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## CELEBRATING: 100 Years of International Women's Days; Marking 30 years of the HIV pandemic

### Welcome to the fifth edition of the Sophia Forum newsletter!

We aim to increase awareness and understanding of women's sexual health, HIV and AIDS amongst health and other professionals, service providers and the public. So read this newsletter, then share it with everyone you know!

***"Join the network; Spread the word; Call for action"***

### CELEBRATING 100 YEARS!

8<sup>th</sup> March 2011 is International Women's Day, when people around the world unite to recognise and celebrate the economic, political and social achievements of women. This year is even more special, as it is the 100<sup>th</sup> anniversary of the Day. All around the world, national holidays, events and campaigns are held to mark the day. Sophia Forum is marking the event by highlighting how women, in the UK and internationally, are affected by HIV.

### HOUSE OF LORDS MEETING.....

The most recent Sophia Forum event, held on the 18<sup>th</sup> January at the House of Lords, was a roundtable meeting to discuss the many ways in which women in the UK are affected by HIV. Kindly hosted by **Baroness Gould of Potternewton**, the event brought together over 50 people, representing sectors as diverse as health, law and education, and from professional and civil society organisations. Speakers and participants in the event highlighted the key issues facing women with HIV in the UK, shared existing knowledge and identified essential areas for research, and for action.

**In this edition...** of the Sophia Forum newsletter, we share the presentations made at this event. We hear from **Silvia Petretti** of Positively UK on the links between HIV and gender violence and how women living with HIV are especially vulnerable to dangerous relationships. Silvia also describes the value of peer support for women living with HIV, and the need for more research to support the benefits of this..... see page 2

**Sophie Strachan**, also of Positively UK details the issues facing women living with HIV in British prisons. Confidentiality is the key problem, with lack of education for prison staff and respect for privacy leading to confidentiality not being respected, with serious psychological implications..... see page 3

**Professor Baron Peter Piot**, Director of the London School of Hygiene and Sophia Patron, reminded us not to let AIDS fall of the agenda.

From **Dr Jantine Jacobi** of UNAIDS and the Global Coalition on Women and AIDS, we heard about the international dimensions of HIV in relation to women, and how these affect and apply to the UK.

**Professor Jane Anderson** of Homerton University Hospital, another Sophia Patron, described how women's experience of HIV in the UK is complicated by migration, impact on family life and other key issues.

**As we celebrate** International Women's Day, it is vital that, as well as recognising what has been achieved by and for women, we also remember how much further there is to go. **30 years into this pandemic**, women in the UK, and internationally, who are living with and affected by HIV, continue to face the threat or reality of violence, lack of support, violations of privacy, stigma and discrimination.

Nearly **100 years on** from winning the right to vote in the UK, women **still** need opportunities to participate meaningfully, access to peer support, protected services, good education and services for girls and young women especially: and support also for all the women who are lonely care-givers, isolated by the stigma of this pandemic.

**There is still so much we can do.....**

## Visibility, Voices & Vision: a strategy for Women & HIV in the UK

*\*Silvia Petretti, Positively UK*

**'It takes more than pills to live with dignity and safety'** I am a woman living with HIV and I work at Positively UK. We speak to hundreds of HIV positive women every year. We meet them in support groups, through the help-line, in hospitals and during outreach to prisons.

From a strictly bio-medical point of view many of us are doing really well. And I have heard so many times that HIV should be 'normalized' and treated like diabetes. But for most of us who are living with HIV in the UK I know that it takes more than pills to live with dignity and safety.

**Dangerous relationships** Positive women find enormous difficulties in the area of relationships. The pressure of being in a relationship, combined with the anxiety of being rejected because of our HIV status pushes us very often into dangerous relationships.

2011 has started with some stark reminders of those dangers. During the Christmas holidays I was threatened with violence by an ex partner: the fact that I am a woman living with HIV, made me a potential 'killer' and of course of dubious morality. This was very much at the centre of the verbal attack and the threats of physical violence. In my ex-partner's mind I obviously deserved to be treated like that because I have HIV. I was shaken, and hurt, but thanks to the support of friends and family I was able to feel a certain degree of safety. For many women for whom HIV is still a dark secret to be protected at all costs, it would be impossible to talk to anybody about such an episode and this sense of safety would be unattainable.

**Links between HIV and gender violence** I have used my personal example because I want to dispel the myth that violence against women is something that affects only 'certain' women: the 'vulnerable', or the 'African Community'. Among women with HIV in the UK, this goes across class and colour: it's part of our reality. Poverty, immigration issues, isolation and fear of HIV status being revealed create extra insurmountable obstacles that lock positive women in these dangerous relationships.

Globally, the UK's Department for International Development has widely acknowledged the strong link between gender inequity, gender

violence and HIV. However this link has never been acknowledged in any national HIV policy strategy here in the UK.

**Peer support** Obviously when HIV positive women face such complex and difficult circumstances as those we highlight here, it is no surprise that our health, physically and mentally, is affected. Research shows that women have worse outcomes in regards to HIV treatment. This is due to several factors, including low numbers of women in clinical studies, and lack of studies focusing on women's issues outside pregnancy. It is no wonder then that there are still only about 30 of us women who are fully open about our status here in the UK: just 30 out of about 33,000 women who have HIV here.

However, I know from the work we do that peer-led support enables women to regain a sense of self-worth, and this has a positive effect on our mental and physical health. Peer support is important in enabling us to disclose our status, or in giving us the confidence to leave abusive or violent relationships. Being more open about HIV also improves our adherence. Finally, when women are appropriately supported in their psycho-social needs they require less face to face contact with their health-care providers. In brief: peer-led support for HIV positive women not only has health outcomes, but makes economic sense.

**'Stigma will end when we are visible'** To conclude I would like to point out some recommendations which will allow us to continue to do our work:

Firstly, we need some robust evidence to back our work. We need resources to develop participatory research around how gender, HIV related stigma and gender violence affect our lives as well as research on the effects of peer-led interventions.

Secondly, we need better partnership between the scientific community and HIV positive women. Scientific research, including clinical trials, should involve and support HIV positive women at every stage, from formulating questions, to collecting and analyzing data.

Thirdly, and most importantly, that support for women's centred services and networks has to be long term and sustained, so that we, who are directly affected, can develop and maintain the strength to challenge negative societal views of HIV positive women. **Stigma will end when we are visible.**

*\*(This is a slightly edited version)*

## Prison work: Issues facing women living with HIV in prison in the UK

*\*Sophie Strachan, Positively UK*

### Challenges: Confidentiality policies

Confidentiality issues factor largely for the women in prison with HIV who need to access support. Women find it too difficult to engage with those trying to support them: appointments are made and then often cancelled at the last minute. Our caseworkers have been informed by health care workers in the prisons that women have hidden from them, in order to avoid being seen regularly leaving the prison wings with a health care worker. Instead, the women ask to be taken down to meet the caseworker by a prison officer, instead of a health care worker.

A woman received a 'movement slip' through her cell door, which was seen by another woman in the prison. On the slip it had the name of our organisation. An officer also requested to sign this slip. This left the woman concerned extremely upset and anxious of repercussions when returning to her wing. Such incidents provoke a psychological/emotional impact, with feelings of a violation of right to privacy, safety and of discriminatory practice.

**Educational needs** Basic HIV knowledge is required for HIV-positive women in prison. This is evidenced through our outreach work, where we regularly see that long-term diagnosed women have still not been educated about the basics of their condition. For instance, this includes: understanding the meanings of "CD4" and "viral load". Moreover, potential drug interaction information for drug-using addicts needs to be passed on to women in prison.

**Prison responsibility** Prison Health Performance standards and Quality indicators are in place to measure the quality of prison health services. Indicator number 1.32 outlines the standard set for sexual health. It is important for prisons to remember that even if a woman in prison receives a negative HIV-test result, she should not be excluded from the opportunity to receive non-judgmental education around risk and prevention methods. Indeed, there should be robust education programmes, embedded in prison education, highlighting blood-borne viruses in prison and prevention education.

## Management of medication through prison pharmacies

Prison pharmacies are not effective in supporting women with HIV. This raises important adherence implications. For example, women in prison are given a 3-month prescription for ARV's by their hospital, yet a pharmacy within the prison will only give them 1 month's supply of this prescription. Even when giving a prison pharmacy prior notice for more medication, its supply is frequently delayed. This is ineffective practice, is a violation of this woman's rights and interrupts the effectiveness of adherence.

### Ineffective practice for woman accessing HIV care from outside of the prison

The responsibility lies within the prison to ensure effective coordination in making follow-up appointments for women in prison. Communication between and within institutions is imperative. For example, an HIV-positive Zambian woman is still waiting to recommence treatment since her detention in October 2010. She had informed the prison authorities of her previous medication regime, and took tests to assess her resistance to the ARVs she had been taking. However, the prison has yet to make the follow-up appointment at the hospital for her to commence a new regime of medication. This woman, who is still in prison, is now showing clear signs of opportunistic infections.

*\*(This is a slightly edited version)*

## Legal Aid Support

On the 19th & 20th February, Matthew Weait and some of his law students at Birkbeck College walked 40 miles to fundraise for the River House Law Clinic - a new venture that will provide free legal advice and assistance for people living with HIV. Legal aid is being drastically cut, and the poorest will suffer most. People living with HIV - many of whom experience financial hardship - continue to face disadvantage and discrimination in housing, employment, access to health and other services and in family matters. River House will provide service users with a much needed resource... **It's not too late to donate**, either anonymously, or named. Simply follow this link: <http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserProfilePage.action?userUrl=bbkthames2011&isTeam=true>

**THANK YOU!**

## Some new resources.....

**Health workers:** Angelina Namiba of Positively UK also spoke at the House of Lords meeting. Her project, **From Pregnancy to Baby and Beyond**, is a ground-breaking peer-mentoring project, co-led by women living with HIV and leading HIV physicians. To hear more about Angelina's project, follow this link: [http://www.youtube.com/watch?v=2Tf\\_vXKq3Rw](http://www.youtube.com/watch?v=2Tf_vXKq3Rw)

**See also:** a new research report from Positively UK on "Primary Care Access: How General Practice can better respond to the needs of People living with HIV" available to download at: <http://www.positivelyuk.org/docs/PCAP%20Report%20Final%20Version.pdf>

**Educationalists:** Watch, listen and be inspired by the film "Courage and Hope", about teachers living positively with HIV in Africa, who are shining role-models to their students and communities. Watch the film on **YouTube at:** [http://www.youtube.com/watch?v=2Tf\\_vXKq3Rw](http://www.youtube.com/watch?v=2Tf_vXKq3Rw)

**Media:** Lifeboat is a terrific programme based in Holland which documents the lives of people living with HIV in Europe. Watch, for example, the 5-minute clip here about a young mother who fled the Rwandan genocide became a refugee in Europe, then discovered she was living with HIV: <http://www.lifeboatfilms.org/>

**Lawyers:** Sophia Forum belongs to the ATHENA Network, a global network addressing issues facing women in relation to HIV and sexual and reproductive rights. Sophia contributed to a booklet called "**10 reasons why Criminalization Harms Women**" – you can access the report at: <http://www.athenanetwork.org/index.php?id=39>

**Facebook:** Sophia Forum is on facebook. Join us to spread the word and receive regular interesting and informative updates on issues about women and HIV in the UK and globally: <http://www.facebook.com/pages/Sophia-Forum/335015640845?ref=ts>

## EXTRAS.....

**Survey of our supporters** In July 2010, Sophia Forum surveyed our database of 700 supporters and over 100 facebook supporters (some of whom overlap), to learn how we are doing. **Many thanks** to all those of you who took part! **Overall, responses to the survey suggest Sophia Forum is doing well.** The majority of the few *negative* comments reflect the desire for Sophia to expand its work, and to ensure it is clear in stating its purpose and the needs which it seeks to address. **Positive** feedback pointed to the value of involving women living with HIV in events, and the impact that the learning from these events has had on other supporters' own lives. See our website for more.

**Strategic Plan** For the next two years, we will focus on issues facing women living with HIV in the UK. You can read the details of our strategic plan on the website.

**Shop for us!** You can do your own shopping and browsing online *and* support Sophia Forum for **FREE!** Simply use [easyfundraising.org.uk](http://easyfundraising.org.uk) for your online shopping and [easysearch.org.uk](http://easysearch.org.uk) for your online searches: register as a Sophia Forum supporter, and every time you search or shop, Sophia will receive a donation. **It is easy and the pennies soon add up for us.....**

**Young talented artist supporting Sophia** Beshlie McKelvie, award-winning artist, designer and friend of Sophia, is designing "The Sophia Collection" - an exclusive collection of clothes made by women's groups in Kenya. All profits will go to Sophia, while the women's groups also benefit from the income. The collection will launch soon, and will be announced to all our supporters. In the meantime, Beshlie's website will give you a flavour of what to expect:

[www.beshliemckelvie.com](http://www.beshliemckelvie.com)



**Did you know...?** One of the fastest growing epidemics for women and girls and HIV is in Eastern Europe. Through our Facebook entry (see left) for 8 November 2010 you can watch 3 short moving films about the positive effects of methadone substitution for young women living with HIV in Ukraine....

*Newsletter Credits: Jacqui Stevenson, Sophia Volunteer*

**HAPPY INTERNATIONAL WOMEN'S DAY FROM ALL THE SOPHIA TEAM**