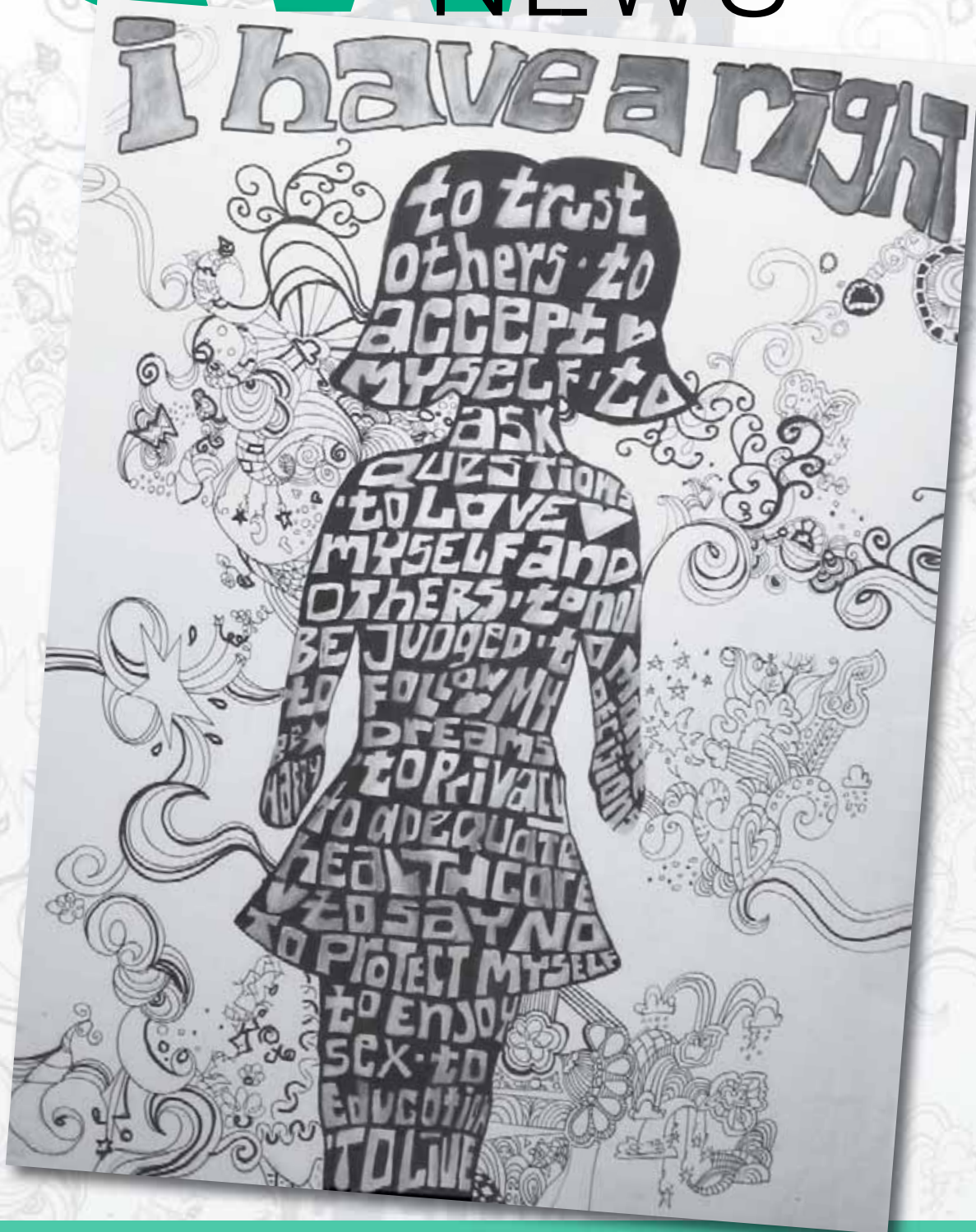
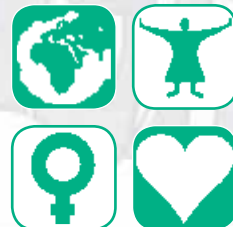


# ICW NEWS



**Special focus...** The Words We Use: Reflections on Language

**inside:** Vienna2010; Remembering Lynde; Positive Prevention; The power of language; M&E definitions and questions; Mothers and children; Personal testimonies from Namibia, Cambodia and Nepal; Positive asylum seekers in the UK & more...



# 2010 International AIDS Conference in **Vienna**

Making Links with European HIV Positive Women

ISC member, and HIV and AIDS coordinator for World YWCA, **Sophie Dilmitis**, ICW Global Advocacy Officer, **Beri Hull**, and **Corinne Miele**, ICW's Funding Officer, have all contributed information about the upcoming conference in Austria. Also see information about a new *Friends of ICW Europe* Facebook site you and your HIV positive and negative friends and contacts may want to join.

In 2010 the International AIDS Conference (IAC) is taking place in Vienna, Austria. The conference is a key event for women living with HIV and AIDS. It is an opportunity to network, caucus and strategise, while promoting HIV positive women's achievements and expertise. It is also an opportunity to mobilise partners around the priorities and realities of women living with HIV and AIDS.

The conference is a wonderful chance for ICW to strengthen our membership and activities in Europe. It will create great potential to engage Central Asia and Europe, especially Russia, in addressing HIV and AIDS. Russia accounts for two-thirds of all HIV cases in Eastern Europe and many believe Central Asia has one of the fastest growing epidemics in the world. Given that we all have limited resources we have created a Facebook page for *Friends of ICW Europe* that you are all welcome to join in order to share information and ideas.

## Harm reduction movement

As the strong commitment to policy change around drug use and harm reduction from UNAIDS galvanises advocacy strategies and planning around key fora, the upcoming International AIDS Conference is a major opportunity for many groups in Europe and in the rest of the world to raise the visibility of the harm reduction movement as a key part of the response to HIV and AIDS. In addition to these efforts, women living with HIV are keen to scale up their own advocacy in the harm reduction movement, as data is often not disaggregated and information about the health and rights of HIV positive women using drugs rarely available.

### Vienna Information:

ICW does not have the capacity to fund individual women to attend the conference. Therefore we urge you to get your organisations, networks and groups involved: start thinking about fund raising to attend, and about whether you should submit an abstract. To keep up-to-date on deadlines and general information about the conference go to: [www.aids2010.org](http://www.aids2010.org)

## Join ICW Europe on Facebook

Join people around the world and become a friend of ICW Europe on Facebook. You do not have to be HIV positive to join this site - you just have to stand in solidarity with HIV positive women who live in Europe. ICW members, please note, this is an open group and we are unable to provide any level of confidentiality if you choose to be open about your HIV status. <http://www.facebook.com/group.php?gid=76471389170> ♥



For Lynde

A Poem from your  
African Daughter:

Sunset at Noon

You brought laughter to many  
You brought warmth to all  
You were the light in the lives of many  
Yet this sun did not shine for long

You remind me of Africa  
The pride in the Sahara  
The Africa of our roots  
The Africa of our youths

You were the voice of many  
The hope of so much more  
The inspiration of the ghetto  
The link between generations.

The sun has set before its time...  
So we think; so short a life...  
Yet fate alone knows  
Why you achieved so much in so little time

Goodnight Lynde  
We bid you farewell  
All you stood for will be continued  
For you passed on the baton

We will never forget you  
and your spirit will live in  
us forever.

Esther  
Sheehama ♥





# Hope is Vital

writing words in **loving memory** of Lynde

**Lynde Francis**, long time member of ICW and ICW's International Steering Committee, who lived in Zimbabwe, died on 31 March 2009. **Sophie Dilmitis** and **Jo Manchester** share their memories and feelings about the importance of Lynde in their lives. Remembering Lynde through writing is in a tradition of women living with HIV and AIDS continuing to hold their departed sisters dear in their hearts.

## Passionate, Joyful, Wise

The death of a remarkable and wonderful woman like Lynde is a desperate loss to everyone who knew and loved her. She was a passionate, joyful and wise woman who lived life to the full. Lynde's contribution to the knowledge and understanding of HIV in Southern Africa is immense. As a qualified nutritional therapist, a trained healer (a Sangoma) and diagnosed HIV positive herself in 1986, she established The Centre for people living with HIV in Harare. I was fortunate to visit The Centre many times and it was always a special place. My memories are of hugs and laughter and such a diversity of clients – young /old, black/white, straight/gay, women and men. All the staff at The Centre were HIV positive which made it such a relaxed and welcoming environment.

Lynde developed her own international network of supporters who sent vitamins, medicines, clothes and money for the Centre. She expanded this by 1997 to include ARV drug donations and against all the odds she managed to access treatment and medical support for her clients who needed it most.

## A creative force

Lynde was an activist in so many areas, nutrition, health, women's rights, education, anti-violence, ACTS. She was creative, a wonderful cook, keen gardener, loved singing and had a beautiful energy. She was driven by her spiritual beliefs and was always ready to help and guide anyone experiencing difficulties. Lynde shared one of the most precious moments of my life when I found out I was pregnant with my daughter. She was thrilled, and the next day said she'd dreamt of me in a kitchen with a curly haired child with huge brown eyes. My daughter was born with blue eyes and straight hair – maybe Lynde didn't know everything? But while I type this my second daughter Phoebe is playing close by and has just looked up through her mass of curls with her big brown eyes and so, as ever, Lynde was right after all. Lynde your spirit lives on through all of us who knew and loved you and we will miss you.

**Jo Manchester** ♥



Lynde and friends.

## A Great Powerful Spirit

There are some people who leave a mark on you after you have met them, whose words you hang on to and whose advice you cherish. Lynde was one such person, not only to me but also to many people around the world.

I met Lynde over ten years ago at the age of 22. I had just been diagnosed HIV positive and my doctor had very little information on HIV. Life felt overwhelming and it was Lynde who explained to me what HIV was, how it worked and how I could look after my body. I was confused and trying to process many different opinions about what I should be doing. It was Lynde who took the time to deal with the rage that consumed me. She nurtured and invested in me so that I am fortunate enough to be in the position that I am in today.

“Lynde always used to say that HIV stood for Hope Is Vital. Lynde believed in the power of hope. People could make do without a lot but they need some kind of hope.”

Sophie.

## Giving and open

The more I saw of Lynde the more I realised that she was like this with everyone and always gave so much of herself. Like some of us, Lynde may have been afraid sometimes but in all the time that I knew her, I never saw her back away from a challenge. She was open and available to all who needed her and she had a heart of gold.

Lynde taught me that your life is your responsibility – she showed many people how to fight and take responsibility for their own lives. Lynde had the greatest respect for people and their culture. She taught me that it is important to meet people where they are mentally, emotionally and culturally instead of pushing them to meet you.

Lynde celebrated 23 years of living with HIV in March this year. She leaves behind a huge family around the world including ten grandchildren. Lynde we will all miss you. You were so much to all of us and all we can do now is hold onto the memory of your great and powerful spirit and ensure that you live on in all of us whose lives you transformed.

**Sophie Dilmitis** ♥

# Words are **Powerf**

Do we always say what we mean? Or mean what we say? Who decides what words mean? Can they mean different things to different people? Should there be 'rules' about the language we use?

Women living with HIV and AIDS use language like anyone else, language influenced by culture, class, race and geography, among other things. But there is also a whole AIDS language, grown out of AIDS activism, organisations and networks, as well as language which has arisen from more formal responses within the AIDS industry, such as UNAIDS, governments, research initiatives, donor interests. If we then put on a gender lens how do these words look to HIV positive women? How do they resonate with the way we live our daily lives?

## **Commonalities and differences**

Furthermore, how do we spell out in words the differences between us? We are all HIV positive and that holds us together. But other things such as class, geography, race, age, access to resources and so on may also divide us. It's not a question of 'anything goes' or it doesn't matter what language we or others use. *ICW News*, for instance, will not print racist or homophobic words or views, full stop. Those views, expressed in words, would reflect, foster and bolster power imbalances and inequalities.

But *ICW News* would print other words which some women are critical of and others not. For instance, Alice Welbourn puts the case for avoiding any negative language in our vocabularies, including the words fight, battle

## Positive Prevention by and for People Living with HIV: **Positive Health, Dignity and Prevention**

What is Positive Prevention? Words can mean different things in different contexts, languages and perspectives. *ICW* and former staff member, **Philippa Jungova Lawson**, reports on how people living with HIV and AIDS are defining Positive Prevention for themselves

Positive prevention discussions have often not included women and other people living with HIV. People who *know* their HIV positive status were rarely involved in defining positive prevention or in related policy, programmes, monitoring and evaluation, research and funding. This has created two problems:

1. An overemphasis on HIV testing rather than on the needs of people who already know their status
2. A focus on preventing HIV transmission rather than on preventive health services for people living with HIV.

Since January 2008, *ICW* members have worked with the Global Network of People Living with HIV/AIDS (GNP+), UNAIDS, and other partners under the *Living 2008 Partnership*<sup>1</sup> to assess the words' meanings, and to explore if PLHIV own and claim 'positive prevention'. Through researching what is known and through consultations with many (over 1,000) people living with HIV, a literature review and a background paper was completed<sup>2</sup> based on the following questions:

- Why should you/I as positive people care about positive prevention?
- What is positive prevention to you?
- How would you define positive prevention?

- What activities or services are included?
- What is the difference between positive prevention and just prevention?
- Should positive prevention only be targeting people who know their HIV positive status?



Ale Trossero, Ruth MuKonde, Angelina Namiba, Beri Hull, Martha Shindi and Philippa Lawson in Tunisia.

During the August 2008 *Mexico Living 2008 Summit*, not all PLHIV participants agreed that PLHIV should be involved or even engage in discussions around 'positive prevention'. Historically and currently the term 'positive prevention' includes a focus on HIV transmission from positive to negative. Therefore some PLHIV stated that the existing term could be utilised by donors, governments and others in a discriminatory and 'dangerous' manner, relating it to criminalisation and blaming those of us who know our HIV status. Due to possible mistranslations of 'positive prevention' into local languages, the term could be understood as being about quarantining HIV positive people, or for instance, 'stopping the people with HIV'.



Rob, Philippa and Beri.

# Ul and Pliable

and struggle. Yet other women, for instance Jeni Gatsi, regularly signs her articles with the rousing phrase, A Luta Continua (the struggle continues) and many other HIV positive women find that the word fight describes accurately what they must do in their lives and organisations. *ICW News* believes there is room for both approaches in its pages - and many others besides.

## Honouring our emotions

One other important way women living with HIV use words is to express their emotional realities, whether facing fears, creating hopes, or sharing personal testimonies. In *ICW News*, we hope to produce a nourishing mixture of many sorts of writing, addressing different subjects, realities and aims, including debates, reports, activism, news of ICW projects, personal testimonies, poetry, and information vital to positive women's health and well being.

In the next six pages **Philipa Lawson** explores the different meanings of the words Positive Prevention; **Heidi Nass** describes how the cover image was designed by a group of young women using a female form inscribed with words; **Alice Welbourn** spells out why she and others believe that transforming our language can transform society, **Luisa Orza** demystifies Monitoring and Evaluation and the language it uses; and **Jeni Gatsi** uses the language of personal testimony to powerful effect.

## Shared responsibility stressed

During Mexico and the follow up consultation (in Tunisia, April 2009) shared responsibility was stressed as one of the most critical components for any discussion or intervention. How various countries have defined 'positive prevention' has made the term offensive and puts blame for transmission on people who know their status. Some people stated that transmission should not be part of positive prevention. They felt the term was negative and insisted that it needed to change. A *Living 2008* participant stated, 'I was surprised to hear yesterday that some people believe that the term positive prevention is discriminatory; I believed it was a positive term, but if positive people believe it is stigmatising then we need a new term.'

Overall, *Living 2008 Summit* participants agreed that whatever the term is that:

1. It must be centred on the efforts of people who know they are living with HIV to help them to learn and practice ways to promote their own health and prevent disease.
2. Although it will also reduce HIV transmission, it is not **only** about preventing HIV.
3. It is inextricably linked to access to treatment, care and support.
4. Combating stigma and discrimination is essential to its success.
5. Everyone has a role to play and responsibility must be shared.
6. It also requires addressing social vulnerabilities such as poverty, gender based violence, xenophobia and homophobia.

## Tunisia meeting: importance of a human rights approach

From 27-28 April 2009 an international technical consultation on 'positive prevention' convened by GNP+ and UNAIDS took



Positive Prevention Consultation.

place in Tunisia. More than 50% of the 'expert' group were positive people, with numerous ICW members participating (several ICW members, especially from the Middle East, were not comfortable disclosing their name or photo). The group discussed research and evidence on serodiscordant couples, undetectable viral load and how they could potentially affect transmission, sexual and reproductive health and rights, criminalisation, and existing policies and programmes. The World Health Organization led a discussion on 'Framing Positive Prevention within Universal Access' and on developing guidelines on *Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings* <http://www.who.int/hiv/pub/plhiv/interventions/en/>

Participants stressed that a human rights approach based on legal protections and a policy environment free of stigma and discrimination needs to be the basis for any prevention intervention related to PLHIV and:

*recommended programmes promote holistic health and wellness, including access to HIV treatment, care and support services, and by doing so contributions are made to the health and wellbeing of their partners, families and communities. Additionally, it was recommended that ... efforts should be responsive to the needs of key populations.*<sup>3</sup>



<sup>1</sup>LIVING 2008 Partnership: GNP+, IAS, ICASO, ICW, IFRC, International HIV/AIDS Alliance, IPPF, Mexican Network of People living with HIV, Sidaction, UNAIDS, WHO.

<sup>2</sup>The working paper was produced with the support of the US Agency for International Development under the USAID Health Policy Initiative. The

views expressed in the publication do not necessarily reflect the views of the US Agency for International Development or the US Government.

<sup>3</sup>From GNP+ May 8, 2009 Press Release: Moving forward on 'Positive Health, Dignity and Prevention' <http://www.gnplus.net/content/blogcategory/13/34/>





The group agreed that no name or words would fit every language and context. As one participant stated, 'In Africa, we have many names, my father and mother have given me a different name; the name is not important... ; what is important is the definition and how we describe it.' An ICW member from the Middle East stated, 'Positive prevention is meaningless in Arabic.' The concept of dignity and focus on health was important for most, though some from Eastern Europe and Middle East stated 'dignity' did not have meaning in their countries. The group decided on the term **Positive Health, Dignity and Prevention** and agreed on the key elements for policies, programmes, research and monitoring and evaluation. ♥

*In the next issue of ICW News Philippa will continue looking at the key elements of Positive Prevention and some questions that still remain unresolved. Please refer to GNP+ website for more information on the process and the results of the consultation. Plus, you can download presentations and documents that you could use in your country. <http://www.gnpplus.net/>*

Do you have any examples of how positive prevention works or worked in your personal life that you would like to share? We are trying to get together a booklet of case stories, 1 or 2 paragraphs of examples of how PLHIV practice positive prevention. Send to me at my email below.

Philippa Jungova Lawson, ICW member and Senior HIV Advisor, Futures Group International, USAID Health Policy Initiative, Task Order 1. Email: [plawson@futuresgroup.com](mailto:plawson@futuresgroup.com)

## Words, Body, Image:

# i have a right

**Heidi Nass** tells us the story of how a group of girls came to create the words and images on this issue's cover.

I am an ICW member. I was diagnosed in 1995 and I know it wasn't terribly long after that I discovered ICW. I live in Madison, Wisconsin, USA. I am a lawyer turned community advocate and treatment educator.

I am based in an HIV clinic that serves 800 patients, where I work as a peer advocate and direct community outreach and education. I am also part of a national coalition of treatment activists seeking to improve drug development and treatment access. I am a member of the USA HIV treatment guidelines panel. After I sent ICW the image on the cover, the editor got in touch and asked me to tell its story.

### How Shaneiquia, Cinnamon, Precious, Julianne and Dianna found their image.

'I have a right' was created by five teen girls who live in my community who had formed a group called Project Create. When I met them in November of 2007 they had just finished writing and illustrating a 'zine for teen girls called 'ey, girl'. The girls wanted to create art for *AIDS Action 2007: Express*, the World AIDS Day art show I was putting together, but they wanted to learn more about HIV/AIDS before they created it. Their mentor knew me through my work as an HIV/AIDS community advocate and asked me to talk to them. The girls didn't know I had HIV or know anyone with HIV/AIDS.

What was to be a 45-minute discussion on HIV/AIDS turned into a two and a half hour conversation on what it means to be girls and women in this world. A few weeks later, when I saw the piece they created, I was struck by how fully it captured the thoughtful conversation we had together.

When the artists at the World AIDS Day show all spoke about their art, Project Create was represented by Cinnamon. She talked about how the women's HIV epidemic is basically a symptom of bigger problems and that all the things, including the words they put into the piece, are things that should be the right of girls and women, but aren't. All women, Cinnamon said, whether they have HIV/AIDS or not, are entitled to them. ♥



“ I was struck by how fully it captured the thoughtful conversation we had together. ”

Listen

Question

Trust Ask

# Vision Matters, Words Make a Difference

In a world of increasing aggression, an issue which occupies me a lot is the overall approach and language which we all use in our daily lives and work. In this personal reflection I explore how the words we use as HIV positive women and in ICW matter and how we might make more effective change through vision and positive words. **Alice Welbourn**

I am glad that more donors are providing funds to 'combat stigma and discrimination' and to 'stop gender violence'. I would like to suggest that these issues are addressed through positive rather than negative language. What we are all aiming for is surely a world where all people, irrespective of gender, age or other categories which are used to divide and drive inequities, can enjoy their human rights, regardless of their HIV status.

Instead of employing phrases or objectives which are essentially very negative like 'reducing stigma', imagine how the world might be if we framed these around the positive aspects of what we want to achieve.

A growing literature base supports this suggestion, confirming how the language which we all use influences the way that we address life. This approach can mean something as basic as starting work through a process which is life affirming, creative and energising, rather than through the traditional negative root of a 'needs assessment exercise', which often produces a long account of sadness and pain.

## Begin with a vision

The principle of the approach I favour, 'appreciative inquiry', has four basic elements of engagement: 'Discover, Dream, Design and Deliver'. Its practitioners certainly see the need, and make space for analysing the challenges which stand in the way of turning visions into reality. But through the process of beginning *first* with the creation of a *vision*, we create a sense of energy and opportunity, which then drives the whole process. Participants, once energised, then find more and more creative, innovative ways over or around the challenges which they go on to identify, than they do if no vision of what *might* be has been created first.

In terms of the issues facing us as ICW, I suggest that the mindset normally used in relation both to 'stigma and discrimination' and to 'gender violence', though well intentioned, is in fact flawed, through falling into the same negative entrapment. People are using negative terms to overcome negative terms - thereby creating a much harder journey for themselves.

Maybe we should *always* seek a different understanding and awareness of the world, a new set of parameters for engagement, whereby we begin with creating a vision of what *might* be - followed by objectives to make a world where we

as HIV positive women are fully integrated into our societies, respected, nurtured, supported, involved; a world where we have full confidence to think, speak and act in mutually respectful ways with one another.

If we were to agree with others at the outset of our work programmes a common vision, and then define positive rather than negative objectives for ourselves, our intimate relationships, our families, our communities, our nations, I believe that we would then find it easier to produce results of real change.

## How we got our ICW vision in Pretoria, 2003

This is what ICW did with our International Strategic Plan. We joined together to create a huge vision tree, which stretched across the floor, connecting us all with its branches and foliage. The creation of that tree together provided us both with the practical framework for the details which we wrote in our ISP, and also with the spiritual dimension of having shared that experience together at that time and place. Its leaves became our indicators, its branches our objectives, its canopy our vision and purpose, its trunk our strategy. We also created ICW's values statement, which was essentially an expression of the air and water and other resources which we breathed together at that workshop, and from which we wanted this tree to grow over the years, in order to enable it best to fulfil our shared dreams for its growth.

Using positive language all the time is hard. I have to work hard at it myself, but feel glad when I have done so. I often realise that I fall back into using the language of domination and oppression, with words such as 'fight', 'target', 'struggle', 'demand' - effectively using the language of those in power in our lives - those whose policies and activities I am seeking to change. I also find it much easier to frame my wishes in negative rather than positive statements. All the more reason, I believe, to turn my back on it and find a new way of shaping and describing the world that I would like to live in. What do you think? ♥

To learn more about appreciative inquiry, go to: [http://en.wikipedia.org/wiki/Appreciative\\_Inquiry](http://en.wikipedia.org/wiki/Appreciative_Inquiry)).

Build **CREATE** Love  
Reach Share

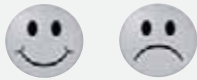
# The words behind the letters



## M & E

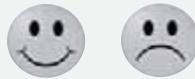
ICW's former M & E officer, **Luisa Orza**, leads us through the meaning and uses of Monitoring and Evaluation for a network like ICW and explores what some of the language means within an M & E framework

**Monitoring and Evaluation** are an important part of our work, but what do they mean, and why do we do them? Monitoring is the act of looking at our work and asking 'What have we done?' and 'Have we done what we said we were going to do?' Evaluation is about looking at those activities and asking 'What changed?' 'Who changed?' or 'What difference has our work made?' These questions are important to show that we are **accountable**. That is to say, that we are making good use of resources **entrusted** to us: the network's **'human capital'** – the collective skills, abilities, knowledge and other *available* resources (including financial and time) of all the people involved in the network: members, staff, activists and volunteers. We must also account for the technical skills, credibility and affirmation of partners, and the financial contributions of donors. But also so we can learn from what has gone before, and by looking at our achievements gain confidence and strengthen commitment as an organisation.



Some of the challenges we face in monitoring and evaluating the work of ICW – a social change network – are that a lot of our work is about relationships, perspectives, beliefs and attitudes: things which are difficult to see, count and measure. Second, the types of changes we hope to influence are long-term political changes, influenced by many different factors, from global politics to local economies, conflict situations and environmental issues. When change occurs it is often the result of many actions by many

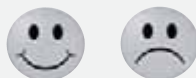
different players, and it can be hard to assess the extent of one organisation's contribution. A third challenge is that ICW's activities (and one of the strengths of being a network) take place in different locations and environments at the same time, some at grassroots level and some at international policy level. These activities are linked through the values and goals of the network, but no one in the network can know about everything the network is doing.



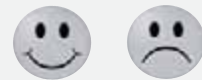
**"I started to believe and trust myself that I have quality that some one took away from me – HIV is not a death sentence."**

ICW member evaluating a workshop.

At ICW we use a range of different monitoring and evaluation techniques and activities to look at the difference our work is making. Some are very quick and easy – like giving out a postcard after an event and asking people to give the event a score, or say what they liked, didn't like or learnt from the event. Others are more complicated, such as a report card we developed last year to look at the involvement of HIV positive women in the Mexico City International AIDS Conference. We distributed the questionnaire among delegates at the conference, asking about their experience of working with HIV positive women, and compiled the results into a lengthy report with recommendations for our work and others.

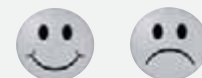


Our M & E can give us a picture of how well we are doing, but they can never give us the whole picture, because of the challenges described before, and because we interpret success in different ways according to our realities, priorities and experiences. Too often the words used in monitoring and evaluation are dictated by others – donors, partners, programme implementers – rather than by the people most involved in and affected by the work. These words help to determine what the people evaluating the work look for, expect to find, and see. The danger is that they will see only what they are looking for, and not the many other meanings, realities or experiences of the people on the ground. Story-telling (which can be done through workshops, case studies or interviews that use open questions) allow the person telling the story to present what is important to them – not just what we say should be important.



Opposite are some of the words we use in an M&E context. Some are technical terms and tools – we need to think about how we use these to allow for the different realities of our members. Others mean different things to different people, and are difficult to measure. But they are also important to our monitoring and evaluation activities and frameworks, so it is useful to revisit and continue to discuss the different ways in which we interpret them.

*Simple forms of evaluation sometimes use the happy or sad faces seen here.*





**Indicator**

This is a term often used in monitoring and evaluation which refers to a 'sign' or form of evidence that a change we wanted to happen has in fact occurred. For example if an organisation aimed to increase the availability of condoms, an indicator of achievement might be 'the number of condoms delivered to a particular place or group of people'. However, this would not tell us whether or how the condoms were used, or by whom. Indicators to assess difficult-to-measure things like empowerment, stigma, or well being can be tricky. For example, some women may be given condoms at their clinic, but may not be able to persuade their partner to use them. These are also words that may mean different things to different people, so our indicators around these areas need to take into account what each of them means to the people concerned. For example, to some people empowerment might mean the ability to go out to work and earn an income; to others empowerment might be the ability to talk about sex openly with our partner. If we only look at the number of women who work, we will miss those who feel empowered in other ways. Indicators are political tools: it is possible to use them to look only at the things we want to see and not face the realities that are disagreeable to us.

**Inputs resources/activities) and outcomes (results/changes)**

Inputs are the activities and resources that go into an area of work, be it a project, programme, advocacy campaign, or on-going networking and dialogue building. Input can include time, money, staff, volunteer or activist knowledge and skills, and so on. Outcomes are the changes that result from the work. But some resources can be both inputs and outcomes. For example, at ICW we promote a form of leadership that encourages the development of new leaders. So leadership could be both an input and an outcome. Similarly, as a network trust is an important resource. Trust breeds trust, so this could also be both input and outcome. Other areas that this applies to are agency, solidarity, identity and self-determination – many of the words that we associate with empowerment, and that ICW considers important in both the way we do our work, and the outcomes we would like to see for our members and the strengthening of our network.

**Risk and Trust**

Risk is about taking chances; about deciding to do something, even though you don't know what the outcome may be, which can include putting ourselves in potential danger. Organisations have a legal requirement to weigh up and minimise risk in order to protect the people who work for them, the beneficiaries or any investors. How do organisations decide what the risks we are facing are? How do they assess whether these are big or small risks, and how to mitigate them? And how do we balance risks against trust, for example trust is a necessary characteristic of a network, where many people are working independently from one another, perhaps in different parts of the world, with little communication, and even fewer opportunities to meet and discuss things. The relationship between these two things is very interesting. Often we take risks (like crossing the road, or falling in love) because we trust



ICW members taking part in M&E

that another person – be it a stranger or an intimate partner – actively wants to avoid putting us in danger. Cautionary actions that minimise risk can also erode trust. So how do we decide where to place the balance between risk and trust that the network needs to survive and thrive? And how do we measure these? It is interesting that tools and measures abound to carry out a 'risk assessment', but I have never heard of a 'trust assessment'. What do we do to promote, strengthen and measure relationships of trust? Is it possible to build trust while also putting measures in place to reduce risk?

**Identity**

As a network, ICW's identity is the product of both the commonality of our members being HIV positive women, and the values which the network adheres to: commitment to advocacy; commitment to the greater and meaningful involvement of women living with HIV and AIDS; accountability; solidarity; self-determination and empowerment. Another defining feature that forms part of ICW's identity is the fact that we are a global social change network, which means that our work at the grassroots level, with community-level, national, or regional women, organisations, networks of HIV positive women, service providers, partners, and policy makers, produces and sustains an overarching global advocacy agenda and voice, through which positive women from around the world may speak. Having a clear identity is important for our M & E work and show the on-going need for ICW's work and create commitment around this. But how do we measure our organisational identity? Do we all agree on what our identity is? ♥ 😊

*ICW News* is one of the places where we assess our work, and where we try to create spaces for the different meanings, experiences and realities in the lives of women living with HIV to be expressed. What do these words mean to you? Can you add in other key words?

**Leadership; Trust; Participation; Empowerment; Identity; Transparency**

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# Passage of Anxiety

Dear Friends,

I would like to take you on a journey I recently experienced, which was a passage of time, anxiety and a lot of stress but also an eye opener. As a woman living with HIV and living in Namibia, I have always been careful to go for Pap smears. But I started to ignore this carefulness in 2007, putting my work first rather than my health. At the beginning of this year my instincts kept pushing me to go for a smear, so much so that I forced myself to take time off to go.



Jeni feeling strong again.

My Pap smear was done on the 5th of February 2009. At the same time they also examined my breasts (which I always do every two weeks). I was told they suspected a breast lump and I should go for a mammogram. With the letter provided by the Cancer Association, my doctor managed to book me but not until the 19th of March.

In Namibia, only the middle class and rich can afford this and only if they have medical aid as it is costly. I imagined our women who cannot afford this and who do not have access to screening. What happens to them?

## Waiting with apprehension

When my booking was secured my anxiety started. I was asking myself if it comes back that it's cancerous, can I handle it together with my HIV? How are people going to see me? Are they going to discriminate further? How are the young people I work and engage with going to take this? Are they going to lose hope in the work we are already successfully implementing? How long will I live?

All sorts of questions were occurring and making me more and more confused. I started to stigmatise myself by not wanting to discuss the suspect lump with my colleagues as I did not want to raise fear. I only told a few people who are partners in our projects and I received wonderful support. Through this and their words of encouragement, I managed to persevere while waiting for the mammogram.

On the 19th of March, I went for the mammogram and the results were good, I do not have cancer. This made me realise the importance of screening for cancers, be it for the cervix or breast, and the importance that these services be available in public health centres.

This morning I called the Directorate of Primary Health in the ministry to find if they offer these services. I was told that because of staff turnover there had been delays. However, the Cancer Association had now trained a number of nurses and the services were now in place. I decided to follow up at two clinics by seeing whether I could have a screening.

## Are services now in place?

At one clinic I was told I had to make an appointment but the sister in charge of this was not in for the whole day. I asked what to do and I was told to try again tomorrow. You can imagine that a disadvantaged and illiterate woman is going to find it difficult to follow-up on making an appointment or be motivated if there are such obstacles. Imagine a village woman who has travelled for more than 10kms to go to the clinic for a full screening then being turned away because the nurse in charge is not there.

At the second clinic I was told the nurse had not shown up even though she was supposed to be at work. I tried to ask the male nurse whether they did full screening on cancers and he told me that it had been introduced at the beginning of the month but only one nurse (the absent one) was trained. I also asked him how they would make sure that women, including women living with HIV, know about this service and he said they were going to put posters in the health centre. I guess we will have to follow up after a month to see whether this is the situation. A lot of work to do indeed!

This is my story I wanted to share with you and also hear from others how they manage to tackle this kind of challenge.

Keep well and A Luta Continua, **Jeni Gatsi** ♥

*Note: Jeni's piece first appeared on the Athena website.*

# HIV Positive

## Women Asylum Seekers in the UK

What happens in the UK when HIV Positive Migrants or Asylum seeking women face removal to their countries of origin? **Deborah Singer** of Asylum Aid describes an innovative partnership of three organisations: Positively Women, Asylum Aid, and, during the second phase, ICW. Their project provided a holistic response to the women's needs with a particular emphasis on legal advice about asylum and immigration law.

During the project one case unfolded which examined the circumstances in which the removal of a person living with HIV could constitute a breach of their human rights because appropriate treatment would not be available or accessible in their country of origin. The case went all the way to the European Court of Human Rights and was unfortunately unsuccessful. *'The House of Lords and subsequently the European Court of Human Rights concluded that the Convention did not encompass the right to social welfare for people who lacked the legal right to stay in a country. Therefore it was not a breach of her human rights for a woman living with HIV to be repatriated, even where the treatment she relied on to prevent the progression of her illness would not be available to her.'* It had a major negative effect on the potential for the project's clients to obtain protection from removal to their country of origin. The decision resulted in the emergence of a clear protection gap for women living with HIV, which the project attempted to resolve.

To tackle the protection gap the project adapted in two ways. Firstly, ICW was brought into the partnership. Through linkages to ICW's membership, regional offices and links to positive women's networks at local and national level, ICW staff were able to establish the situation in women's countries of origin regarding medical treatment and discrimination. They discussed this information with clients, and linked them to local sources of support prior to their return, to reduce fear and anxiety.

*E faced being returned to Jamaica and was given very little time to prepare for her departure. ICW contacted a member working at the Jamaican Network of People living with HIV*

### Asylum Aid

By combining expert legal advice work with campaigning activities, Asylum Aid responds to asylum-seekers' immediate legal needs and addresses the underlying causes of the difficulties they encounter during the asylum process. The Refugee Women's Resource Project (RWRP) at Asylum Aid provides a unique blend of legal casework, information, research, and policy work and campaigning for women seeking asylum.

*A positive partnership: The HIV Immigration Project 2003-2009  
a joint project by Positively Women, Asylum Aid and the International Community of Women living with HIV/AIDS  
Report available at [www.asylumaid.org.uk](http://www.asylumaid.org.uk)*



European Court of Human Rights

Image: Eugene Regis

*(JN+). JN+ figured out the support E would need on arrival in Jamaica and offered to meet E on her arrival at the airport with medication, if this was needed. E contacted JN+ and received advice and support from them on her return to Jamaica.*

### Possible solutions to emerging problems

Secondly, Asylum Aid explored alternative legal avenues to obtain protection. These included focussing on the risks to a positive woman's child, whether HIV positive or not, such as extreme poverty or lack of appropriate health care. In one case the Court of Appeal held that subjecting the mother to seeing her child's suffering or death constituted the sort of inhuman treatment prohibited by the European Convention on Human Rights.

The report highlighted a number of areas which may offer ways of helping HIV positive women asylum seekers in the future. But while these examples provide new possibilities for women living with HIV, they are limited to those in certain circumstances and depend on the facts of each case.

In fact, the majority of HIV positive women asylum seekers still face removal from the UK. They will continue to live without formal immigration status in the UK with all the difficulties this entails or they may have to return to countries where the provision of life-prolonging treatments are less effective, not available or only available at great cost. ♥

“ICW staff were able to establish the situation in women's countries of origin regarding medical treatment and discrimination.”



# Preventing HIV Transmission in Women, Mothers, and Their Children

ICW member **Alice Welbourn** reports on the work of the Inter-Agency Task Force on PMTCT (IATT) which consists of various international NGOs, government bodies, and organisations, including ICW. It aims to prevent HIV transmission and improve the health of HIV positive women, mothers and their children.

The IATT's original purpose was to contribute to improving and scaling up programmes to prevent HIV infection in pregnant women, mothers and their children, in accordance with the Declaration of Commitment on HIV/AIDS of the United Nations General Assembly Special Session on HIV/AIDS in 2001.

This goal was expanded in 2003 to include the following four components:

1. primary prevention of HIV infection among women of childbearing age
2. preventing unintended pregnancies among women living with HIV
3. preventing HIV transmission from a woman living with HIV to her infant
4. providing appropriate treatment, care and support to mothers living with HIV and their children and families.

## A wider remit: care and treatment for children

In 2006, the IATT decided to expand its focus to include improving and scaling up HIV care and treatment for children to cover early diagnosis, expanded treatment access and increased integration of HIV care and treatment.

The IATT also aims to strengthen partnerships that address the broader health concerns and survival of women, infants and children within the context of HIV. Within the framework of their respective mandates, comparative advantages, capacity and technical expertise, the IATT partners are committed to addressing issues related to policies, strategies, mobilising and allocating resources, providing technical assistance to governments for accelerating the scaling up of programmes, and tracking the global progress of the prevention of mother-to-child transmission of HIV and HIV care and treatment for children.

“We are also concerned that there should be no criminalisation of HIV transmission during or after pregnancy.”

## Next step: a questionnaire

In 2007, the IATT produced a document entitled *Guidance On Global Scale-Up Of The Prevention Of Mother-To-Child Transmission Of HIV: Towards universal access for women, infants and young children and eliminating HIV and AIDS among children*. Since then it has recently agreed on the use of a questionnaire which will enable health care providers and others to establish an indicator of unmet need for family planning. This will be a valuable measure of programme performance by indicating the extent to which women living with HIV not intending to get pregnant are able to obtain a birth control method of their choice, and help focus attention on integration of reproductive health care within HIV treatment and care. It will soon be decided which countries will pilot the questionnaire.

## ICW's perspective

ICW's concern throughout this process is that positive women are fully respected and supported in all their choices regarding whether or not they want to have sex, to have (more) children and to stay supported in their treatment and family planning options by all health workers and others involved in the welfare of themselves and their children. This provision should reach far beyond the pregnancy and birth of a child, throughout the life of both the woman and her children, for the woman's own sake and her human rights, as well as for the sake of her children and their human rights. In this respect, we would also prefer it if this process wasn't called 'PMTCT' at all, but something more holistic, such as 'positive parenthood'.

ICW believes that the best services for positive women are likely to have openly positive women themselves among the professional trained health care staff; and are also likely to have openly positive women offering the provision of good support for all HIV positive women clients and their children. One organisation called M2M is doing fantastic work in this regard

in Southern and East Africa.

It is also ICW's concern that all testing of pregnant women is conducted on a voluntary, confidential and respectful basis, that ensures pre- and post-test counselling and also ensures that women, if they test positive, are not at risk of violence or other forms of stigma or discrimination from health care workers, partners, or other family members. We are also concerned that there should be no criminalisation of HIV transmission during or after pregnancy, for fear of undermining all the important work in this area. If women fear that they will be criticised or criminalised, even women who are not positive avoid going to their local ante-natal centre for care. ♥

For more on these issues, please see the ICW website.

**Beri Hull**, Global Advocacy Officer for Access to Care, Treatment and Support, is the 'focal point' for ICW for this work. She is supported by staff member **Aziza Ahmed** who is ICW's legal adviser; and volunteer ICW members **Dawn Averitt Bridge** and **Alice Welbourn**.

See box on next page for more information on IATT



Picasso, Mother and Child by a Fountain (detail). Flickr image by \*clarity\*

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This provision should reach far beyond the pregnancy and birth of a child, throughout the life of both the woman and her children.”

## Organisations on IATT

The Inter-Agency Task Force on PMTCT (IATT) which was founded in 1998, is a working group of representatives of many different organisations, including WHO, UNFPA, UNICEF, UNAIDS, Columbia University, CDC, The Global Fund, IPPF, the World Bank, USAID, DFID, FHI, the Population Council, ICW and several others. In 2001 it was renamed the Interagency Task Team on Prevention of HIV Transmission in Pregnant Women, Mothers and their Children.

# SWAA Ghana: Empowering Women

**Angelina B. Ephraim**, SWAA Ghana's Public Relation Officer, sent the following report.

The Society for Women and HIV/AIDS in Africa (SWAA Ghana) is a branch of SWAA International. SWAA was established in 1988 as an NGO with its headquarters in Dakar, Senegal. It has branches in 43 African countries including Ghana. SWAA Ghana was established in 1990 and has since then been actively involved in education and advocacy programmes on HIV/AIDS. It has branches all over the regions of Ghana and there are 42 people living with HIV/AIDS network groups.

SWAA Ghana plays a major role in the advocacy and sensitisation of the people in Ghana about women and HIV/AIDS. Women are specifically vulnerable in the society and when infected they lose respect and become stigmatised.

The trauma married women face makes them lose focus on playing their vital roles in their homes. Others lose their marriage or are called witches if their children are dying without their HIV/AIDS status being known to them.

In the case of working class women, some lose their jobs whether in the NGO sector,

private companies, as food vendors or second hand clothes sellers and so on, because they are infected with HIV/AIDS. Unmarried women also lose their partners and sometimes are assaulted. Some can never get married. Others commit suicide just to end it all.

## Empowerment

SWAA Ghana among other things has empowered some of the people living with HIV/AIDS, and supported their leadership qualities so they are now able to defend themselves. Most of them are now using skills acquired to set up income generating activities like tye & dye batik, soap making, pomade making, bead making and some have gone for loans in order to trade. Some women are in adult literacy programmes and are now able to read and write.

Our aim is to advocate on behalf of women, children and families in the fight against HIV/AIDS and mobilise communities by strengthening their capacity to control, prevent and mitigate the impact of HIV/AIDS. ♥

## Listen to Estela and Maura

Following on from our information about Estela (ICW News 43) and Maura (ICW News 44) in recent newsletters, you can hear their full stories and their advocacy messages to policy makers at [www.stratshope.org/d-audio.htm](http://www.stratshope.org/d-audio.htm) as a part of a project on HIV, Women and Motherhood by Alice Welbourn. A CD copy of this project will soon be available - please check the next ICW News for details.

## Thank You!

Big 'Thank You' to all contributors to this issue including: Katy Proctor, Franck Pertois, Jeni Gatsi, Esther Sheehama, Alice Welbourn, Philippa Lawson, Emma Bell, Luisa Orza, Jo Manchester, Sophie Dilmitis, Fiona Pettitt, and Deborah Singer. A special thanks to Heidi Nass for sending the cover image and to the girls who created it: Shaneiqua, Cinnamon, Precious, Julianne and Dianna

## Get the Newsletter by Email

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

## ICW NEWS ISSUE 45

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



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

This is a general issue so it's a chance for everyone to send their personal stories, any articles of interest to HIV positive women, debates, poetry, and drawings, photos or cartoons. How about some letters too! Send to Sue and Katy Proctor at the ICW London office, or email to: [sue@icw.org](mailto:sue@icw.org) and [kproctor@icw.org](mailto:kproctor@icw.org)

**Issue Number 47**  
**Deadline: December 1**



# ICW Staff and International Steering Committee Contact Information

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

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

### Patron: Mary Robinson

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\*All ISC places are voluntary and unpaid.

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## ICW members

### ICW Members Receive the Newsletter Free

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

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

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

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

English  Spanish  French

NAME

ADDRESS

POSTCODE

COUNTRY

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

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

## ICW needs

### your support

#### ICW friends\* and supporters

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

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

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

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

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

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