



ICW News

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THE INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS

VISIBILITY, VOICES AND VISIONS

A Call to Action AT BANGKOK

The Thai Women and HIV/AIDS Task Force, ICW, the Women's Caucus of the International AIDS Society (WCIAS) and UNIFEM invite you to be an active participant for gender equality at the 15th International AIDS conference in Bangkok.

We call upon you to commit yourself proactively to the following actions both in your preparations for the AIDS conference, and during the meetings and sessions that you attend at the conference.

In particular we urge you to join us in committing yourself to the following actions:

- **Ensure** that gender equality issues are raised in every meeting, session and activity that you attend at

the conference, particularly in reference to: unequal access to care

- treatment and support
- equal participation in medical and other trials based on ethical principles
- sexual and reproductive health and rights
- funding for microbicides
- availability of female condoms.

- **Highlight** the strong bonds between the rapid escalation of the epidemic and particular economic, political and social realities. Poverty, violence against women, lack of property and inheritance rights – all of these are intensified through unequal power relations between men and women, high illiteracy rates, lack of employment opportunities for women, stigma and discrimination.

- **Find out** what HIV positive women and girls are already doing, and identify ways to support them. Demonstrate solidarity with women living with HIV and AIDS individually and through local, regional and international networks in whatever way you can.

- **Promote** gender equality and issues relating to unequal access in all areas with the media.

Although this statement has been issued for the Bangkok conference, the Call to Action will continue to have relevance for ICW members in many other situations long after the conference is over.

WOMEN AND GIRLS are disproportionately infected and affected by the AIDS pandemic worldwide. This reality is grounded in gender inequality, which more than any other single factor, fuels the rapid escalation of the epidemic. Fifty percent of people living with HIV globally are women; 58 percent in Africa, and in some of the hardest hit countries, young women are six times more likely to be infected than their male peers. A broad range of inequalities – including legal, economic, cultural, sexual, religious and political – are the mainstay of the epidemic.

As a result women often find themselves invisible, unheard and ignored. Stigma and discrimination weave a taut thread through the daily rising infection rates. This impacts on the ability of women and girls to access care, treatment and support, or to be part of vaccine trials, and underscores the urgent need for microbicides and affordable female barrier methods.

Planning ICW's work and direction for the next year: ICW trustees, staff, and volunteers meet in London in April. (See page 6).



inside:

Thai women, Young Women's Dialogue, Transsexuality, Microbicides, Men and more

Introducing

KOUSALYA

AND GCEBILE



Kousalya has joined the board of trustees

Exciting Plans for Southern Africa

Fiona Hale, welcomes Gcebile Ndlovu

ICW would like to give a very warm welcome to Gcebile, who started work as ICW's Southern Africa Regional Coordinator in April. Gcebile lives in Swaziland, and her job over the next six months will be to set up an ICW Southern Africa Regional Office. She will be establishing contact with ICW members and national organisations of HIV positive women throughout Southern Africa, making sure that the voices, visions and visibility of women living with HIV and AIDS in Southern Africa are raised.

Gcebile

My appointment to this job excites me, as it is a unique opportunity to interact with the many thousand women living with HIV and AIDS in the region. We will share our joys and sorrows as we try to cope with the challenges of the epidemic at the same time maintaining our dignity. While we cannot wish away the virus within us we want draw lessons from it and live our lives to the fullest. It is no way going to be easy, as

we have learnt in the past years when we have been treated as mere statistics, and had decisions taken on our behalf as if the virus has taken our brains.

I wish to thank ICW for selecting Southern Africa to be the first region to pilot strengthening ICW regional networks. It is worth noting that we are in the region that has the highest HIV prevalence. I believe addressing issues pertaining to women and HIV will go a long way in reducing the impact of AIDS and further reduce the number of new infections.

My dream is to see ICW membership double in the next six months, which calls for a lot of effort from existing members. We will work towards creating a forum where we can meet and discuss how best we can participate meaningfully in all areas that concern our lives. In acknowledging the fact that ICW membership development is at different levels in the different countries in the region, I also envisage opportunities of learning from each other.

I hope to use every opportunity to make ICW's vision and values widely known in the region. ■

A New International Trustee from India

Fiona Hale, ICW's International Network Manager, talked Kousalya about positive women's lives in India and her plans to challenge discrimination.

Q: You are one of ICW's newest international trustees. Can you introduce yourself?

I'm from India, from Tamil Nadu, Chennai. I'm a founder member and president of the Positive Women's Network, which started in Southern India, and now has a national voice.

Q: What are the main issues facing HIV positive women?

In my own country, women face lots of discrimination in the health care setting, within their own families around property issues, and with their children. The children face discrimination in the schools – this is a major problem – so my work is to involve people in the school curriculum.

Q: Your visions and dreams?

I'm positive, and that's why I came to this work. This is a commitment for me – I can do something in my country, advocating for women's issues – and after that I can spread that experience in other countries. That is my ambition.

Q: How can ICW help you to make vision a reality?

In training – For instance, I didn't know a word of English, but after the virus came in my body I learned to speak English. Now I'm learning to write it. ICW should make sure language is not a barrier.

We are running a legal literacy workshop in four states, with the support of UNIFEM. We are planning to do some training modules and we've produced a CEDAW (Convention on the Elimination of All Forms of Discrimination Against Women) report which we'll be circulating in India this year. We have also developed some gender guidelines for media people. I am happy to share all this with people in other countries.

Q: What would you like to tell the world about HIV positive women?

We should join together – that way we can make changes for the world.

This interview is from a video recording made in London, November 2003

Gcebile joins the ICW international team



Rung's STORY

Rung is a Thai woman who has been living with HIV since 1995. She is 37 and has a daughter, aged seven. Jiranuch Premchaiporn (Jiew) interviewed her for ICW News.



Rung

If there really are 'good women' and 'bad women' as society defines and then divides us, I proclaim that I was a 'good woman' who always behaved in whatever ways a 'good woman' is supposed to. I grew up in a family in which the father had absolute power in the house. Following Chinese family culture, and because I was a daughter, I didn't go on to higher education, as I would belong to another family when I married. Nonetheless, I was raised with strict controls from my parents as they were afraid that a daughter might besmirch the family honour. As an ancient saying goes: 'Having a daughter is like having a toilet in front of the house'. I behaved myself in order to meet the standards of a high class toilet – clean and no smell. I adhered strictly to the Thai maxim of keeping your virginity until marriage. My first sex was when I got married at 28 to a man whom I considered a responsible and loving husband.

We thought we were safe

Before getting married, I asked my boyfriend to take a blood test and show me the result. At the time, there was a tremendous campaign by the government. I remember clearly one TV ad saying that 'It's not important how much the dowry is, but the HIV test result is a must'. However, what

we didn't know was that taking a blood test did not tell you anything about your HIV status if you didn't specify that you wanted an HIV test.

My boyfriend went for a blood test and found out that he had no health problems. Therefore, we had our wedding in 1995. He had to borrow money for both the dowry and the expenses for the wedding ceremony. Then early in 1996, when I was four months pregnant, I went to the hospital

'I was raised with strict controls from my parents'

for antenatal care service. It was there that a nurse told me I had HIV. My life fell apart. Abortion was the only solution I could think of. I thought my baby would also be infected, and even if the baby was fine, I didn't know how long I would stay alive. I found out it cost 3,000 Baht (US\$75) for an abortion at four months. It might seem a small amount for many, but I couldn't afford it, as I still had wedding debts. I decided to take some drugs to cause a miscarriage, but I didn't succeed. I had no choice but to keep the baby.

I tried suicide

Meanwhile, my husband fell sick. His discouragement at discovering he had HIV and guilt for passing the virus to me, contributed to his illness. I was furious. However, I had no choice but to stand by him and encourage him that we had to face the situation together. I was under stress and desperate about my baby, taking care of my ill husband, and doing his janitor work at the school. I tried to commit suicide three times by taking all kinds of drugs, but it never worked.

My husband died when my daughter was 15 months old. After he'd gone, the insurance benefit freed me from debts. I also kept some savings for my daughter's future – the daughter I didn't feel 'love' for at all. After she was born, every time I looked at her, I could only think of all the sadness and misery in my life. I would have continued being a strange mother, except one day, my daughter – who by then could talk – said, 'I love and care about you; I want to have a mother'. I was speechless and could feel what she needed. At that moment I realised I must live on because she needed me. While watching her, I asked myself, 'Is this the little one I once wanted to kill?'

Ten years on

It has been almost ten years now that I have lived with HIV. Bad dreams turned into an understanding that AIDS is not fearful, nor sinful. I have gained more understanding of life after sharing my sorrows, tears, and happiness with my positive friends, most of whom are widows like me. I became a committee member of the Thai National Network of People Living with HIV/AIDS. At present, I work full-time for the network on a project aiming at strengthening PLHA groups in order to be part of the ARV treatment and comprehensive health care system. I have joined the Thai Women and HIV/AIDS Task Force, for I myself have seen and faced gender bias and the nonsense of inequalities.

I have learned more about HIV/AIDS. I understand that when my husband went for a blood test, it was a general health check-up, not an HIV test. I think perhaps there are many people out there who still don't know about HIV/AIDS. Just like me. I want them to know more. I want them to know it is never too late. ■

Ms. Waranuch Chinvarasopak, a programme officer of PATH, kindly translated this article for ICW News.

Thai Women IN VIEW

Monruedee Laphimon (Pat) and Supecha Baothip (Chompoo) from the Thai Women & AIDS Task Force, give a picture of the exciting work of bringing women together to share and discuss issues of gender and sexuality.

The Thai Women and AIDS Task Force (TWAT) is a country-wide informal network of women living with HIV/AIDS, women from non-governmental organisations and individuals working to eradicate HIV/AIDS and its impact in Thailand. The group started in late 2002, with support from member organisations of the Thai NGO Coalition on AIDS (TNCA).

The TWAT methodology includes making sure we hold our meetings in a friendly and enabling environment. This greatly helps participants to reach a deep understanding of the complexities of gender. It leads to an ability to incorporate gender into programme activities for HIV/AIDS prevention and access to health services for women and girls. Our shared belief is that women and girls have capabilities which can be strengthened so they can take up stronger positions in their families and in society.

‘She facilitated a very friendly and lively discussion on women and pleasurable sex’

Learning more about our lives

TWAT always partners with a local organisation of its members. During the 9th National Seminar in July 2003, Jiranuch Premchaiporn from AIDS Access Foundation launched a workshop which introduced the topics women living with HIV/AIDS, and access to services. An informal survey of the female delegates was conducted to learn more about what impact HIV/AIDS had on the lives of women.

In August 2003, Supecha Baothip, a TWAT member, facilitated a very friendly and lively discussion on women, pleasurable sex and masturbation. Although we only drew

in about ten participants, we learned about the importance of exchanging experiences and dialogues which are based on direct personal experiences. Both are powerful ways for women to fully understand the lives we live and the realities women face.

TWAT has continued to conduct forums based on the recommendations from previous meetings. More women are taking part. The topics covered have ranged from women’s socialisation and HIV/AIDS, to women and sexual health. The forum on how religious practices and beliefs impact on the lives of women shed light on the negative impact religious practices can have, and how the core teaching of individual religions, for instance, Buddhism, Islam and Christianity, are often interpreted by people with biases against women. All our discussions have extended our understanding of gender and power relations. As a group we have explored how the process of socialisation and gender stereotyping influences women’s values and roles.

Exploring Sexual Realities

Sixty-two members of TWAT came together for a bimonthly forum held in Chiang Mai in May 2004. There, we examined the issue of women’s sexual health. We had the opportunity to explore together the diversity of women’s lives and sexual relations. We looked carefully at how women become spiritually dependent on men, at our interaction with male counterparts, and at divisions between women. Our discussions revealed that a woman’s sexual relations with her partner, and/or her sexual orientation or identity (heterosexual, lesbian, mistress, married, or single) are fundamental to understanding why women’s communities sometimes fragment. Women are not always aware that we are willing to blame, or attack other women, all in the pursuit of men’s satisfaction and needs.

Our discussions also reflected the reality that some single women have

more freedom of choice because they are able to ignore the judgmental views of their communities and get on with their lives. In relation to sexual health, they may be able to explore more prevention methods and have better knowledge about protecting themselves from STIs and HIV/AIDS and related reproductive health complications.

We also found that women living with HIV/AIDS still struggle on a daily

‘All our discussions have extended our understanding of gender and power relations’

basis to take responsibility with their new male partners. One member said, ‘He insisted on making love without using condoms. I had to tell him several times that I was HIV infected.’ We saw that when a man insists on having unprotected sex, the woman tends to put the blame on herself, instead of seeing that we all have to be responsible for our own behaviour.

This discussion is an example of how TWAT tries to build up the capacity of women and girls, and achieve in-depth understanding of how HIV/AIDS impacts on gender and power relations.

The fact that more than 200 women from all over the country participated in previous forums/workshops is evidence that these discussion opportunities fill a need. An environment which promotes open discussions and dialogues on how to challenge practices which lead to social inequity is important for women and provides a unique opportunity for mutual learning. ■

From Dialogue to Deed

'I have a new identity – I am not a person living with HIV, I am a young woman living with HIV.'

(Kanjoo Mbaindjikua, Namibia workshop participant)

Background

In recent years international attention has focused on the vulnerability of young people to the AIDS pandemic. In addition, there has been significant attention paid to the stigma and discrimination faced by people living with HIV/AIDS in communities around the world. Yet, there has been little recognition of the challenges faced by those whose identities lie at the intersection of all of these 'vulnerabilities' – young women living with HIV/AIDS.

While most efforts in the arena of youth development focus on prevention, the reality is that there are millions of young women who are already HIV positive. Young women are not simply older women packaged in smaller bodies. They are a vital part of the youth movement and play a significant role in women's movements. Despite this, their activism and commitment to the fight against AIDS, and to raising their siblings and children, educating communities about stigma and discrimination, and building their nations, is seldom recognised.

To begin to address this lack of visibility, ICW, the Youth Against AIDS Network (YAAN) and the Gender AIDS Forum hosted *A Dialogue for Young Women living with HIV/AIDS* held in Durban between 18 – 23 April 2004. The dialogue brought together young African women living with HIV/AIDS in a safe space for them to share experiences about the challenges of HIV/AIDS and to develop advocacy campaigns for highlighting the gender and human rights-based challenges faced by participants in each of their countries.

Participants

Participants were chosen to attend the dialogue based on a set of criteria as well as on personal motivations, and all were endorsed by their organisation. It was also important to get a geographical

spread. ICW set up a selection committee to assess the applications. In the end 14 young women participated. These young women living with HIV/AIDS represented eight countries in Eastern and Southern Africa: Kenya, Lesotho, Malawi, Namibia, South Africa, Swaziland, Uganda and Zimbabwe.

Different identities that were acknowledged included: breadwinner, heterosexual, married, single, lesbian, activist, community worker, mother, counsellor, role model, black, white, daughter, sister.

The participants also had diverse expectations of the dialogue. Expectations included needs around capacity building on gender and advocacy, knowledge on treatments as they relate to young women, and new scientific inventions, including microbicides and vaccines.

The Process

In the initial planning for the dialogue the following objectives were identified:

- To strengthen advocacy skills by developing a step-by-step campaign
- To incorporate gender analysis into campaign planning
- To listen to, and document the experiences of young women living with HIV/AIDS
- To build capacity in working with the media to further advocacy goals
- To build capacity in understanding how government, parliament and budgeting works

Capacity building sessions covering the following topics, were conducted by the facilitators:

- Gendering our responses
- Why women are vulnerable
- Practical needs and strategic interests
- Advocacy

Outcomes

Based on the extensive list of issues identified a number of themes were listed. From these themes the group identified three critical advocacy issues for young women living with HIV/AIDS.

Issue One:

- There is a lack of meaningful and active participation of young women living with HIV/AIDS in developing, implementing, and evaluating policies and programmes at the leadership and management levels, locally, nationally and internationally. →



Issue Two:

- Young women living with HIV/AIDS are unable to access appropriate treatment for opportunistic infections, ARVs and prevention methods.

Issue Three:

- Young women living with HIV/AIDS are unable to access their sexual and reproductive rights at a personal, programmatic and societal level.

Advocacy strategies were developed for each of the three issues. Groups worked on goals, and an analysis of the problem, objectives and messages. These advocacy strategies are being developed by ICW as advocacy plans for young women living with HIV and AIDS in East and Southern Africa. In Southern Africa, some organisations, including UNIFEM have committed funding to carry out the advocacy actions from the Young Women's Dialogue.

Each country met to discuss their future plans for action based on the dialogue and to identify support needed to fulfil their plans and capacity building. The general evaluation was very positive. ■

DIALOGUE RESPONSES

As a young women living with HIV and AIDS I need to understand my rights and to use this to help others.

'There is so much power in this room.'

I know why people discriminate against people living with HIV and AIDS, because we discriminate against other marginalised groups.

'I am an advocate in my own right.'

I am confident to claim my identity.

'Everyone was taken seriously.'

This workshop empowered me to deal with my fears – I know if I don't others will suffer in silence.

'We have a voice and we must use our voice.'

We will not get things on a silver platter – sometimes we must demand what we want.

'I have an identity beyond story telling.'

Even if I regard myself as small I can still challenge and fight for the rights of young women living with HIV and AIDS.

'Great that the workshop was just for young women living with HIV and AIDS.'

Thanks and appreciation to Vicci Tallis and Sisonke Msimang for facilitating the Dialogue. Full report accessible via ICW'S website www.icw.org For further details contact Promise Mthembu: pmthembu@icw.org

ICW's Work: Achievements and New Priorities

ICW hosted a week-long residential workshop for all its UK based and International staff and trustees last month from 26th-30th April. Twenty-five people attended for all or part of the week including 13 out of the 15 members of the international board of trustees.

The purpose of the workshop was to review the International Strategic Plan 2003-2007, just over a year after its launch in January 2003, to measure progress against its objectives and to identify areas that need more work. It was also a time to consider the wider context of our work and to respond to global changes and events by addressing burning issues in new areas. Finally, the week together provided the opportunity to catch up with old friends and make new ones with participants ranging from founder members of ICW to brand new members of staff. It was a time to build trust and friendship across the history and geography of the network.

The workshop resulted in the production of a workplan for the coming year. Much work was done on issues of regional autonomy with participants reaching consensus around the desirability of regional autonomy and the need to take this forward over the coming months. Sessions were also held that examined the structure of the network and visualised the different ways in which it could develop. The roles and responsibilities of all those involved in ICW – members,

staff and trustees – were also a subject of much debate, and several consultations were set in motion to bring clarification around these issues.

Luisa Orza, Special Project Officer

ICW would like to thank the Department for International Development for supporting this project, and WAGGGS for allowing us to use their World Centre, Pax Lodge to host the workshop.



Visualising Connections

A 'New' Gender FOR A 'FOREVER' WOMAN

*Learning is a life long process. There is always something new to understand; the positive experiences of humanity are endless. If we could open our minds and hearts in the same way we want people to open to us, wouldn't the world be one step closer to harmony? We are not all the same, nor do we need to be. But we are all human and that is what must unite us. The article below was written by a courageous Brazilian HIV positive woman, **Jacqueline Rocha Côrtes**. Jacqueline was born a biological boy, but from a very early age knew she was a woman in all ways.*

The global understanding of a transsexual is not yet harmonised or agreed upon. People still think that a transsexual is a man who has changed his sexual organ into a female one, or a woman who has changed her sexual organ into a male one. Actually, this is not the truth. We women-transsexuals, or transsexual-women, or trans-women, have always been, felt, and understood ourselves to be women. We see the world through a woman's eyes, and more than that, we live our lives being a woman. Therefore, we are not men who became women; we are women who have re-adapted our genital organs in alignment with our souls and entire being. In Brazil we don't use the term 'sex change operation' because a trans-woman doesn't change her sex, rather she is transitioning into her rightful state.

Here in Brazil, we transsexuals believe there is a difference between transgender and transsexual. What most of the public understands is that no matter if you are a drag queen, a transvestite, or a transsexual, you are a transgender. Although we might have been considered a transgender for some of our lives, as soon as we correct our gender, we no longer belong to that 'category'. This is our understanding, our feeling, and attitude towards this issue.

Besides, one is what one feels, lives, and believes, as well as one's history and what remains in people's memories. Our legacy is that we are 'special' women who have always faced misunderstanding, prejudice and lack of respect. We are women who spent our 'peculiar' childhood locked in a 'male' body.

We are not very well understood by most populations, and sometimes we are not even regarded seriously. But, as

with any other woman, we are sensitive, brave, and dynamic. We suffer discrimination and fight for our inclusion in the world. Let us put it this way, in general a trans-woman lives an ordinary female life. I mean, we work (when this possibility is given to us), have our own families, social life, and we hold a great deal of love. We go to doctors, we often visit our gynecologists, we have to follow-up our women's health issues such as undergoing routine exams, breast examinations, or hormone replacement therapy.

'We HIV positive trans-women have a similar reality to other women living with HIV/AIDS.'

Once we have our legal documents changed so we are recognised as female (if that is possible in the country we live in) we fully belong to the female gender. This includes all the challenges and issues other women face, for example, prejudice and 'machismo'. I might cite too the well-known belief that 'being a woman is being a part of the fragile sex'. This is indeed a mistake!

Politically speaking, we understand that we have to be included in social movements for women, led by women, which have women as the subject of change.

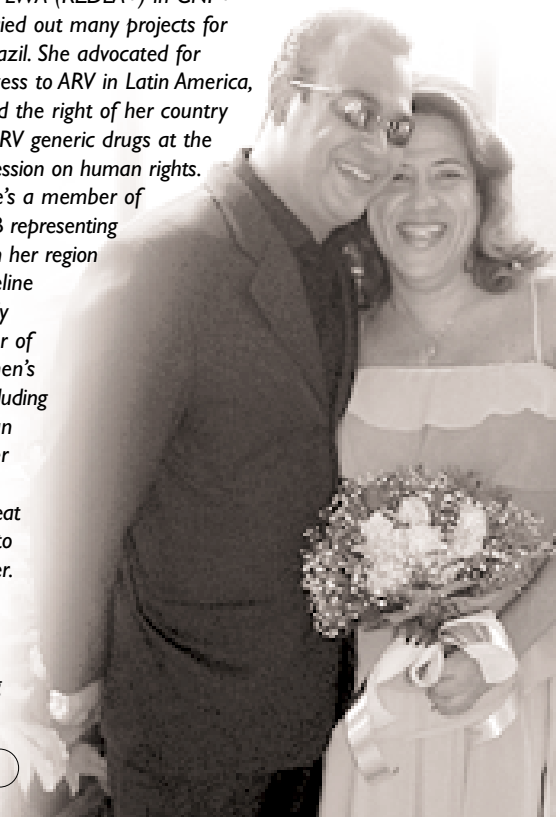
Hopefully we will come to the point where among all the women in the world, a 'new style' of woman is welcomed – the trans-woman, who has the female sex, gender, and life. She is a new woman with all the old issues and

challenges of women in general. She needs to be included and respected as any other woman needs, wants, deserves, and struggles for. Men feel as if they are superior. As women our work opportunities and salaries are not the same as men's. Domestic tasks in the home are not fairly shared. Gender balance is what women have struggled for and what we transsexual women are part of too. Our voices have to be widely heard and we need to be globally understood. ■

Jacqueline Rocha Côrtes is an educator, a trans-woman who has been HIV positive since 1994. She is 44 and legally married to Vitor Côrtes. Their wedding was in February 2004. Jacqueline is a member of the Brazilian Network of PLWA (RNP+). She represented the Latin American Network of PLWA (REDLA+) in GNP+ and has carried out many projects for PLWAs in Brazil. She advocated for universal access to ARV in Latin America, and defended the right of her country to produce ARV generic drugs at the UN's 58th session on human rights. Currently she's a member of UNAIDS PCB representing civil society in her region (LAC). Jacqueline would happily be a member of positive women's networks, including ICW. Being an ICW member would, she says, be a great opportunity to work together.

A Valentine Day wedding

We welcome your thoughts on this article.



Microbicides:

SO NEAR AND YET SO FAR

The 3rd international conference on microbicides took place in London at the end of March 2004. ICW trustees **Angelina Namiba** and **Marijo Vazquez**, and Global Advocacy Officer for Sexual and Reproductive Health, **Promise Mthembu**, report.

The drive to discover and successfully trial a microbicide is at a critical stage. No one expects a marketable product very soon, and yet the search needs positive developments and forward movement. By the end of the conference, HIV positive women present were left wondering if this search was taking their needs into account. Promise explores this in her response, while Marijo tells us why a session on anal microbicides was important to women as well as men.

Why Microbicides for HIV Positive Women?

Angelina Namiba

The development of successful microbicide agents is extremely important to women generally but even more so to women living with HIV. This is because inequalities between women and men lie at the heart of the HIV/AIDS epidemic, as well as the spread of other sexually transmitted infections, and life threatening illnesses like TB and malaria. Realities such as gender violence, lack of property rights for women, unequal burdens of caring for the sick, unequal access to treatment, and unequal access to appropriate prevention information all mean that women are at greater risk of getting HIV and generally feel the impact of the epidemic more acutely. The failure of HIV and AIDS and other social interventions to take into account the different needs of women and men directly undermine their effectiveness. The Development of successful microbicide agents will go a long way to addressing some of these gender inequalities that make it difficult to put effective prevention programmes into place.

This is an extract from a much longer article in *Positively Women*.

New Issues

Promise Mthembu

For the first time in the history of a microbicides conference there was a closed satellite for women living with HIV and AIDS. Although relatively few women attended it, we did get a lot discussed, and it was a wonderful networking opportunity for everyone who participated. The meeting helped us to go out and engage in the conference with one voice – as women living with HIV. I also felt that there was fair representation of civil society organisations and presentations during the event and there was a recognisable increase of interest in microbicides activism, particularly from the Global South communities present.

The high level of awareness and commitment to microbicides advocacy was demonstrated by the success of the African Microbicides Group (AMAG) satellite meeting which ICW co-organised. The quality of issues and concerns registered in the meeting demonstrated that the message had finally got home – the message that AIDS activists and women's organisations, and those working around gender, should mainstream microbicides in their work. The pressing issues raised were around the research ethics, access to microbicides when they become available, and, indeed, the needs of women living with HIV and AIDS.

Meeting with researchers

ICW had the opportunity to meet with top microbicide researchers in scientific and social fields. Our objective was to dialogue with researchers in an attempt to get them to take issues of women living with HIV more seriously in microbicides research and development.

These issues include:

- involving positive women in all phases and levels of research
- identifying interactions between microbicides, anti-retroviral treatments and other HIV related medications
- exploring the ability of positive women to utilise microbicides and the impact of microbicides on the lives of women living with HIV
- care and treatment packages for women who sero-convert during trials and also for women who test positive at the trial entrance phase.

To our astonishment, we realised that even less research, if any at all, is done on HIV positive's women reproductive system. We always imagined this was the case, but the meeting clarified that the problem was actually deeper than we had envisaged. →



Angelina

Microbical After Thoughts

Marijo Vazquez

I would like to mention the fantastic sessions on anal and rectal biology. Discussions of heterosexual sexual practices seldom include any mention of anal penetration, despite the fact that the few studies carried out on this issue show that anal penetration is common in sexual relations between men and women. In general, anal sex is considered to be exclusive to men who have sex with men – leaving discussions of women's sexual behaviour to fall – again - into stereotypes. This leads to serious delays in the adoption of adequate preventative measures. We should be promoting research into anal microbicides as a prevention option for women, as well as for men who have sex with men.

→ In response to this discovery ICW is now in a process of making sure researchers know about what is going on in our vaginas! We are initiating negotiations with medical and physiological research agencies and fraternities to try and address this gap in HIV and AIDS research.

This has also raised new ethical questions that ICW is posing to researchers. HIV positive women account for 40 million women worldwide. How do you research an intervention like microbicides, while ignoring the needs of such a significant number of the population? ■

Thanks to the Global Campaign for Microbicides and International Family Health for giving us support, resources, and a place at the table for us to represent our issues and concerns in microbicides development debates.

‘We know very little about what goes on in HIV positive women's vaginas.’

(A researcher from a credible research institution at the meeting)

Transforming Society – WHAT ABOUT MEN?

In 1992, around 56 HIV positive women came together to form an independent, global network of HIV positive women. In doing this, the founders of ICW followed the path of many women's projects over the last 30 years. Strong women left organisations they had helped create, determined to build new ones in which women would be able to play equal and self determined roles.

But, where are we today? Are men and women working together productively and as equals? In many societies women have not achieved true equality or social and economic rights, and yet, HIV positive women and their organisations have grown in strength. How, when, and under what conditions should we work with men? To open the debate **Marijo Vazquez** and **Promise Mthembu** share their views.

Everyone Must Be Involved in Change

Marijo

After more than twenty years trying to fight to slow down the AIDS epidemic, it is still spreading inexorably, and mainly among women. Gender inequality is a key factor in putting women at greater risk from HIV. So it is no surprise that it is in male dominated societies that AIDS is having its most devastating effect.

The fight against HIV must change, adopting an approach which emphasises individual and collective responsibility, and demanding the involvement of all sectors of society, working both separately and jointly. Above all, it is vital to have men who are in positions of power and decision making at all levels, participating in our fight. Not necessarily within the ICW structure but surely involved in what we consider crucial for both women and society as a whole.

Women's greater vulnerability to infection has led to women the world over uniting to fight for our rights, and to have the information, support and training we need to allow us to take charge of our own lives. But the changes we are proposing do not just mean changing the attitudes of a particular group on some occasions. We are talking about *transforming* society – and for this to happen everyone must be involved in the change. That means men and women the world over taking up their responsibility and working in unison towards what must become a common goal.

This is not about just improving the lives of women, but about the survival of all humanity. It is not just important and necessary to continue to put efforts into training women, it is also vital for men to free themselves from their gender stereotypes. And for this to happen, they must realise that women will not be the only ones to benefit – men will also see new opportunities opening up for themselves.

So it is of crucial importance for men to take up their role in bringing up children, to seek ways to develop new concepts of masculinity which are not based on the abuse of power, but on respect and equality. Boys need role models to follow as they grow up, and this will not be possible if men continue to remain at the margins of, or against the building of a new, equitable social order.

While I believe that our task in this struggle continues to be about gaining full enjoyment of our rights, I think it is appropriate for us also to demand that the responsibility for this task is shared. Men are part of the problem, and must also be part of the solution. ■



Marijo

Independent and Positive

Promise



Promise

ICW was founded on the belief that HIV positive women need autonomy and that given a safe space, women can solve their own problems. I bear this in mind when thinking about the role of men. In order to create equity, you need to address existing inequalities. You can't claim equity when inequalities are so prevalent. In other words, if you want men and women to be equal, you need to create an independent space for women to grow in confidence, and to develop and nurture their strengths. How can you deal with power if you have no power? Yes, we know that men are not all equal; nor do they have equal access to power. And yet, in relation to the majority of women, most men access power more easily *and* with a sense that it is somehow 'naturally' theirs.

I'll give you an example. In 2002 I visited an HIV positive women's organisation in Nairobi that had decided to bring in men and get them involved. I met with a group women and men from this organisation for a session on

microbicides which lasted about one hour. I estimate that one man in the group spoke for approximately 45 minutes out of that hour. Women's voices were overshadowed, even in their own organisation.

In my experience, this also happens in HIV positive support groups which include men and women. So it's when women meet in women-only spaces that they get their issues out, where they feel safe, begin to have the confidence to speak out, define their needs, and make decisions.

ICW should continue to be a strong, and independent organisation which does not directly involve men in its work. Of course ICW should attempt to influence men and the organisations they belong to. This does not mean that ICW is anti-men. We will continue to work with men in specific alliances and we can learn a lot from each other in these alliances. It does mean that we are dedicated to HIV positive women achieving equality and realising their rights. We can reach

these aims most successfully in an HIV positive women's organisation. In order to get our issues out there, strong and clear, it's important that we are a *women's* network. In this way our influence on other organisations – at all levels – and on the members of those organisations, including men and women, will be strongest. In this way women will most successfully empower themselves. Let's not apologise. Yes, we exclude men from membership, but not from our lives, alliances, and concerns. ICW is the International Community of Women Living with HIV/AIDS. I feel comfortable with that. ■

Readers, we welcome your views on this subject.

ANNOUNCEMENTS

Access to Treatments – A New Global Role for ICW

We are pleased to announce that ICW has been chosen to act as the convening agency for the treatment and care arm of The Global Coalition on Women and AIDS. The Coalition is a new UNAIDS initiative made up of activists, government representatives, community workers and celebrities, that seek to stimulate concrete action on the ground to improve the daily lives of women and girls. Its efforts will focus on preventing new HIV infections among women and girls, promoting equal access to HIV and AIDS related care and treatment, accelerating microbicides research, protecting women's property and inheritance rights and reducing violence against women.

Asia – Pacific Report by HIV positive women

'Oh, This one is infected!': **Women, HIV & Human Rights in the Asia-Pacific Region**, a report prepared for the UN Office of the High Commissioner for Human Rights was published recently. Written by Susan Paxton, with Alice Welbourn, P. Kousalya, Anandi Yuvaraj, Sapana Pradhan Malla, and Motoko Seko, it contains powerful messages about HIV positive women's lives in the region.

Stop Press! ICW Vision Papers Now Available

ICW is pleased to announce six new publications which will be launched in Bangkok. The five ICW Vision papers have been written for HIV+ members and our supporters to use when advocating and organising around ICW's visions, aims, and objectives. In them you will learn what ICW's positions are and be able to represent ICW well at any meetings or in any groups you attend, or if you are asked in any circumstances to explain what ICW stands for. The series outlines ICW's position on: access to care and treatment; political rights and participation; gender equity/poverty; human rights; and young women and girls. The sixth publication is aimed at policy makers and is called, **Visibility, Voices and Visions: A call for action from HIV positive women to policy-makers**. All the publications are available in English, French, and Spanish and all language versions are also featured on the ICW website at www.icw.org Electronic copies are available on request.

GREETINGS FROM THE Australia/Asia-Pacific REGION

International trustee, **Bev Greet**, writes that with the XVth International Aids Conference being held in Bangkok this year there will be a stronger emphasis on the Asia/Pacific Region whose issues have often been minimized or overlooked at previous International HIV/AIDS Conferences.

As a member of the conference Community Program Committee (CPC) I have attended several meetings in Bangkok and engaged in extensive email contact with the Thai community committee and staff. They are passionate about and particularly committed to the issues pertinent to the region: women, activism, youth, drug use, and access to treatments. I am looking forward to welcoming all fortunate enough to be in Bangkok to share the culmination of their hard work and enthusiasm.

News from Australia

In Australia there has been a baby boom among HIV positive women who are in the privileged position of being able to access treatment and care which significantly reduces the risk of perinatal transmission.

A national positive women email group has been set up to help overcome isolation, discuss issues and to work toward a National Positive Women's Conference in 2005 which would ideally involve positive women from throughout the region.

The facts are bleaker for Australia's indigenous community where women now constitute 26% of all new HIV infections as opposed to 8% in the broader community. Many of these women live in extremely isolated communities and must travel long distances to gain access to medical treatment and other services.

I am proud to announce the launch of **SNAKE CONDOMS**, a project undertaken by the Victorian Aboriginal



Connecting at the ICW meeting in London

Community Controlled Health Organisation in partnership with Marie Stopes International, Australia. We worked with Indigenous youth from a rural community to design, name, promote and sell the first 'Koori youth-friendly' condom brand which aims to reduce unplanned pregnancies and the spread of STIs and HIV. This is a pilot program which has already enjoyed such success that it will now be extended statewide and then nationally. **SNAKE CONDOMS** will be presented in Bangkok by the youth themselves.

I'm looking forward to the presence of women of our region at Bangkok and to seeing the ICW community.

ICW News issue 26

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Sue O'Sullivan: editor
DS Print & Redesign: design and print

Coming up: Report from Bangkok
Deadline: July 26 2004

ICW News welcomes feedback. We look for short articles from HIV positive women (personal experiences, news, debates, information, and ideas for future issues), as well as letters and photos. We cannot guarantee publication. Send by post or by email to Sue O'Sullivan at ICW: sue@icw.org

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ICW is an international network of HIV positive women, founded in response to the desperate lack of support and information available to many of us worldwide. Our aim is to improve the situation of women living with HIV through self-empowerment and dissemination of information. Our membership is open to all women living with HIV.

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