

# POSITIVELY WOMEN

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**co-infection** the sum is more than two

personal stories

news and views

what's on at PW

# HBV, HCV, HIV one



Silvia

**In this article, Silvia tells of her experience of co-infection. Originally, this was part of the speech that she presented at The Haemophilia Society HIV and Hepatitis Co-infection Conference 2003. It tells her personal story of diagnosis and experiences within the medical system as a woman co-infected with the HIV and hepatitis viruses.**

I am going to talk about my experiences with three blood-borne viruses: Hepatitis B (HBV), Hepatitis C (HCV) and HIV. Acquiring those viruses is deeply linked to difficult and painful moments in my life, but instead of getting lost in explanations on how and why, I will instead try to just highlight how those viruses affected me and what helped me, or did not help me, to deal with them.

## HBV

I was only 16 when I got Hepatitis B (HBV). I won't go into the details of my precocious drug use. However, this disease gave me an early insight on how precious the liver is. I spent four weeks in hospital, with a transaminase count of 1,600, yellow like a lemon. It was not fun, especially as a teenager. If I have to think what helped me, I can't say – probably being so young! After six months my antigens became negative, and that was it. One down!

## HCV

I was 27 when my GP in Italy advised I get tested for Hepatitis C (HCV). I had gone for a check up and there were some abnormalities in my liver tests. My GP gave me the results over the phone. It was confirmed; I had HCV. He also advised me not to have children because of the risk of pre-natal transmission. Nothing more. No further explanation or counselling was available. I was shocked, and didn't know what to do.

I decided to contact a couple of friends who I knew had HCV as a souvenir from their drug use and who were crippled by chronic fatigue. When I talked to them, they advised me not to go on the interferon, which was the main therapy at the time. One of them had tried it and said, 'under its effect, I considered going back to opiates'.

How did I cope? I opted for denial. I just didn't think about it. I was lucky because I didn't have any strong symptoms. However, at least I had been able to get support and advice from other people in the same situation and that had helped me in my 'choice' of no-action.

## HIV

In 1997, three years after HCV, I was diagnosed with HIV. One would think that because of my life experience I should have been prepared. I wasn't. Shock, terror and tears came with my diagnosis. When I managed to ask doctors about how HCV would interact with HIV, I was more or less told that since HCV was a slow developing disease, it would not have time to affect me. I would have died of AIDS first.

Unlike with Hepatitis C, I did not feel like I could talk to anybody who could fully understand and empathise with me. I did not know anybody who was open about their HIV status. In Italy, as in most of the world, stigma and discrimination around HIV is rife. I felt terribly isolated. Having to think about dying at 30, when most of my friends were planning babies, was very hard but it meant I had to think clearly about how I really wanted to live.

I made a plan. I love books. Books are what saved me from addiction. I decided to come back to London, where I lived during my early 20s and study for a Postgraduate Degree in Development Studies. I dreamt of working for an NGO.

## HCV + HIV

When, in 1999, I finally arrived in London, my HCV was still not addressed for a couple more years. Then finally, more than a year and a half ago, the doctors decided it was time to deal with my Hepatitis C. I was attending an HIV clinic in south London, and they referred me to the liver clinic that was in a totally different department of the hospital. I had to wait four months for an appointment, and when it came it was very difficult. I had become more relaxed towards HIV, as I was confident that HAART would allow me to live much longer than I expected at the time of my diagnosis.

# down, two to go!



However, I still had to overcome my denial of HCV, and acknowledge that this virus was potentially lethal too and even more so in conjunction with HIV. During my first interview with the doctor I held back the tears while repeating my story all over again. At the end of the visit, I was told that after some preliminary tests I should have a liver biopsy, and possibly start treatment for HCV.

I had seen friends on HCV treatment – pegylated interferon (peg-interferon) and ribavirin – going through incredibly tough side effects. I knew a lot about genotypes and how they affected prognosis and length of treatment. I had made my mind up that if I had genotype 1, the hardest to treat, I didn't want to go through the pain of HCV treatment. I already had enough with over four years of HIV treatment! So I asked to have at least the genotype test done before deciding whether to have the biopsy. I was told it was not possible because the hospital did not have enough money. The biopsy was the most important exam to assess liver damage, and they would do that first. So against my wishes I booked myself in for a biopsy. The waiting list was long, more than two months.

As the date of the biopsy approached my doubts grew. I was scared because I had heard quite painful tales of liver biopsies. Moreover, I was not convinced this was the right procedure. After many discussions with other women at PW I was told that there was a hospital in north London where I would have had my HCV genotype and viral load done first, as routine, and then I could choose whether to have a liver biopsy. In this hospital they had a co-infection clinic and you didn't have to leave the HIV clinic to have the hepatitis treated.

The choice of changing hospital was a very difficult one. First of all, it would take me over an hour from my home in deepest south London to travel to a hospital in the posh North. Secondly, I was worried I would have to wait another six months if I needed a liver biopsy. However, a week before the biopsy the fear won. I made my mind up and I called the north London hospital. They confirmed that they would do all the possible blood tests before doing 'such an intrusive procedure as a liver biopsy' (their words), including HCV genotype. I was so

happy to have a professional agreeing with me! I quickly cancelled my appointment for the liver biopsy and I booked myself in at the new hospital.

On the first day in the north London hospital, my blood was taken and I was tested again for HIV and HCV (just in case there had been a mistake). On my second blood test, without a need for lengthy referrals (and to my delight), I was tested for HCV genotype and viral load! In a matter of few weeks I had seen a co-infection specialist and I had received the good news that my HCV genotype was one that responded very well to treatment.

Relieved, I finally consented to a liver biopsy and I had it performed at the beginning of October. Things worked fine for me and I feel optimistic I have enough support around me to deal with going on HCV treatment.

I think it is quite clear from this last part of my story that one of the things that most helped me in making decisions around how to deal with my co-infection has been support from other people living with HIV and HCV.

What has left me with a feeling of malaise (that is not caused by my liver) is the following thought: how can standard of care be so different between two hospitals that are separated only by a few miles? Shouldn't all people in the UK who are living with two life threatening viruses such as HIV and HCV, be entitled to equal standards of care?

## **Silvia**



*Babs, who organised the conference*

# Hepatitis C – basic facts

## Transmission

### Drug use

The most common route of transmission is by sharing needles and syringes and injecting drug paraphernalia. This means that anyone who has ever injected drugs – even once – is at risk of being chronically infected with HCV since it is unusual for first injectors to do so on their own. Other risks are thought to include sharing of straws when snorting cocaine.

### Needlestick injuries

Healthcare workers may be at risk of infection from HCV through needlestick injuries in their workplace.

### Sexual contact

The risk of the virus being passed on through sexual contact is thought to be very low, around three per cent risk for the duration of the sexual partnership. However, people co-infected with HIV and HCV are thought to have a higher level of HCV in their blood and this could mean that there is a greater risk of transmission. Additionally, people with HIV are at a greater risk of contracting HCV. Some sexual practices, such as fisting, can heighten the risk of the transmission of HCV.

### Mother to child (vertical transmission)

A mother may pass the virus on to her baby but again the risk is very low at around five per cent. Women who are co-infected should be aware that there is a greater risk of transmission.

### Breast-feeding

Breast-feeding is thought to be safe provided bleeding does not occur from chapped nipples. Again, there is a greater risk of transmission for those that are co-infected.

## Websites and other resources

### National Hepatitis C Resource Centre

Tel: 020 7735 7705  
email: [advice.info@hep-ccentre.com](mailto:advice.info@hep-ccentre.com)

### The British Liver Trust

provides leaflets on hepatitis C and information on other forms of liver disease on their website.  
[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)  
email: [info@britishlivertrust.org.uk](mailto:info@britishlivertrust.org.uk)

### The Haemophilia Society

have a hepatitis worker & HIV/HCV co-infection worker to provide information and advice to anyone who has haemophilia or von Willebrand's and their families. They also publish a Hepatitis C newsletter.  
Helpline: 0800 018 6068  
email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)  
[www.haemophilia.org.uk](http://www.haemophilia.org.uk)

### The Children's Liver Disease Foundation

36 Great Charles Street, Birmingham B3 3YJ  
Tel: 0121 212 3839  
email: [info@childliverdisease.org](mailto:info@childliverdisease.org)  
[www.childliverdisease.org](http://www.childliverdisease.org)

## Other useful websites

[www.doh.gov.uk/hepatitic](http://www.doh.gov.uk/hepatitic) – Department of Health official hepatitis C website  
[www.doh.gov.uk/drugs](http://www.doh.gov.uk/drugs) – Department of Health drugs website including guidance on hepatitis C  
[www.nice.org.uk](http://www.nice.org.uk) – current NICE Guidelines on Hepatitis C treatment  
[www.hivandhepatitis.com](http://www.hivandhepatitis.com)  
[www.pulse-insurance.co.uk](http://www.pulse-insurance.co.uk) (experience in HIV and viral hepatitis)  
[www.howsthat.co.uk](http://www.howsthat.co.uk) (+ve Magazine and The Rough Guide to Hepatitis)  
[www.hepctrust.org.uk](http://www.hepctrust.org.uk) – The Hepatitis C Trust's Website

## Treatment update

### Tenofovir drug interactions

Several anti HIV drugs, other than FTC, interact with tenofovir. The mechanisms for some of which are not completely understood, although known interactions are listed below:

#### Tenofovir and ddi

This interaction is widely known. When used in the same combination, the dose of ddi should be reduced (from 400mg down to 250 mg; or from 250mg down to 200mg). Both drugs should be taken together, with or without food.

#### Tenofovir and Kaletra (lopinavir/r)

Kaletra increases tenofovir levels by about 30 per cent, this isn't considered significant, and hasn't led to any increased report on tenofovir toxicity.

#### Tenofovir and atazanavir

Tenofovir reduces levels of atazanavir (AUC by 25 per cent through levels by 40 per cent); this is significant. The recommendation is to boost 300mg atazanavir with 100mg ritonavir when tefonovir is in the same combination. Atazanavir concentration is then well above the levels achieved with 400mg unboosted dose. Although tenofovir levels are also increased, this has not led to increased tenofovir side effects.

#### Tenofovir and methadone, oral contraceptives

No interactions have been found between tenofovir and methadone, oral contraceptives, other nukes, Pis or NNRTIs.

***Comprehensive slides on the data are posted to the iBase website ([www.i-base.info](http://www.i-base.info)) for the November CAB***