

ICW NEWS



Nairobi Highlights

Hilda Esquivel and
Ratri Candrika Phalita
in Nairobi



Special Focus: why we love the ones we love!

Injecting Drug Use: Women Living with HIV and Hepatitis C

inside:

Positive women and their beloveds; Networking in Africa; Nairobi Summit Reports; Injecting drug use, HIV and women; Staff and ISC news, and more.



Nairobi Notes: HIV Positive Women

Very recently ICW members, staff and ISC members took part in a conference in Kenya. **Luisa Orza** gives us a brief overview of ICW's important participation in the Nairobi Summit, while **Fiona Pettitt** reports on a 'town hall' meeting for local HIV positive women, which she attended. And we learn about the ICW members who were honoured during the conference.

ICW brings sexual rights to the fore in Nairobi summit

Luisa Orza reports

ICW congratulates the World YWCA for bringing about the ground-breaking International Women's Summit (IWS) on Women and AIDS, and is proud to have co-organised the first day of the Summit – a Positive Women's Forum (PWF) for women living with HIV. Of the approximately 2000 women attending the IWS, up to a quarter were living with HIV and for once the voices and presence of positive women were felt by all. The PWF provided an opportunity for positive women to explore issues around young women, sexuality, participation, leadership, violence, access to care, treatment and support, economic (in)equality, gender, and the human rights of women and girls living with HIV and AIDS – including their sexual and reproductive rights (SRHR).

Many of the discussions initiated in the Positive Women's Forum were carried forward into the plenary sessions, breakouts and workshops that took place during the rest of the Summit to be shared with non-HIV positive delegates. ICW also collaborated with allies Athena, Voices of Positive Women, and Blueprint, to bring about the Women's Networking Zone in the 'Sokoni' (market place) area. ICW also took part in

one of a series of Town Hall events taking place in different locations in Nairobi, which broadened the reach of the conference, and allowed for the participation of local women living with HIV who were unable to attend the conference.

Sex and motherhood

The theme of positive women's sexuality and sexual rights were especially brought to the fore at this event. Southern Africa regional coordinator **Gcebile Ndlovu** focused her address on the sexual and reproductive rights of HIV positive women during the opening ceremony of the PWF. In her opening address to the rest of the International Women's Summit, long-standing member and International Steering Committee chair, **MariJo Vazquez**, spoke of the importance of recognising that HIV positive women are equally as entitled to experience sexual pleasure as HIV negative or untested women. The areas of sexuality and sexual rights were also addressed in several sessions including a workshop for positive women on 'Love, Sex and Abstinence' and a breakout session on SRHR both led by ICW's new project officer in Kenya, **Elizabeth Akinyi**. The Town Hall event, which ICW also co-organised, focused on the areas of sexual and reproductive rights. The event was attended by 500 women living with HIV from in and around Nairobi, and involved a line-up of speakers from Africa, Asia, Europe and North America.

A Call to Action

The summit's Call for Action – a 10-point pledge of commitment – also included a focus on promoting the sexual and reproductive health and rights of all women and girls. It had a particular emphasis on women's ability to enjoy healthy sexual relationships which put neither themselves nor their partner(s) at risk. Led by **Alice Welbourn** from ICW, co-author of the Call to Action, the 2000-strong audience of conference delegates included several prominent public figures. **Musimbi Kanyoro** (who stood down as General Secretary of the World YWCA during the conference) was a strong presence. ●

MariJo Vazquez stepped down as Chair of ICW's International Steering Committee at an ISC meeting in Nairobi. MariJo has been a stalwart of ICW and the ISC. **Thank you MariJo.**



“It doesn't work to pretend that sex isn't happening.”

Lutanga Shaba, director of The Women's Trust, Zimbabwe

Speaking Out

Reaching Out to HIV Positive Women in Nairobi

Fiona Pettitt attended a 'Town Hall' meeting, which allowed HIV positive women not at the conference to be part of a discussion about sexuality and motherhood.

It may have been cold and wintry in Kenya on Thursday 5 July, but the sun was shining on Nairobi City Hall where 500 HIV positive women and their supporters met to discuss the sexual and reproductive health and rights of HIV positive women. This event was particularly important, as it gave HIV positive women from Nairobi the opportunity to participate in a conference, which for many was inaccessible given the high registration fee.

The panel comprised HIV positive women from all regions of the world who spoke powerfully about the impact HIV and associated stigma has had on their lives, particularly in relation to their rights to sexual pleasure and to found a family. The resounding call was embodied in the following quote from ICW member, Louise Binder. *'We're entitled to live. We are entitled to the same rights as all women. We are not victims, vessels or vectors; we are strong and proud leaders in our families, communities, countries and around the world.'*

There were a number of calls to action, among them:

- End the stigma which makes us question our right to found a family
- Ensure that all HIV positive women have access to ARTs to prevent transmission of HIV to our children, and to prolong our lives
- End women's powerlessness through protecting our rights and educating us about our rights
- Ensure the right to freedom and safety from violence
- An end to macho culture, which perpetrates the abuse of women's rights
- End the hypocrisy which expects women to abstain when young, and be faithful when married to men who are expected to have multiple partners in order to impress their peers.

I found this session to be incredibly powerful. As an HIV positive woman I draw a huge amount of strength listening to and discussing with my peers issues affecting our lives, and knowing we have the support of many women who are not HIV positive, or untested. ●

ICW Members Among Fourteen Women Honoured at the International Women's Summit

Women leaders from various countries were honoured with awards for their efforts in responding to HIV and AIDS in their various communities during the opening plenary session of the YWCA International Women's Summit in Nairobi. The President of the Republic of Kenya, Honourable Mwai Kibaki and the President of the World YWCA, Monica Zetzsche presented the awards. The fourteen women were selected by a panel from the many nominations. ICW News congratulates all the recipients and is proud of our members, **Gracia Violeta Ross**, **Kousalya Periasamy**, **Anne Ntombela**, and **Alice Welbourn** who have been honoured.



Women receiving certificates from the President of Kenya

Selina L. Mudavanhu reports from Nairobi

The awards were divided into seven categories and there were two recipients per category. For the **Providing access to treatment, care and support** category, the recipients were **Rose Auma**, 35 years from Kenya and **Anita Isaacs**, 48 from Namibia.

Gracia Violeta Ross (30) from Bolivia (who was not present at the ceremony) and **Madeleine Lubuya Mbuji** (26) from the Democratic Republic of Congo scooped the award in the **Addressing gender inequalities** section.

Kousalya Periasamy (32) from India and **Anne Ntombela** (35) from South Africa were proud recipients of the awards in the **Addressing stigma and discrimination** section.

For the **Innovative leadership** section, the awards were presented to young **Tashinga Matindike** (25) from Zimbabwe and 48-year-old **Alice Welbourn** from the United Kingdom.

For their outstanding work in **Policy and advocacy**, **Irina Borushek** (43) from Ukraine and **Veronica Kini Morfaw** (47) from Cameroon received the awards.

Dawn Averitt Bridge (38) from the USA and **Neema Mgana** (32) from Tanzania were honoured for their achievements in the HIV and AIDS **Prevention programmes** category.

The **Lifetime achievements** awards were presented to the deserving **Professor Miriam Were** (67) from Kenya and **Dr Shiela Tlou** (53) from Botswana. ●

HIV Positive Women

In this issue HIV positive women talk about the ones they love and care about. How do we relate to our partners, family, friends, children? How do we talk to each other, love each other, and gain strength from each other? Here, very different women, all infected or affected by HIV tell us their stories.

Why We Love the Ones We Love – The words of Women from Botswana and Namibia

Emma Bell talked to women she met on a recent ICW work trip about their beloveds. Who were they? What did they do? Some women also talked about troubles in their relationships.

My Family Mean Everything to me

Noluthando Kaulinge is originally from South Africa but now lives in Namibia.

My loved ones are my immediate family – mum, dad and two brothers and two sisters. Without them I don't know where I'd be today. They motivated me and gave me 'oomph' for life. When you hear something like being HIV positive it shatters you. I was just waiting to die. But you can become the next managing director, Bill Gates, or Einstein. My family has always supported me right from the start. Not once did they doubt or discriminate. ●

Veronica Kalambi is from Namibia

I want to talk about my sister – my sister is always supporting me and she asked me not to worry about the past. She encouraged me to get on with my life. And she is the one who is supporting me because I am not working. She has always been there for me. My sister also supports me with my studies. She was the one who paid for my school fees. My sister is married with four kids, three daughters and one son. I also get on with her children – they are like my own. ●

Noluthando Kaulinge
in Namibia



Love's Not Always Plain Sailing

Steady Chick is from Botswana

I want to talk about my boyfriend. I love him; he helps me; he looks after me; he makes sure that I don't sleep before eating. He brings food for my kids. The only problem with him he doesn't want to get tested. He says he doesn't want to know. I love him and want him to stay healthy and get the treatment. He doesn't know about my status. I want to tell him but don't know how. That is why I want him to get tested so we can go together.

My mum also helps me a lot with everything. My mother knows about my status. At first she was upset and it wasn't easy for her, but now she is always encouraging me, like making sure I check my CD4 count.

I love my two sons who are both negative and living fine. But sometimes they ask about their late father. I know they are missing him and that gives me some stress. The first is nine and the second nearly seven. The first has a bit of knowledge about HIV. I told him I was HIV positive and he says he understands. They are taught about it in school. But when I told him he wanted to know if I was going to die. I told him no. If I am healthy I will be fine. I told him if my CD4 count drops I will have to take treatment.

I love my older brother who is sick and he is on treatment right now. He got the illness through sexual abuse. I always try to look after him to make sure he takes his tablets on time and that he is eating well. ●

and Their Beloveds



Sometimes It's Tough

Nelao Martin is from Namibia

It's tough to be a young mother with a young son. Having to drop out of school to look after my son and having to sell flat cakes to buy clothes for him. Things that I never thought I would do. One day, standing under a tree when my son was still a baby, I remember one of my teachers telling me that I had to drop out of school. He said I could start again after a year of breastfeeding.

One day, I was selling flat cakes and waiting for students to come out for break. The principal gave them a lecture about how they must not end up selling flat cakes under a tree. He was talking about me. And he used to be my teacher.

It's difficult; it's quite tough. Who would provide for me? My mother helped but it was not enough. It's tough time now as I am not working and my son is on treatment and he needs nutrition and the father does not want to take responsibility. My son is with my mother on holiday but the issue of his father not wanting to help out made me feel bad. Because there is a difficult relationship between my mother and me. She shows that she is angry with me for being infected and young and it has been some months that we have not spoken.

My son needs some winter clothes. What do I do to get sneakers for the winter? Yesterday when everyone went out I cried tears by myself. If I end my life it will be done – but then I said my son will never forgive me. I went to social worker and they went to the father and he agreed to provide but he never did. I don't regret having a child but I do regret what I am going through. I want to hear him say that he understands what he is going through. Now he does not understand why he has to take these drugs every morning. But he gives me hope and I want him to grow up and accept his status and forgive me for the fact that I came out in public. ●

Project Officer Jeni Gatsi
with Nelao Martin

I Love My Kids

Kenole Leinatsela is from Botswana

I am 29 years old. I love my kids very much – there are three. One is a daughter and she is ten, the second is a boy and he is four, and the youngest, a boy, is two. My daughter is doing standard 4 at the moment. I think she knows about my status. She is negative.

I always take the medication together with my second child and my daughter even helps administer the medication to the boy. The two boys are like twins they do everything together. When one wants to pee the other pees. When you buy them clothes they want the same clothes. They bring lots of joy to

me. I love them so much I cannot do anything without them. They come first even before their father. He is the father to the last one only, but he loves them all just the same. He knows about our status and he's so protective and supportive. ●

'They bring a lot
of joy to me.'

Kenole

Giving Ourselves Permission to Talk about

ICW member **Sophie Dilmitis** talks about love, sex and abstinence in the context of an HIV diagnosis. Sophie is from Zimbabwe and works for the YWCA in Geneva.

Talking openly

This is the only personal testimony I've given on love, sex and abstinence. I don't know how else to talk about this except from my own experience and I believe that part of breaking the silence around HIV and AIDS is giving permission to ourselves to talk openly about sex and our sexuality.

Internalising stigma and encountering ignorance

I was in a caring relationship and unfortunately one night we had unprotected sex and that was all it took. Seven years ago when I heard that the above-mentioned partner had died of an AIDS related illness, it killed anything sexual that was alive in my body. By the time I was actually diagnosed I had locked up my sexuality and thrown the key away.

At the time of my diagnosis I was in a good relationship with someone else and although we had always had protected sex I could no longer have sex with him. I felt dirty, disgusting, used, and as far from sexy as humanly possible. The relationship ended and I spent the next four years celibate. All I could think was: 'they could not possibly want to be with me. I am never going to have sex again.' This is the perfect example of how stigma can sometimes be internalised and actually has very little to do with the outside world.

I missed being in a loving and caring relationship that included sex. I missed someone touching me, feeling every inch of my body with every inch of his, having someone want me, desire me, desire my juice and not be disgusted by it, being connected so intimately, being comfortable with someone when our clothes were off and our bodies intertwined.

Rediscovering a healthy sexuality

During that time I met someone who knew my status and who was HIV negative. It was hard for me to let go. Almost as scary as finding out that I was positive. I was afraid that the condom would break. My associations with sex were not good and I was afraid of what might happen if I ever did it again. I cried like a baby and then had to explain that I had not had sex in four years. I was embarrassed and he was shocked. After that something shifted in my life. I moved from intellectually knowing that I was capable of having a 'normal' sex life to really believing it. Since then I have fallen in love and enjoy good sex in a caring relationship.

Isn't that the way it should be? Young women should have the right to choose when, how and with whom they have sex – or *not*, for that matter. In many cultures it is expected that a woman be chaste and virginal and she is expected to say no when in fact she means yes. Let our NO be NO and our YES be YES. It is so important that when women do become sexually active, when they do say YES, they are clear about why they are having sex and that it is not just about pleasing their partner. It should be a pleasurable event for ourselves and one that we can have as positive women who continue to protect ourselves from re-infection and other sexually transmitted illnesses.

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Sex and Love

Sex messages – let's get real

We all know that Abstain, Be faithful and Use a Condom (ABC) has become a very popular prevention slogan worldwide but it is failing young women as a prevention message. The reason that promoting abstinence-only programmes are failing young women is because it doesn't allow them the opportunity to explore how to make informed decisions about choices that should be available to them.

Just to clarify, I am not against abstinence. I support anyone's right to abstain as I have done on many occasions. It is 100% risk free and you do not achieve that any other way. But some young women choose not to abstain. They need knowledge and support about how to protect themselves and have access to life-saving devices like condoms, especially the female condom.

Which brings me to the B – for Be faithful. I think we need to become realistic about the fact that people come and people go and very few partners remain together for a lifetime. How many women become infected in the marital bed? Am I being a cynic – or would the right word be a realist?

Oh yes, I almost forgot, use Condoms. Condoms give me the security to know that I am protecting my partner and myself but even I am sometimes unable to negotiate safe sex. Once I started talking about this with other women, I found that I was not the only one who was educated, economically independent and aware of my sexual and reproductive health and rights who was unable to always negotiate safe sex. We often refer to women who are poor, economically dependant on men as being unable to negotiate safe sex but I think most women lack control in this department.

Young women – talking about sex

It is vital that youth today have all the facts and not just the information we think they are 'ready' for. Young people have sex for exactly the same reasons older people do. For procreation, pleasure, income – or to avoid being beaten. How will youth know how to avoid harm if we are not even talking to them about sex? Isn't our own embarrassed and shuffling silence blinding our youth to the risks of unsafe and uninformed sex? Are we not part of the problem when we argue for protecting the young against necessary information?

It is often said that talking to young people about sex and sexuality promotes promiscuity. Therefore the subject is avoided, perpetuating the lack of knowledge that exists among young women. Yet many different studies have proven that talking to young people about sex and issues of sexuality enables them to make informed and educated decisions. They are more likely to delay their first sexual experience or abstain. If they do decide to have sex, they will have the knowledge of how to practise safer sex. We have a right to have a healthy and safe sex life and with that comes responsibility. Responsibility is the ability to respond to any given situation. It is our duty to respond now. ●

Love Can Conquer Difficulties

Carmen Tarrades talked to some of the women she met at a recent harm reduction conference about finding and sustaining love while struggling with the stigma and discrimination of being an injecting drug user and co-infected with HIV and Hepatitis C.

Men and Sex

Erin, who lives in England, talked to **Carmen** about her realities and how they impact on her relationships?

When I think about relationships I suppose there are two things that surprise me. I've been a drug user for a long time and most of my friends are drug users as well. So when I was diagnosed I was worried about the future of relationships. I remembered my own fear before I was diagnosed. Then I wondered how I would react if I met somebody who was HIV positive.

Initially I thought it would be very difficult to talk about my HIV positive status with somebody I had just met. In fact when I was first diagnosed I answered an ad in *Positive Nation* from somebody else who was positive. I

Erin

didn't know how to enter a relationship with somebody who was negative. The situation was a bit difficult because the person I wrote to had just met somebody and fallen in love and they were really happy. But they told me to hang in there and don't worry, and don't fear, don't concern yourself too much about it because love does conquer these difficulties. And it really has!

At first I thought men might have an issue if I said, 'I'm HIV positive', but I think that men's desire for sex completely overrides HIV. I was really shocked! Some boyfriends were even prepared to sleep with me without a condom. That's a difficult thing, especially if you are with somebody you love and you have been together for a while – it puts you in a very difficult borderline situation. On the one hand you think, 'Hang on! No! That's impossible. You don't really understand what you are saying', but on the other hand, the person is grown up, we speak about HIV, he knows the issues. So maybe he does know what he is saying.

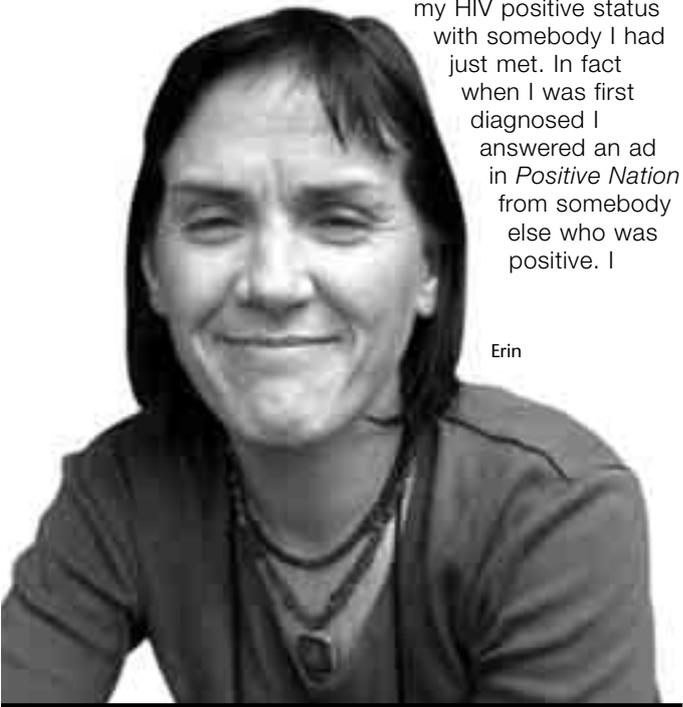
I've had boyfriends where sometimes we didn't use condoms. But I made sure that they took that responsibility. I have just finished a relationship – and he was negative as all my boyfriends have been. We used condoms all the time. It was really amazing sex with this person!

I think that while there are a lot of messages about using condoms, we could do more.

There is information out there about how you can have sex without penetration and stuff like that but there isn't a lot. Information could be more innovative. I always find that lubricants are really important. But often lubricants get left behind when condoms are being given out.

Something I learned from my sex-work days is that lubricants can encourage you to do much more without penetrative sex. For women that's good. But it really needs to be assertive! Someone said the other day that in Africa they were giving out female condoms to women. Obviously there are issues about them, but they persevered. The point was that some of these women were saying, 'you know, my husband comes in and he is very drunk and he wants sex and he won't use a condom, but sometimes he is so drunk that if I use lubricant and a femidom he doesn't even know the difference'.

That's about giving control back to women rather than having the condom that has to be put on the man. It would be good for women to have lubricants with condoms all the time, to have more messages about ways in which women can encourage men to use them, maybe using the same language as men in sex. Because men do have issues about condoms and unfortunately it's not difficult for men to overpower women's decisions. ●





Milena

It's a Lifestyle

Carmen interviewed **Milena** from Bulgaria who describes her history of love and loss.

At the moment it's not a priority for me to test my HIV status. So many people are HIV positive already. HIV in Eastern Europe is so closely connected with drug use that being infected is a matter of time – especially if official policies don't change and if people aren't reached.

I have a friend here who got infected by her boyfriend. He knew, she knew. She loved him and let him infect her without thinking about the future. When you are stoned you do some stupid things from time to time and probably it's as much due to love as dope.

Being a drug user is not only using drugs or dope, it's a lifestyle. This is the only community where you can talk to somebody today, have a great time, and the next day he's dead. It happens regularly among us. Sometimes it's an overdose, sometimes it's bad dope.

We were speaking about love before. I have lost tens, and tens and probably thousands of friends.

People like me who survive for more than ten years, we're the unusual ones. People come to you, you love them, you get used to them, and then they go away forever.

I told you about my two boyfriends. The first died in my arms. He was supposed to start methadone treatment, but before he did he OD'd (overdosed). I weigh below 50 kg but I buried two men – fighters – who were both about 120 kg. Both of them died so unexpectedly and so suddenly. It could crush you. There are not many people who can survive that shock. With my first boyfriend I was pregnant. Several weeks after I lost the father, I had contractions – and the baby went away.

I tried to commit suicide twice. The first time I took a huge OD – and I was saved. The second time I took even bigger OD and cut my veins. But still they managed to save me, probably because my father wouldn't agree to have the life machine turned off, even though the doctors explained that I would be a vegetable when I woke up. I am not a vegetable but I am not the same person. I could never be the same person when within a month I lost the child I had been

waiting years for and the man I loved for more years.

For one and a half years I was crazy. I was stoned to death; I didn't care about anything; I felt sorry for myself; I felt lonely. I haven't lived with my family since I was 15. I have nothing. If I don't work to pay my rent, I am homeless.

But years later I fell in love again. I never believed it could happen. And then I lost this guy too. He was also a drug user but this time it was diabetes. I was at a conference in the European Parliament. On Sunday evening he took me to the airport. He was in the best mood I had seen him for years. We talked so much; we made so many plans. On Wednesday morning he was dead. I left him for two days and my life changed so suddenly and so thoroughly that it is indescribable. But this time, although I am totally devastated, I am thinking about my work as much as I can although I have lost everybody I love in the end. ●

Network Round Up in Africa

Luisa Orza and **Emma Bell**, from ICW's London office, recently visited Botswana, Tanzania, Kenya and Namibia to look at the impact of positive women's networking in the four countries, which is part of the *Parliamentarians for Women's Health Project*. This project is supported by a group of International NGOs and aims to improve women's access to health by empowering members of parliament, community-based organisations and women to work together.

'Now we can see that we have a point where we can channel our concerns. Before when you spoke to MPs they were distant'

Botswana

Emma started in Botswana where she met with 14 positive women from Gaborone. They are keen to run their own organisation. In fact some of the women have already set up *Bomme Isago* – an HIV positive women's network. As yet they do not have enough resources to do much work through the new network.

Thanks to links with the *Botswana Network on Ethics, Law and HIV/AIDS* (BONELA) there have been some training sessions for the women including sexual and reproductive health.

ICW's project officer in Botswana, **Grace Sedio**, explained to Emma that one issue that came up strongly with the women during this training was the right to choose whether to have children or not.

Grace reports:

In Botswana prevention of mother-to-child transmission (PMTCT) falls within the health system. In Botswana PMTCT is considered by the health system to be for women who do not know their HIV status. Sadly HIV positive women who become pregnant have been chased away from support groups. Also, the women taking part in the training told how even if they did not want to have children they had little choice. In fact, because of the policy of routine testing in Botswana most women know their status. Therefore, if they are HIV positive it means they are not considered for PMTCT. Also they are not provided with female controlled methods of contraceptives. Then, unbelievably, members of parliament have blamed HIV positive women for transmitting the virus.

They have claimed that because HIV positive women want to get pregnant they are putting their partners at risk. They don't consider that women could have got HIV from their partners or that many women may not be able to argue for condoms. They also fail to see that if a woman wants to get pregnant, with the right services and support she can greatly decrease the risk of transmission both to a negative partner and to the baby. ●

Namibia

Emma met with seven members of the 13 member Women's Khomas Health Committee, made up of mainly HIV positive young women. ICW's project officer in Namibia, **Jennifer Gatsi Mallet**, described the committee and its work.

The Women's Khomas Health Committee in Namibia aims to empower the 13 members based in Windhoek and four female Members of Parliament through a series of trainings, which include sexual and reproductive health and rights. Those 13 women will then be linked with MPs and with a committee of 26 women to be selected later in the year from the 13 regions of the country. The 13 original women will train the committee members so that they can spread information to women across Namibia, including to women in the villages.

All the women will also be involved in monitoring services and talking to community members so that they can bring important issues to the policy makers. Through training parliamentarians we hope to build the capacity of those in positions of power to engage with HIV positive people in ways that are equitable, respectful, and productive for all involved. 'Now we can see that we have a point where we can channel our concerns. Before when you spoke to MPs they were distant and it was difficult for a community to imagine reaching them.' (Member of Family Hope Sanctuary in Namibia)

Most of the women who met the deputy health minister were surprised by her understanding and enthusiasm for the project. They also said that women that they had spoken to in their communities were excited about this new channel to MPs. ●



Grace Sedio at the International AIDS Conference in 2006



Sithembile Madonko – I am from Zimbabwe originally and I am 35, a mother of two and divorced. I am a third year student at the International University of Management in Windhoek, studying HIV/AIDS management. I have been living with the virus for four years now. If there is someone out there not willing to come out they can come to us and talk to us and we are here to build the confidence in them so that they can live positively like us. Together we will fight, divided we will fall. ●

Nolutthando Kaulinge – I am originally from South Africa. I work for the National Organisation for PLWAs. *Lironga Eparu* means 'learn to survive'. I am 25 years old. I am a young, proud, very strong mother with two children – a girl and a boy. I tested positive in 2002 and am not yet on ARVs. By the grace of god I have not been ill yet. I have support from family and friends that has made me very strong.' ●

Veronica Kalambi – I am a 32-year-old woman from Windhoek and I am a volunteer with AIDS Care Trust helping to register the orphans and vulnerable children (OVCs) and new members who want to join. We have positive women and men as members. I am happy because I belong to a group of women where I can share and learn experiences from them. ●

'Being part of the committee and working with other positive women – it has made me realise that I am not alone and there are other people like me. It has given me the courage to move on with life. I've made friends and I know who to go to if I have a problem. I am no longer shy and locked up in my own worlds and trying to suppress my ideas and myself. I am now open. It has released that inner person and psychologically I am no longer that stressed and oppressed.'

(ICW member from Namibia)



CJ

Lena Nakatana – I am a strong woman activist especially when women's rights are violated on sexual and reproductive issues. This is where the exploitation happened and we are not able to say 'yes' or 'no' to these things in our culture. ●

Penny Shillula – I am a member of the people living with HIV committee. I am a very strong woman and very energetic and an activist. This group has encouraged me to have an HIV test. I like knowing more things, learning, talking to people, helping out where I can. ●



Penny, Jeni, Emma and Lena in Namibia

Martha (CJ) Shindi – I am 29. Seeing people stand up for their own lives gives me hope. When people find out they are HIV positive they lose hope. It is high time to start looking after ourselves. Stand up, go for treatment and live positively. ●

Nelao Martin – I am currently not with an organisation apart from being a member of ICW. I am from Windhoek – I am 24 and a mother of a seven-year-old boy who is also living with HIV. ●

Current and Ex Injecting Drug Users: The Politics of Living with

Carmen Tarrades interviewed some of the women participants at the recent European AIDS Treatment Group meeting about their lives and their thoughts about the most important issues that their community needs to address.

Stigma, drug use, and the media in Bulgaria

Milena from Bulgaria.

I believe global drug prohibition plays the biggest role in ruining the lives of so many young people. For example, in Bulgaria, we have had two years when *any* dose, the possession of *any* quantity, *any* kind of narcotic substance is punished by 3 to 15 years in prison. No other option.

That means if you take drugs with your friend and you see that he has OD'd you have to decide to spend 15 years in prison if you call an ambulance. In those circumstances, many people run away and most of the victims then die without medical help. People are afraid of spending the next 15 years in jail. Maybe if you compare it with saving a human life it is worth it. I don't know, and I thank god I have never been in that situation. I guess you always hope he will recover by himself, without any other medical help. Prohibition has led to enormous rise in the HIV prevalence in Bulgaria.

I really want to tell you about the stigma of being a drug user, and of being infected with Hepatitis C or HIV. To a big extent stigma and marginalisation are on the hands of the TV and the media. The most desperate drug users always appear on TV and inevitably they are homeless, have no moral values, no family, no friends, absolutely nothing, and they look dirty. For a small amount of money to buy dope they are ready to appear on national TV.

Normally if drug users agree to appear on TV they're either filmed from the back, or with a covered face, and a changed voice so nobody will recognise them. Because they hide, the public think we are ashamed of who we are. Then they treat us like we are scumbags. In other words, if she (a drug user) is ashamed and feels guilty, then she should be guilty and ashamed.

But if you stand on national TV and say – with your face showing and in your own voice, 'Yes. I am HIV and HCV positive and a drug user. I want you to understand that my infections are due to your attitudes and to global drug prohibition', then you begin to get respect. After you repeat it several times people begin to listen to your morals. They begin to hear what you say and that you are not ashamed. It's



Milena

then that people start to respect you, despite the viruses you have, despite the drug use.

So, a big part of the stigma is due to our sense of ourselves. If we feel that we don't deserve respect – then they will not respect us. When we stand with our faces open, when we say with our voices: 'Look at us – you have made us be like this. You made injecting drug users look rebellious and not like losers. And the global drug prohibition stops us from going to harm reduction programmes, or from using clean needles. That's why we are infected', they will start to believe you. I don't know what they say behind my back, but to my face they treat me with respect because this is the truth. ●

HIV and Hepatitis C

We Can't Wait for Things to Change

I'm Erin and I live in the UK. I got HIV in 1993 and I was diagnosed in 1995. I'm co-infected with HCV as well.

Something really hit me in this conference. It's to do with harm reduction. We'll have to use more innovative ways to implement harm reduction but it will continue to be a struggle until we start really challenging stigma and the law. Because until the fundamental attitudes and policies change we will be doing this forever! We should be trying to bring harm reduction together with drug law reform much more tightly. This is probably the way forward!

Also I think there are waves of huge energy in the user movement itself and then after a few years some weariness. Paul said that we could learn from the gay rights movement. I've thought about that numerous times! I have got a book at home called *Guerrilla Grass Roots Organising* (or something like that) about taking lessons from the Gay Rights movements and Women's movements. It's about taking more direct action and being a bit more confrontational about the high numbers of people that are dying, about how while HR can be empowering it can also sometimes side-track us a little bit from the issues that make us keep doing HR. There are issues like the battle between taking funding and then having to toe the funders line to an extent. But I think you can merge these things together. You could have different groups – for instance one with an HR approach, and a link with people who are a bit more radical. Because we need to address the fundamental changes that need to be made so that we don't just keep perpetuating the way things are.

In England, for example, they do guidelines and education and then wait for people's responses to change. And then they change the law! Whereas sometimes I think that maybe you have to change the law for people's attitudes to be forced to follow. Attitudes can be very hard to change – it's like behaviour.

Like with the discrimination laws – even though people say that political correctness has gone a bit mental – it was really important to do that. If we had waited for attitudes to change we wouldn't have a discrimination law! ●



Erin

In Poland They Think You are Trash

Mariana Iwulska, age 30, is from Krakow in Poland. She is co-infected with HIV and Hepatitis C.

There is very little HCV treatment for us. And as for HIV, if you are an active drug user, if you are not on methadone or a programme like Narcotics Anonymous – you will not get ARVs. They think you are dumb, some trash who cannot remember when to take the pill. As for HCV, you have to be clean from methadone, or any other and then they will give you interferon.

There is nothing like child support on methadone programmes. Many women on methadone have children already or get pregnant during replacement treatment and nobody cares about these babies. Nobody is researching whether they are healthy or not or how the methadone affects the children or pregnancy.

On methadone programmes in Poland, if you don't have a job, or they catch you taking a drug, you can't have 'take home' methadone. You have to take it where they give it to you. Many mothers are spending a few hours every day with their children with all the other people who are on methadone at the programme. I think psychologists should take care of these babies because they are different from other children who are not in such an environment. Nobody cares about the mental health of these babies.

One of my friends went to the child psychologist because she was interested in how her little boy was developing and the psychologist said my friend was drunk. She said no, she was on methadone, not drunk! But the psychologist insisted that she was drunk and wanted to speak about her, not the baby. This was one time when somebody was trying to do something for the mental health of the baby. ●



Mariana

Should ICW's Website have a Memorial Page?

www.icw.org

Is it possible to have a Memorial Page on the ICW website for all the sisters we have lost? Perhaps a place where we can see their lovely faces, read their stories and perhaps a place where friends and family can post memories? A.

This suggestion, posted on the ICW members' e-forum, started a lively discussion. Here are a few more of the comments members made.

Great idea, but there have been so many. Yet it's brilliant since their legacy lives on within our hearts and work. P.

It might be a good idea but remember that not all of us are out and that we would need to ask permission from their closest families. We cannot make decisions on behalf of our sisters who are no longer here. C.

I understand. Perhaps those of us who know family members of sisters who passed on can ask for their permission and those of us still alive can give our permission now so that we can be remembered by those closest to us. I have no family contact but would want to be remembered here at ICW more than anywhere. A.

I share C's thought. It is a good intention but the reality is different. Some persons are not open and the space we share as peers is just one of the two or more lives they live. From experience, I do not visit in hospital or attend funerals of network members unless I knew the family before, because many times they have not informed the family and it puts you in a difficult position. We must respect the individual position in our good intentions. O.

I support the idea totally and more so if we could spare that suggested space for the faces, and permission from loved ones would do no harm! J.

What so you think? Maybe it's not an either/or situation. Could we figure out a way to meet the desires of A. to be remembered in ICW? And also respect the women who have passed on who were not necessarily 'out' to their family and would not want to be listed on such a page?

What do you think? Send your thoughts to the newsletter by the next deadline on October 15th. ●

Welcome on Board!

Elizabeth Akinyi Osewe, ICW's new Project Officer in Kenya sends her warm regards to all.

I am 32-years-old and a mother of three lovely children aged 14, nine, and two years respectively. I have lived with HIV for the last nine years and have gone public about my status to assist women who are silently suffering behind closed doors for the sake of marriages and loyalty.

I am a trained secretary but after my diagnosis I went back to college and pursued a diploma in Community Health work alongside counseling classes. I've just enrolled for a Bachelor of Arts degree in Social Work.

I was working as a volunteer in a sexual and reproductive health institution called Family Health Options of Kenya (FHOK) as a Community Health Worker.

My main area of interest centres on proactive policy and advocacy in the HIV/AIDS field and on sexual and reproductive health and family planning. 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.

I believe that it is important to empower women, young girls and children about positive health and positive responses to HIV/AIDS. I also strongly believe in advocating for those whose voices are not heard especially in Africa where gender and culture are great barriers. I am willing to undertake challenging duties that will make the world a better place for everyone. I know that with your support and teamwork we shall overcome. ●

New ICW Network Manager



Helen with ISC member, Bev Greet, in Nairobi

Message from Helen Kirkland

Helen Kirkland has joined **Fiona Hale** in the London office as a job sharing team of two. ICW is lucky to have two such strong and skilled women putting their energies in our network.

I'm delighted to be working for ICW and have appreciated the warm welcome from members and staff. Going to the meetings in Nairobi on my third day with ICW was probably the best induction ever – a fantastic opportunity to meet so many ICW women from around the world and to hear about the ways in which they are leading and supporting positive women's groups.

What particularly excites me about working for ICW is our focus on the rights of HIV positive women. It wasn't until I did some research in South Africa, as part of my masters' degree, that I really understood that gender equity is fundamental to addressing HIV/AIDS around the world. I was shocked to hear young teenagers talking matter-of-factly about sexual violence towards women, increasing levels of rape and

men's sexual 'entitlement'. I also began to comprehend the level of stigma and discrimination against positive women – even in subconscious minds of young people creating dramas around HIV/AIDS issues, women were always portrayed as the transmitters of the disease.

So I'm looking forward to settling into the job share role with Fiona – helping ICW to develop and adapt to the rapidly changing world around us and continuing to promote and defend the rights of HIV positive women. There's a lot to do! ●

Note: New email for Helen and Fiona:
inm@icw.org
Please do not use Fiona Hale's old email address.

Helen Kirkland

Thank You to everyone who contributed to this issue: Emma Bell, Marijo Vazquez, Franck Pertois, Carmen Tarrades, Fiona Pettitt, Jeni Gatsi, Sophie Dilmitis, Helen Kirkland and Luisa Orza.

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. 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

Can you draw cartoons or illustrations?
ICW News needs them!
 Please get in touch.

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 38

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



Issue Number 39
Deadline: 15 October 2007

Focus: News and views from the YWCA/ICW conference in Nairobi. We would also welcome letters and articles responding to articles in past issues. Especially male circumcision and questions of sexuality and power in general.

Issue Number 40
Deadline: 15 January 2007

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

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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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.