCA delegate from Northern Europe commented:

I have never been so emotionally challenged by the International Women's Summit. I had no idea until this meeting what an enormous issue HIV and AIDS is for women in the world. Meeting and hearing so many positive women speak out about the issues has been extraordinary. This has been an immensely positive experience, which I will never forget.

Goals for future meetings

Because the size and scale of the Forum was unprecedented and there was so much to cover in one day, we were unable to put forward recommendations to the positive women's movement as we had intended. Future meetings of this kind need to be sustained in order to build upon the learning they generate to guide future policy and action. As one participant reported:

We need to intensify advocacy and mobilisation at all levels. Issues were articulated well but it is up to us to take it further for action. It is still a dream that many poor countries need clear strategies. I am realising that I have been a bit weak and selfish in my community. I need to bring other positive women on board to add their voices.

Although the Forum addressed many challenges faced by positive women, issues around economic empowerment require stronger engagement by the HIV positive



This kind of capacity, leadership and confidence building was one of the desired outcomes, which was successfully met for many participants.

- **Addressed specific issues central to the lives of positive women.** Opportunities to meet other HIV positive women at events such as the Positive Women's Forum can be a highly emotional and life changing experiences. They are often the only time when support is readily available and where common challenges can be shared in a safe and non-threatening environment.

- **Offered support to HIV positive women who may not have been connected to the HIV positive women's movement.**

There were stories of participants who had left their home countries for the first time to meet other positive women from around the globe. This gave positive women an opportunity to connect to the global movement of HIV positive women.

- **Integrated the HIV positive women's movement into the broader women's movement.**

Important progress was made in this area. Alice Welbourn, former ICW Chair, remarked during the Summit, that at the World YWCA's last IWS in Brisbane four years ago, there was one openly HIV positive woman to every 200 women who attended and HIV and AIDS only had a small part on the agenda. Since Nairobi there already are regular reports of collaboration taking place between ICW and the YWCA.

From the personal to the political

In Nairobi we created space for HIV positive women to share their stories and experiences with each other towards the goal of developing a common advocacy platform. As Darien Taylor reported back in the closing of the Forum:

There was lots of storytelling throughout the day.... something that tends to happen whenever HIV positive women have an

“The time was too short, the numbers so large, the people are so right, the languages so diverse, the feelings intense. Each story is worthy and each takes time.”

Nairobi participant

women's movement to ensure that women are economically independent and are in a position to make safe life choices

At the closing of the Positive Women's Forum Darian Taylor urged that:

We must continue to share our stories, growing an openness that encourages others to change perceptions and create new ideas. We must maintain contact and keep up the momentum, be proactive with any and all opportunities that come our way, empower one another and

ourselves, enjoy pleasure in our lives and sexual relationships and continue to bear healthy children. We must continue until women's rights, especially HIV positive women's rights are upheld and

respected at all costs. HIV positive women are strong partners who are fighting for their own lives as well as the lives of those in their communities and are not helpless marginalised victims. ●

“For the majority of women, networking, partnership building and sharing experiences were the motivating factors and benefits of attending the meeting.”

If You Don't Know Where You're Going, Any Road Will Get You There

“I had a boss who used to use this expression to explain the value of planning and evaluating any situation or project. It has stayed with me and influenced the way in which I do my HIV work.”

Louise Binder writes here about the value of country level report cards as an advocacy tool.

When the 2006 International AIDS Conference was announced for Toronto, women who worked in the AIDS and women's health communities and a few far sighted men in Canada, developed a plan to ensure that women's issues were squarely on the international agenda at the conference.

In Canada, we had alleged that women's issues were not top of mind for governments, researchers, pharmaceutical companies, the media and other key opinion leaders. In order to prove that, we needed a strong evidence base to present to the world. Thus, we decided we needed a Canadian report card to make public at the AIDS conference, much like the old fashioned kind we used to get in school with grades.

First, we needed a blueprint of demands, the equivalent of the school curriculum of subjects. We needed research, epidemiological and other published support to defend the demands. We needed the report card followed by a communications plan to disseminate at the Conference.

We believed it was worth the effort to have a baseline for our advocacy work. We also planned to develop a second report card for the 2008 conference to show what progress, if any, has been made.

More countries could create their own report cards to bring to AIDS 2008 in Mexico. Report cards could also be useful within countries and regions. You can also use report cards for advocacy wherever you live.

I recommend this as an excellent tool for each country and for each HIV community. To help those of you who are interested, here is a step-by-step guide to what we did.

Creating a Report Card

1. Bring together a small group of women to brainstorm areas, which can be measured, that will improve the situation for women, including HIV positive women in your country. Determine who you need to help you, such as experts in

each area. For instance, you might need experts to help you define and grade areas like prevention, treatment, care, prison, sex workers, drug users, reproductive rights, to name a few. Include as many people who are HIV positive or in high-risk populations as you can.

2. Raise funds to bring women together or to have some form of telecommunication.



Louise Binder



3. Bring women together to develop a set of demands in all of the areas that you consider important to turning around the tide of this epidemic for your country and for women. Keep adding people as necessary.
4. Divide people up into expert area groups to complete the demands.
5. Get an interdisciplinary team to write the final draft of the demands and get whole group to agree to the final draft.
6. Raise funds to hire a consultant to write a research paper to support your demands.
7. Hire a researcher or find someone with the necessary skills to develop a background paper that has evidence to support each demand. It will include epidemiological data about infection rates and groups, funding sources and amounts, research on women, government laws, policies and practices that affect dealing with HIV issues. Evidence may be directed specifically at HIV positive people or indirectly, for instance by criminalising sex work, tying funding to abstinence, poor reproductive rights laws, non-existent or poor gender-based violence, rape or property laws, and micro credit plans.
8. From the demands and background research, the team develops a report card – one page if possible – because that makes it easy for the media and press. Rate the stakeholders responsible for the area from A to F, A being exceptional, B very good, C passable, D needs improvement, F fails.
9. Print copies and make a huge poster of the report card. Hold press conferences at AIDS 2008, or at national forums to announce the results and to demand action from the stakeholders who have failed.
10. Present your findings in the Women's Networking Zone. Speak at every opportunity to policy makers in your country, researchers and politicians – everyone you think can help, including the media – to get the word out.
11. Don't stop after the Conference. Keep targeting politicians and other stakeholders and advocate for implementation.
12. If other countries in your region have done a report card use it to embarrass your country into action.

Creating more country report cards

As I have said this report card can be an excellent tool for public awareness for people in your country as to the state of affairs there. It will also serve as an excellent advocacy tool to get commitments from our governments to act. If we can get report cards from countries from the same area, hopefully some competition will develop. A joint press conference will certainly lay bare these differences and the reasons for them. It will open the discussion about why some countries do so well in some areas and others not.

The sheer number of report cards we can get from different countries will show our strength and our commitment to work together around the world and in partnership with ICW to ensure that women's issues are not ignored on the world stage. ●



Stephanie

Something to Say to the World

Stephanie, a young HIV positive woman from Australia spoke powerfully to the Nairobi meeting.

I was born HIV positive 15 years ago in Australia. You may think that because the medical care is so good in Australia, the social side would be good too. But you would be wrong. Today I'm not like the other schoolgirls.

Well, I am, but I also have to deal with secrecy, discrimination, uneducated attitudes at school, what to tell my negative friends, and the constant fear of being

found out. A fairly normal activity for an Aussie teenager – sleeping over at a friend's house – demands more consideration than simply packing pyjamas and a toothbrush. It becomes a major issue, with having to hide medications from friends and their family.

“Go out today with the power of speech.”

But the very fact that people like me are still here, shows that people with HIV are some of the strongest people in the world – the survivors who have lived through the war of HIV that the newly diagnosed have no concept of. I was born during that war, and survived. No one expected me to live, because of ineffective treatments back then.

School discriminated against me

Medications are much more effective now, but what can make life hard is the attitude and stamp society have put onto my mum and me.

For any teenager high school is hard. But the cloud of secrecy looms over my head every day. I've heard the worst-of-the-worst AIDS jokes, even at the private catholic school I used to attend. I separated myself from people who told those jokes – which were pretty much every student there.

And when I told the vice principal that I was positive I was told to leave, unless everyone was informed. I was shocked and horrified to see my nightmare come true. Even though it is illegal, the school continued to discriminate against me – and told all the staff of my HIV status. I bailed out, knowing I could not win.

Camp Goodtime

The only time in my life when I don't have to be scared of discrimination is once a year at a national camp for HIV positive children and their families called Camp Goodtime. We know as we enter camp, we are going to be 100% understood and loved. I can tell you now, there is nothing like the bond between positive teenagers. When we get together there is no stopping the laughter, tears, support and stories of past camps and memories of members who have died. This camp means more to positive teenagers than their medicine. And it is horrible that no one will fund it.

I will never forget a speech given by 16-year-old Shannon at a camp remembrance ceremony, where we release balloons containing messages of love for family and friends who have died. I was ten years old.

Shannon had just lost his parents and he spoke with such love, his voice made everyone go silent – and with the knowledge



Positive Women's Rally in Nairobi

that everyone at camp would get him through this tough time, he spoke about his hardship and his parents for the first time since they had died. He was the oldest positive survivor at camp, and he shared with us a saying that gets me through everyday:

Those who matter don't mind and those who mind don't matter

That saying has stuck with me all this time. And now it is my turn to inspire the younger ones with the same words that got me through.

We may be known as 'The Lucky Country', but we are a country where fear still has a strong hold, and although our education system is good by world standards, HIV education in school is next to nothing.

Inspirations

If it wasn't for one person – my mentor, Bev Greet – my country would have taken a long time to recognise women and children as HIV positive people. She helped start the first women's support group. If it wasn't for her, I wouldn't be here introducing you to the positive teenagers of Australia. She opened my eyes to making the change yourself instead of waiting for someone else to.

I'd like to make a special mention of the HIV Speakers Bureau in Australia – because they taught me how to speak. How to find the strength, and

the right words to touch people's hearts. They truly know the power of words and shared experiences. Don't let anyone try to take away your power through fear or discrimination and remember, you are stronger than you could ever know.

Today I ask you to take my story, and use your own, to make a difference! Speak up for your rights because you are worth it. You are living proof that you can make it in this harsh world with HIV.

My name is Stephanie. I have lived through the war of HIV and I have something to say to the world.

Do you? ●

“The HIV positive teenagers of Australia are not going down without a fight.”

My Passion is Advocacy

Maura Elaripe Mea is from Papua New Guinea, the largest Pacific Island. She is a new member of the International Steering Committee, representing the Asia/Pacific region.

I am a nurse by profession. I was first diagnosed HIV positive in early 1997. I had two babies who both died as a result of stigma within the hospital and also the clinicians didn't know how to care for the babies of positive women at that time (1997-1999). Four years ago I walked out of my marriage as I couldn't handle the expectations, pressure and demands made on me. Since then I have gone from strength to strength learning new things about HIV.

What I am doing?

Currently I am a board member of Igat Hope (the national network of PLHIV in PNG). I am also the Igat Hope representative to the Asia Pacific Network of People Living with HIV/AIDS (APN+), a steering committee member of APN+, and also a committee member of WAPN+ (Women of APN+), as well as my ICW position.

The Women's Wing

In Igat Hope I aim to start up the positive women's group, which is a big struggle for me as there are so many challenges. We started the women's wing in Igat Hope last year and named it WABHA PNG (WABHA – Women Affected By HIV and AIDS). We had our first ever workshop on Training in Advocacy and Positive Living (TOT) in November 2007. That will be followed by a series of workshops on adult literacy as this is what the positive women say is a big barrier in their involvement to HIV activities nationally and internationally.

“Since then I have gone from strength to strength.”

“To be a successful advocate we need to be enthusiastic.”

Advocacy

Advocacy has always been my passion. But being the only one in my country who is exposed to a lot of things both nationally and internationally also makes it hard for me to advocate on identified issues. I do it in a smaller way in PNG. But when I'm given the privilege to present in conferences or workshops I take it as an opportunity to highlight some of the difficulties that we as positive people in PNG face. One of these opportunities was the IAS international treatments and pathogenesis conference in Sydney recently. When I was asked to talk at the opening ceremony as a rep for positive people I grabbed it and made headlines in the media on the issues affecting positive people in PNG and worldwide.

My word of encouragement to all positive women

To be a successful advocate we need to be enthusiastic about it. Keep ourselves updated on latest information and findings about HIV. We have to ensure that we not only attend organised activities but also take part. When you know what you want to achieve it makes a lot of difference to your advocacy plans and strategies. And we also need to learn from our pioneers about what they have gone through and how they have managed to succeed. Information sharing is vital and we all have different experiences in our lives.

I wish you all the best in the years to come and lastly as we say in PNG: LAIKIM YUPELA NATING TRU.... Love you all to the fullest. ●

Breaking the Silence Beyond the Veil

My name is **Kauthar Bitok**. I am the Deputy Director for Muslim People Living with HIV/AIDS in Kenya. I am an active member of ICW.

The purpose of writing this is to show appreciation to the ICW London office for the continuous supply of newsletters for the Muslim women. In the year 2004, I was public about my HIV status and as a woman living with HIV. I was condemned and abused by the mosque leaders and I was not even allowed to attend the mosque prayers. At that time I faced a lot of stigma and discrimination from my Muslim community since they believe that being HIV is a sin or a curse for being promiscuous. I didn't stop but went ahead to form a network for Muslim people living with HIV/AIDS in Kenya. At that time we did a lot of advocacy on prevention and access treatment among the people who live with HIV/AIDS. In our first workshop we called it 'breaking the silence beyond the veil'. This means that as a Muslim women when you have the veil over your head, no one knows that you are HIV positive or about the health problems facing women.

All wanted to be members

In one of the workshops for empowering women, I talked to them about ICW and being members. I supplied them with the membership forms and all wanted to be members. They filled the forms and I brought them to the Toronto conference and delivered them to the ICW booth. Since then, most have come out publicly. We always meet and share our experiences. We do home visits, volunteer counselling and there is *no more silence*.

Please continue giving us more energy by encouraging us as much as possible. You are our inspiration.

Live longer ICW! Together we shall end the epidemic. Today our youth don't know a world without HIV. We want our future generations to live in a world free from HIV. ●



Kauthar Bitok, Deputy Director for Muslim People Living with HIV and AIDS in Kenya



Elena, her husband Denis, and his son on their wedding day

ISC member from Russia, **Elena Spitsina**, shares a photo of her wedding day and describes her feelings. 'My husband's name is Denis. My marriage occurred on August 25 2007. I am very glad that I have found a good person. Now together we study how to live with HIV. For me the meaning of the life has become even deeper. Because of Denis I have learned to share and talk more about the present. In childhood I dreamed I would marry and be a good wife and mother. My dream has come true. But now I have matured and understand that the main thing is not to marry. The main thing is to find the friend who will understand you. Together we are more cheerful.' ●

Who Am I? No Way!

We all have a mixture of different identities. Imagine that you grow up in one culture, with certain expectations and find yourself living in another land, where your old self is shaken if not wiped out. Here, **Helen NB**, writes about being a migrant, an HIV positive woman, a mother, and a black African woman living in Europe.

Why is it that being a migrant often takes away all that you are and defines you simply as a migrant? I am as human, and as much a mother, or daughter, friend, as anyone else.

I am a mother, but for years I was not able to be united with my child (a minor at that time) because I was a mere migrant. Being a migrant brought my social ties to a halt and the negative experience of losing five years of a mother-child relationship has continued to rob us of harmony in our humble home of two.

I was and still am vulnerable to social and ethical abuse as I strive to prove who I am. Take the example of renewing my residence card. Whereas medical information is supposed to be private, in my case all the administrative workers of my area know about my health records. I had to present a medical form to ascertain that I am still HIV positive as a prerequisite before my card could be renewed. Ironic, isn't it. I'm still HIV positive!

How could I not worry?

While determinants of my health like income, housing, and lifestyle were never harmonised, in the case of a migrant my doctor time and again advised me not to worry. I lacked a sense of self-worth, had no job, no warm shelter, and no communication with my family before I could be allowed in the women's centre. How could I be blind to such happenings in my life and not worry?

Everyone needs to be trusted; but who is going to trust a 'migrant'? When I tried to try to make friends with nationals I was accused of looking for marriage as a ticket to my legalisation in the country or as someone interested in their money be it men or women.

Sexuality and loneliness

I am a woman and very alive. I am entitled to my sexuality. Yet those who approach me runaway as soon as they learn of my HIV status. Rude they are sometimes; as they generalise and say no wonder, all migrants are HIV positive. And sometimes I inwardly

laugh. Most of these people have no idea about their status. They have never tested. At least I know and I get the help I need to keep healthy and live longer

Loneliness surrounds me all the time. During holidays the language school closes and that means no contact with the rest of the world. Believe me, a month of summer holidays can pass without me exchanging a word with another human being.

Education not recognised

I did not survive the marginalisation either. I am educated or at least I believe so, but my degree is not recognised. Each year my host country gives over 70 scholarships to students from my country of origin who are from the same university I studied in and who often have the same Bachelors degree that I possess. Wait! I am a 'migrant' and that makes my degree unrecognisable. I was left to look for cleaning jobs, or picking fruit. Aah! You do not speak the language of the land so go from door to door, farmland to farmland to get a cleaning job at 3 euros per hour whereas the minimum that humans get is 6 euros. But remember I am a 'migrant'.

A migrant and black

Then there is the nightmare of searching for housing. Until I came across a gentleman I consider kind, I moved around and about, getting appointments where landlords failed to turn up. This gentleman said to me, 'sorry, I cannot rent you my studio. Not only are you a migrant but you are also black, you are dirty, irresponsible people'. I thanked him and told him that I admired him. He did not understand but after more than 150 phone calls, 30 bounced appointments, the gentleman was the only genuine person that told me what was really going on. From then on I made calls saying, 'hello, I am African, is your studio still vacant?' I never again got hoax appointments. The first person to say yes, it is vacant was my first landlord who was ready to rent me her studio regardless of status and colour.

It Can't Be!

Lack of understandable information was also detrimental. I am an English speaking person in a non-English-speaking country. For over three years I never made real friends, never expressed emotions, and was not fully aware of what was happening around me.

She laughed

There has been and continues to be innocent discrimination as I live this migrant life. I remember when I got a job as an Administrative Assistant and on my first day the first person to welcome me took me to the housekeeping section and started explaining to me all the cleaning procedures. I told her I was working in Administration. She laughed. 'I thought you were a migrant', she said. What has my migrant status have to do with my capabilities? And trust me this has continued to rob me of job opportunities.

I am a mother, a daughter, a friend and a human being. I have attended orientation courses. I have learnt the language of the land up to the highest level. I have had an opportunity to work in Administration. I proved my humanity and my child was allowed to join me just a year ago in June 2006. At 41 I know the sky is no longer the limit since men have gone to Mars and rockets go right through the sky. To me, in life there are no limits to what I can achieve. I am now a graduate student studying a Masters of Arts degree in Migration Studies. My motivation to apply for this course is that after my course I will be able to:

- Hear the voices of the minority migrants (5% of the world population) and let them be listened to, women and children in particular
- Follow my passion in humanitarian work
- Be a role model and motivation to many single parents, widows, mature people, migrants and HIV positive people that life is there, whenever and wherever you pursue it
- Encourage fellow migrants to stand up for themselves and have life
- Be employable (I hope) on the international arena (wherever I choose to live)

This is to mention a few of my motivations.

I continue to miss the freedom to associate, to act silly (have fun), because every move I make, nationals call the watchdogs that are suspicious. Their suspicions have a direct impact on your file. Buy new jeans and your bank account will be called for inspection.

Never give up

But hey! Not all is bad. I have met wonderful, selfless, non-judgmental, all-embracing friends. Friends that think of me as an angel with a mission on earth. They believe in my courageous, spirited and never give-up attitude. My host country too has given me the greatest gift, which gives me available and accessible healthcare and HIV treatment.

But let us agree that being migrants should not take away what we are in the first place, women, mothers, daughters, and friends. ●



Helen NB

Chairing the ISC –

How do ICW's governing structures work? **Fiona Hale** digs beneath the surface and uncovers what chairing the ISC meant to MariJo Vazquez, and how she embraced her work for ICW so creatively and successfully.

I have had the great pleasure of working closely with MariJo during her time as Chair, and am very sorry to see her go. All of the positions in ICW's governing structures – both the International Steering Committee, or ISC, and the Board of Trustees – are unpaid, and often little recognised. Yet they carry heavy responsibilities. In MariJo's case, this meant around four hours' voluntary work every day as Chair.

Doing what, you may ask?

Networking and representing ICW: As a key representative of ICW internationally, the Chair of ISC is in great demand from the global policy community. So MariJo has dealt with a constant stream of requests for her involvement and comments on issues related to positive women's rights, from the likes of the World Health Organisation and UNAIDS. She has worked with the ICW staff, membership and ISC to ensure that what she says to those bodies reflects broadly the views and priorities of HIV positive women around the world.

Agreeing positions: Often, though, ICW members have many experiences in common, but do not necessarily agree on solutions or ways forward. In that case, MariJo has led us in trying to establish a position, which fairly reflects the issues and the differences.

Take the issue of abortion. For some positive women, this is a right they absolutely want to be able to claim for themselves. In some countries abortion is illegal. For others, on a personal level abortion is something their faith tells them is wrong. In a number of cases we know that positive women have been subjected to forced abortions, against their will, because someone else thinks that women with HIV should not have children.

So how should ICW position itself on this issue, to best represent ICW members of every opinion? MariJo, as Chair, has successfully and tactfully helped policy-makers to understand why it is not always possible to say, 'This is what HIV positive women want' – because it depends on which HIV positive women you are referring to. One of ICW's values is 'self-determination'. MariJo has promoted this by emphasising the importance of each woman living with HIV having the possibility of deciding for herself what is best for her, in her own context and situation.

So besides representing ICW internationally, what else does the Chair of the ISC do?

Chairing: Well, chairing the ISC itself is not a small task! You will know that ICW has been trying to increase accountability within our network, and part of that involves the development of the ISC as a group of women who are elected as regional representatives

by other ICW members from their region. The list of current ISC members is on the back page.

This sounds good in theory. In practice, it means that ISC members are spread around the world, speak different languages, come from different cultures, and have limited opportunities to meet as a group. So the Chair has the responsibility of making sure that all members of the group are communicating with each other.

Since MariJo is fluent in French and English, as well as her own language, Spanish, she has taken on the task of translating all ISC communications so that Francophone African, Spanish-speaking Latin American, and English-speaking members can all understand each other and join the discussions. For some, communicating in any of these languages is difficult, and MariJo has worked to ensure that communications are as clear and as simple to understand as possible. She has also spent many hours calling ISC members by phone to ensure that email is not the only form of communication.

Thinking Internationally: For some ISC members, joining the ISC requires a new way of thinking. For women who have been very focused on calling for positive women's rights in a particular country or region, it can be challenging getting to grips with thinking internationally, beyond specific country or regional contexts. The Chair is required to think internationally herself, and also to help the ISC as a body to think beyond geographical borders. When I asked MariJo for her reflections on being Chair of the ISC, she told me that one of the hardest things for her was:

Getting to be informed about (and getting to understand) what is being done not only in your region but also in the network, so that you

MariJo and Shari
in Toronto 2006



What MariJo Did

can give support at different levels. That is what was most difficult for me because it implies you need to learn more and more about projects, issues, positions, that are not what you can see in your daily work. And though I do not think that I got to it well enough, I have tried hard so that I could have elements of understanding at a global level, which I firmly think is the role of a chair.

In addition, she has organised, with the help of the International Support Office, two ISC meetings during her term of office – one in Toronto in 2006, and one in Nairobi in 2007.

Steering the ISO: And finally, on behalf of the ISC MariJo has carried out the duty of steering the work of the International Support Office of ICW, in London. This involved a meeting by phone every two weeks with the UK Chair and the International Network Manager, plus frequent calls and emails in between, to ensure that

the decisions and direction the work of the ISO is taking remains in line with the International Strategic Plan and the wishes of the ISC, as a governing body of ICW internationally.

I have learnt such a lot from working with MariJo. Some of the things I have most appreciated about MariJo include her ability to understand the details of ICW's work while focusing on the bigger picture; her diplomacy, tact and friendliness; her language and communication skills; her openness and honesty; her keen sense of positive women's rights; her ideas and analysis of the challenges facing ICW as an international network; her warmth and sense of fun.

While MariJo is standing down as Chair, she is of course not leaving ICW, and I'm sure we can look forward to her continued involvement as a strong and passionate advocate for the rights of women living with HIV. ●

Sharing the Role of Chair: welcome Bev and Dorothy

At the ISC meeting in Nairobi, held in July, two long-standing members of ICW's governing body agreed to share the role of Chair until August 2008, which we hope will make it a little less time-consuming for each of them. **Bev Greet** from Australia, and **Dorothy Onyango** from Kenya, will be Co-Chairs of the ISC. We wish them all the best in this role.

Parricia Perez's New ICW Role

Patricia Perez of Argentina will also be an official representative of the ISC, particularly covering work relating to the Mexico 2008 conference, and the Peace Campaign. We are grateful to all three, and look forward to working with them for the benefit of ICW globally.

An Amazing Woman

Alice Welbourn reflects on MariJo's leadership qualities: HIV positive, a storyteller, founder of *Creacion Positiva*, a translator of ICW publications, MariJo is also a long-term member and friend of ICW.

MariJo represented ICW Europe from 1999. During the Barcelona AIDS Conference in 2002, *Creacion Positiva* hosted a free parallel programme. Here the 'Barcelona Women's Bill of Rights' was created, key in defining sexual and reproductive rights of us all, especially HIV positive women. MariJo also co-founded the ATHENA network, serving on its steering committee.

Although MariJo is naturally shy,

she has shown great leadership qualities, guiding ICW as its international chair and representative. She speaks her mind firmly when required.

The Athena Network reported from the July 2007 International Women's Summit in Nairobi:

MariJo Vazquez delivered a riveting opening to the Summit on behalf of ICW during which she spoke of sexual pleasure, the harmful effects

of patriarchal systems, and the advancement of women's rights as central to a successful response to HIV and AIDS. MariJo spoke directly and with passion about taboo topics and critical gaps – and did so with the President of Kenya by her side.

MariJo thank you so much for all that you have done – and will continue to do – for us all. ●

ICW International Steering Committee meeting in Nairobi, July 2007

Marijo Vazquez reports

The International Women's Summit in Nairobi in July 2007 provided a low-cost opportunity to hold a one-day meeting of ICW International Steering Committee, since many ISC members were attending the Summit. **MariJo, Bev, Dorothy, Lynde, Sophie, Ratri, Paulette** and **Hilda** met, and were joined by one of the UK Board Co-Chairs, **Liz**, as well as International Network Managers **Fiona H** and **Helen**.

'We all agreed to support the Peace Campaign.'

New energy

Although this was the third meeting of the ISC since its creation in October 2005, it was the first one for Ratri (who joined the ISC last year), Sophie (elected to the ISC by European ICW members in June), and Liz and Helen from the UK. So along with the wealth of experience brought by long-serving members, we had some welcome new ideas and energies in our discussions.

We were able to discuss some of the policy issues where ICW members around the world have very different opinions. As an example, we used the increasing criminalisation of HIV transmission, where positive women may have very different views depending on their experiences.

Collective positions

We agreed that we needed to come to a collective position for ICW, and come to terms with any contradictions, because they reflect that we represent a very broad network of women living with HIV, who have different cultural and religious backgrounds, and various life experiences.

To enable the ISC to fulfil its role more effectively, we agreed to:

- Develop a global warning system – to consider issues, which are on the horizon and will have political or positioning implications for ICW.
- Establish quick response teams for specific issues, projects, and/or partnerships.
- Agree mechanisms for taking positions, especially where consensus cannot be reached.
- Develop our understanding of multi-agency partnership working at global policy level.
- Ensure clarity where there is disagreement, and name it, rather than try to bury it under a false consensus.
- Develop an induction pack and procedure for new ISC members.



Women in Nairobi

Accountability

We also agreed that the ISC needed to continue to increase our accountability to ICW members, being one element of it that members elect their representatives to the ISC. This has now started to happen in Latin America, Europe and Asia Pacific. The country and regional meetings currently taking place or being planned in Southern and East Africa should continue this development, though there is clearly a lot more work to do on increasing accountability to ICW membership around the world.

To function effectively, the ISC needs a budget, to allow members to communicate with each other, have some translation and administrative support, and to be able to meet periodically. We will work on preparing a budget to allow ICW to fundraise to meet these costs.

Congratulations Patricia Perez

All the ISC congratulated Patricia Perez, ISC member for Latin America, for her nomination for the Nobel Peace Prize for 2007 and we all agreed to support the Peace Campaign she is leading, which aims to use her nomination to campaign for a stronger focus on peace as an opportunity to stop HIV/AIDS. ●

Letters

My thoughts about an ICW website Memorial Page

I am **Misozi Zulu**, from Zambia. I am 27 years old and mother of two lovely children aged eight and three years. I have lived with HIV for the last four years and have gone public about my status to assist women who are silently suffering behind closed doors for the sake of marriage and loyalty.



Misozi Zulu

I am trained in the following areas:

- stigma and discrimination reduction
- management of ARV therapy/ART support

I am working as a volunteer in the support group for the Network of Zambian People Living with HIV/AIDS (NZP+)

My main area of interest centres on proactive policies and advocacy for women in the HIV/AIDS field. I believe in advocacy and it has always been my great desire to have a direct link to policy makers in order to assist voiceless communities, especially women, young girls and children.

Several issues ago you asked if the ICW website should have a memorial page. My thoughts are that it might be a good idea but remember that not all of us are out and that we need to ask permission from their closest families. We cannot make decisions on behalf of our sister who are no longer there. ●

Congratulations Lydia

Lydia Rwechungura from Tanzania, ICW project officer for the Parliamentarians for Women's Health Project, has given birth to twins! Lydia, we wish we could see your little ones and hope they are bringing you and your loved ones much happiness (and not too many sleepless nights). ICW sends its warmest good wishes. ●

Correction: In ICW News 38 we wrote on page 11 that **Penny Shillula** was a member of the People's Living with HIV Committee when she is in fact a member of the Khomas Women's Health Committee. ICW offers our apologies for the mistake.

Can you draw cartoons or illustrations?
ICW News needs you!

Thank You to everyone who contributed to this issue: Emma Bell, Luisa Orza, Franck Pertois, Carmen Tarrades, Sophie Dilmitis, Alice Welbourn, MariJo Vazquez, Helen Kirkland, Fiona Hale, Fiona Pettitt.

All Nairobi photos in this issue courtesy of YMCA website. Thanks.

Please write for your newsletter

We welcome short pieces – anything from 200-500 words from positive women (personal experiences, news, debates, information, and ideas for future issues), as well as letters and photos. First time writers are welcome.

Poetry is welcome as well as photos and drawings you are willing to have published in the newsletter.

We cannot guarantee publication and may have to edit. Send by post (address on back of newsletter) or by email to Sue O'Sullivan at ICW: sue@icw.org

Get the Newsletter by Email!

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

ICW NEWS ISSUE 39

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



Issue Number 40
Deadline: 15 January 2008

Send you news, views, and testimonies for this general issue.

Issue Number 41
Deadline: 15 April 2008

Focus: What does ICW do to encourage involvement, engagement and participation from members, what are the barriers to these, and how can we begin to remove them?

This newsletter will explore issues relating to implementing GIPA principles *within* our global membership organisation.

- How can ICW engender feelings of ownership of the network from the membership?

Network evaluation activities and regional and country level strategic planning meetings shed light on members experiences of participation or exclusion, and issues facing the network.

- How can ICW support ICW members' involvement in areas of policy and programme development and other responses to HIV as well as ensuring access to involvement within the network itself?

- Does a feeling of ownership of the network have to happen first in order for the external engagement to happen?

Do you have any thoughts on these issues? We need articles from all the regions for this issue. So get your pens out or open up your computers and get going!

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

ICW International Steering Committee*

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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

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 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

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