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Raising the profile of **positive** women

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eaves
 putting women first
**We are really sorry to
 hear of the closure of
 Eaves.**

**Last places remaining for our 10th anniversary
 event:**

Wising Up: Women, violence and HIV in the UK

[Click here to book your free place](#)

**Nearly, 10 years on, needed now
 more than ever**

Raising the profile of positive women.

Sophia Forum is celebrating our 10 year anniversary with our event, Wising Up: Women, Violence and HIV in the UK, in London in the early evening of the 25th of November.

We have chosen this date as it is the International Day for the Elimination of Violence Against Women and it marks the beginning of 16 days of global activism against gender based violence,

<http://www.un.org/en/events/endviolenceday/>.

The day is also in National HIV testing week

<http://www.bhiva.org/National-HIV-Testing-Week-2015.aspx> and before World AIDS Day on the 1st of December <http://www.worldaidsday.org/>.

**The end of
 AIDS is a
 crucial step in
 improving the
 lives of women
 and girls**

04 November 2015

Ending the AIDS epidemic is critical to making life better for women and girls and meeting their health and development needs, concluded a United Kingdom parliamentary panel that met in London.

[Click here to read the full article](#)

**Women living
 with HIV and**

We are pleased to have excellent keynote speakers including one of our founders, Dr Alice Welbourn, our patron Professor Jane Anderson, a former president of the British HIV Association and Baroness Gould. In addition we hope to have a recorded message from our second patron Professor Baron Peter Piot the Director of the London School of Hygiene and Tropical Medicine and former UNAIDS Executive Director.

What a star studded cast... there is still time to book to attend and hear more about our work.

[Click here to book your free place now.](#)

Some highlights from Sophia Forum activity over the years have been:

- 2008 An evening with [Cherie Booth QC](#) and [Legal Rights and Social Wrongs](#): Sophia inaugural lecture with Baroness Helena Kennedy QC
- 2009 [In Sickness and In Health](#): Women and HIV in 2009 hosted jointly with the TARGETS Consortium at the London School of Hygiene and Tropical Medicine followed by [Health and Safety: The Challenges for Women of HIV and Gender Violence](#) hosted jointly with the All Party Parliamentary Group on AIDS and the All Party Parliamentary Group on Population Development and Reproductive Health
- 2011 Sophia Forum [Round Table Meeting](#) to address issues in relation to Women and HIV in the UK hosted by Baroness Gould of Potternewton
- 2013 House of Lords: [Sophia Forum Report on GBV & HIV](#) launched, followed by the [Sophia Forum at the \(BHIVA\)](#) British HIV Association Annual Conference in Manchester. We have had a poster accepted about our study of the intersections of Gender-Based Violence and HIV.
- 2014 [The first WISE-UP+](#) advocacy workshop by and for women living with HIV.

At the end of October 2015 we ran the second WISE-UP+ (Women, Inspire, Support and Empower to Unleash Positive Potential) residential weekend. It took place in Manchester and 21 women from across the whole country attended.

There will be more about the event in future newsletters

research: Mind the Gap

I would like to share this presentation that I have made Sunday 8th of November 2015 at a meeting with Eucoord researchers organized by the European Treatment Action Group (EATG).

I made this presentation because I think that it is crucial that both community activists and researchers address the gender gap in research as an urgent priority.

[Read the full article here on Speaking Up.](#)

Silvia Petretti

HIV and AIDS: Language and the blame game

The negative and dehumanizing language used by scientists discussing global HIV policy is sapping the soul of those on the receiving end. The call for an alternative language of nature and nurture must be heard.

[Read the full article here on Open Democracy](#)

[Alice Welbourn](#)

but looking initially at the feedback it has been overwhelmingly excellent and a really well received experience.

What I found personally interesting about the weekend is that it was attended by many women who are living long term with HIV (that is over 15 or 20 years). When we first sought funding for the weekend/s we envisaged that they would be attended by women living with HIV who were more recently diagnosed or who were younger but this has not been the case.

In fact one of the women was talking about her “new” 5 years old diagnosisand it does not seem so long ago since anyone that was diagnosed over 5 years was a long term survivor. How times change.

[Public Health England recently published its annual report on HIV in England “HIV New Diagnoses, Treatment and Care in the UK”](#)

The report is shorter than it has been in previously years and does not separate out the data for women, unfortunately. What it tells us is that, by the end of 2014 85,489 people were seen for HIV care in the UK and 28,142 of these people were women. There were 6151 new diagnoses during 2014 of whom 1,540 were women.

Worryingly the report tells us that two out of five new diagnoses in 2014 had “late stage” HIV, evidenced by a CD4 count under 350. Being diagnosed late means a tenfold increased risk of death within a year of being diagnosed. The report details 613 deaths among people living with HIV and says most of these people were diagnosed late.

There is a lot more work to be done to support the expressed needs of women living with HIV, come along and find out more about the work that Sophia Forum does on the 25th of November and help us step into our second decade standing shoulder to shoulder with you supporting us and therefore all women living with HIV across the UK.

Lynda Shentall, Co-Chair

Raising the Profile of Positive Women

I became Co - Chair of Sophia Forum in early July this year and I am really excited to be part of the organisation as it enters into its second decade.

I echo what Lynda has said, there is still a great deal to be done to support women living with HIV in the UK today and an acute need to raise the profile of these issues to service providers and commissioners across the UK leaving no woman living with HIV isolated or without a service that she can access should she wish to.

As an African woman living with HIV I am keen to raise the profile and support the needs of all women living with HIV and to hopefully show other women living with HIV what can be achieved.

I am heartened to hear of the success of the WISE-UP+ residential weekend for women living with HIV in Manchester. I know that feedback from the weekend has been very good and we will feature more about the weekend in future newsletters. We are continually working on funding and hope that we might secure funding for more weekends in the future.

I hope to meet and speak to some of you at our 10th anniversary event, Wising Up, and look forward to continued or new ways of working with you for the best outcomes for women living with HIV across the UK over a further 10 years.

Memory Sachikonye

Poem from a WISE-UP+ 2015 participant

I come from a line of women who get married twice
I come from a line of women who are oppressed,
abused and beaten
I come from a line of women who have little right and
rarely speak out

I come from a line of women who are submissive but very strong
I come from a line of women who will do anything to see their children doing well in life
I come from a line of women who are strong prayer warriors
I come from a line of women who love looking beautiful for their husbands
I come from a line of women who are full of wisdom and advice to keep one going
I come from a line of women who are bread winners
I come from a line of women who wake up at 6 am and don't sleep before 10pm
I come from a line women who love cooking and can prepare good foods with little
I come from a line of women who are brave, elegant, tall and full of love
I come from a line of women who are striving for freedom
I come from a line of women who inspire me
I come from them, I am them and they are me

A Cloud of Light

My HIV story

Spring of 1990 I was diagnosed with HIV – AIDS. I was 24 years old and I was in prison; remanded in custody for illegal drug possession. Even though I was examined by a forensic medic and it was proved I was a drug user I was kept in prison until the day I was diagnosed.

It was already over a month that I was locked up and I started exercising daily in order to release my energy and my nerves for the turn my life had taken. As I started taking care of my body I noticed some bumps at my neck under the skin like nodules. I visited the prison doctor and he referred me to a hospital for further examination. I remember with a smile now, how 'happy' I was to get out of prison, even if it was going to be in a police van with handcuffs on my wrists.

I was going to eat chocolate, yeah! I never really understood why they were forbidden in prison; Chocolates that is. The big day arrived, it was Spring,

the Greek sun was shining, bathing us with a blessing warmth and I was looking out of the van the people and the busy streets of the city. We arrived at the hospital so the policemen took me to the doctors. They examined my 'nodules' and straight away asked me if I lost weight lately.

Of course I had lost weight, I was a drug user my mind was not on food really. They didn't seem they listened to my reasoning –for some reason I felt I wanted to protect myself. Why did they wear masks and gloves and all this 'stuff'? They then asked me if I ever took an HIV test. WHAT? Why should I? This was the level of my ignorance and it reflected well enough the lack of information those years. I started trembling. Did I want to take the test? I hardly heard myself saying 'yes'.

Back in my cell isolated my mind felt empty and lost. I don't remember much from the days waiting the results until one evening I was called to get ready next morning to visit the hospital. When I was climbing in the van I heard the guards saying that we are going to a different hospital than the one I was examined. Suspicion started crawling into my thoughts.

Why? I felt like a child in the 'Dismaland'; awe and fear and worry and surprise all mixed up making my heart freeze. I was guided in a door, the guard knocked the door and put me in a small room with an office and an examination bed. Behind the desk, two doctors were sitting side to side tight close with each other. I thought that the picture was odd. I sat on a chair and they said "we have the results from your HIV AIDS test." I thought "why do you have it and not the doctors who examined me in the first place?" but I didn't say a word. I was numb. I don't remember talking at all.

One of them said that the test came out positive... I wasn't hearing much anymore, the main thing I remember is the light of the sun coming from the window, diminishing everything else. I was floating in a cloud of light in some messy tiny examination room with two older doctors looking at me with sympathy. Yes, they were polite and good with me. When I opened my mouth, I heard myself asking "am I going to die soon?" And the younger of them doctors said "not sooner than

us I suppose”.

I thought that his attempt to give me hope is not successful. I was already dying. He said that they would keep me in the hospital in order to do a second test, further examinations and most importantly to keep me away from the physically and psychologically unhealthy environment of prison.

Then he asked me “do you mind if I call some trainee doctors to be present in the examination?” “No,” I said but the truth is I didn’t want anyone to come and see me and know that I have AIDS! I didn’t dare though to say no. I felt obliged to the doctors, like I had to do everything they tell me to do. The already tiny room filled up with white robes.

The most embarrassing thing is that the doctor asked me to walk with only my underwear to check my balance. And all these eyes on me. At that moment. It was a torture I didn’t understand ‘now that I’m dying’. They finished at some endless point and they asked for a full body MRI scan.

The guards were crossed. While walking me to the scan room they were talking about me having influence or pulling strings to just stay out of prison and now they had to spare one person 24/7 to guard me in the hospital. The doctor asked from the guard to take the handcuffs off. But even the fact that I was walking around the corridors of the hospital full of people with some policemen around me was enough to feel as embarrassed as ever.

The whole morning passed with exams and exams. In the end they guided me in my room. It was a big room with three empty beds. I took the bed by the big window. I didn’t think to call anyone, no one knew that I was dying. I was alone in a big empty hospital room with a guard outside the door. All the nurses in that ward were wearing plastic covers on their shoes and masks and gloves and plastic aprons. I felt like I was in a futuristic movie and I am the infected parasite. I didn’t cry. Not once. Not even at night.

A very young policeman changed the guard in the

evening and he came in my room without knocking –that was not ok for me! - he checked the window, he saw that it can open and he handcuffed me at the bed rail. Not that I was sleepy, but I was exhausted and I might just faint into a blessed sleep if I didn't have those handcuffs tighten me up with the bed. It was a hell of a night and I didn't cry!

The shock was bigger than tears.

Early in the morning the doctor came in my room and when he saw the handcuffs he went ballistic. "Take them off." he shouted at the guard, which he did, saying that he saw my eyes very sad and he was afraid that I might drop myself out of the window on the seventh floor. Something I never thought to be honest.

The next days I was told that my health is fine and I was put on AZT. My main concern became to keep quiet about my health. The stigma was devastating; I didn't want anyone to know and the doctor had said my father. The same doctor few weeks later abused me sexually, but this is another story. I remained in the hospital without any serious reason for it, just because the doctor was keeping me away from prison. While in the hospital, I was granted bail out and I could go home.

Only my father knew and he didn't want anyone to know. They said some lies to my mum and sister and he made me promise that I would keep my mouth shut. I was just following whatever others were saying. I couldn't have a voice and I thought I was guilty enough for contracting HIV to have an opinion about my life. Hence, I allowed the doctor to take advantage of my vulnerability.

Many years have passed, twenty five. I'm here, healthier than ever, my whole family knows, my friends know, but still many people don't know like my colleagues for example. I don't feel I have to tell all these people. It's none of their business. I keep it in a "need to know" basis. That is good enough. I have forgiven the doctor, my father and so many other people for basically their fear and ignorance.

My HIV status is not the most important thing in my life anymore. It is not the last thing I think before I sleep or the first thing I think when I wake up. Life has been taking over a long time ago.

Avy



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Sophia Forum promote and advocate the rights, health, welfare and dignity of women living with HIV through awareness raising, research and influencing policy.

For more information about women and HIV visit our [website](#).
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With many thanks to
all our contributors.

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