

08 MAR 2019

Witness Name: GRO-B

Statement No.: WITN0862001

Exhibits: None

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4th March 2018.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B, I am known to my friends as GRO-B. My date of birth is GRO-B 54. My address is GRO-B GRO-B North Somerset, GRO-B I am the wife of GRO-B: H I just wanted to take the opportunity to tell you what it was like for me as the wife of someone diagnosed with Hep.C.

Section 2. How Affected

2. First of all this was not about Hep.C it was about AIDS and some things said at clinics at Hospital. There was on one occasion that a doctor wanted

to ask [H] if he had ever had a homosexual relationship and was in fact homosexual. I always accompanied [H] into the room whenever he had a clinic, as I was about to follow him in the door was closed in my face. This made [H] unhappy but he went in on his own. As stated before the doctor asked him the question... [H] answered no, but it sounded from where I sat outside the door as though he was being asked to confess. [H] was able to walk with crutches then and decided that he was not going to stay and walked out. The doctor came to the door and pointed in the direction [H] had gone and in a raised voice said 'Get him back', I just looked at her in disbelief and said No.

3. Then on a regular clinic the doctor asked [H] to come into the office, he had something to tell him, my blood ran cold, if after all the pain he had gone through was he infected with AIDS? He was told that he had Hep.C and would need a liver biopsy and liver scan to see if it was enlarged. This was like a slap in the face for me, for [H] he was unable to say anything for a while and there was a lot of tears shed by us both at home....what was going to happen now.
4. Looking back now, the Hep.C diagnosis made sense, [H]'s lack of appetite, feeling sick always very tired, feeling unwell but not knowing why.
5. The biopsy (1989) involved a 4 day stay in Bristol Royal Infirmary (BRI), as I didn't drive [H] did not want me to make the trip from [GRO-B] on my own, as we had never been apart this was difficult for us both. I went to bed with his sweater as it smelt of his after shave. We did not have mobile phones then and public phones were not so good. Anyway time went on and we had not heard about the results and what would happen next. It took a letter from me on [H]'s behalf to find out what was going on. It appears [H]'s case had somehow been OVERLOOKED.

Section 3. Other Infections

6. In 2004 my husband received a letter from the British Haemophilia Centre, stating that The Health Protection Agency has placed him in the 'at risk of variant CJD for public health purposes' category. This was following being tested for vCJD in 1990.

7. In 1983, my husband received a letter from the British Royal Infirmary (Dept of Haematology) which referred to our concerns regarding infection related to imported Factor VIII. The letter stated that the 'risks of being infected with conditions such as AIDS is extremely small' continuing 'Thousands of haemophiliacs in Europe and America have been treated with Factor VIII concentrates and the number of reports of AIDS have been extremely small', the letter also makes reference to 'The dangers of refusing treatment if only commercial concentrate is available is greater than the danger of contracting AIDS'

Section 4. Consent

8. In discussions with the doctor in charge of the haemophilia clinic, [H] said he did not want to take his Factor VIII until there was some sort of assurance that it was safe. He received a letter to say that he would be affected with haemophilia before AIDS. [H] was true to his word and had a lot of painful bleeding episodes but would not take Factor VIII in the quantities he should have because of the risks, he told me it was like standing on a three legged stool with a noose around his neck.

Section 5. Impact

9. Then started the treatment of interferon (1998), this was in bottles which had to be measured and administered by me, this was stressful for me, although I do [H]'s home treatment which is intravenous, the measuring

and injecting in the tummy was stressful for me and uncomfortable for
[H]

10. I am a carer at work for people in their own homes, I don't earn a lot but need to work to keep our heads above water. The extra expense of travelling to Bristol twice a month was not easy to absorb into a limited finance.
11. [H] had two lots of interferon and we hoped that would be the end, oh no a positive LFT showed that [H] still had Hep.C. He was then put on a dual treatment of interferon and Ribavirin. This was like being in a nightmare from the start.
12. From the start of the treatment [H] descended into deep depression, crying for hours on end, sleeping all day or not sleeping at all, panic attacks, all this happening as I'm trying to keep working and we also had [H]'s elderly mother living with us as she was made homeless when [H]'s Dad died.
13. There were many, many times as I was walking between the homes of people I cared for that I cried, the only release for me as I could not show emotion in front of [H] as he already had enough going on, and his mother just did not understand what was going on.
14. There were times during his depression that [H] would want to be alone. There were times he drove off with no phone or money and I honestly did not know if he'd come back. When he did he was upset that he had worried me and then we had another hour crying until he fell asleep. It was like living with a stranger and I wanted the love of my life back.
15. The interferon was now in a pen-like applicator which made life easier as far as treatment went but the tablets were horrible to take. All in all the two lots of treatment took two years. [H]'s desire for sex was non-existent

and still is, I think it was the fear of infecting me because nobody said it would not. He also had to take testosterone gel as his levels were very low. Thankfully they are back to normal now. We are a devoted couple so lack of sex is not going to end our love for each other, but nonetheless its another thing taken from us.

16. There were times [H] desperately wanted to give up the treatment but we had come so far I could not let him give up. This was taking a toll on our finances, [H] was now in a wheelchair and thanks to his mobility allowance we can lease a car. It's the only thing [H] says that when he's driving he's the same as everyone else not disabled.

Section 6. Treatment/Care/Support

17. I was never offered counselling or support for my feelings.

18. We were unable to renew our life insurance as we had to declare my husband had suffered from hepatitis.

Section 7. Financial Assistance

19. We received a £20,000 payment from the Skipton Fund in 2004 and currently we receive monthly payments of £1500 from the EIBSS.

20. We received a letter from the NHS Executive in 1999 in relation to our request for a special payment scheme for people with haemophilia infected with hepatitis C through NHS treatment, the letter stated that 'Financial help is only given to patients when the NHS or individuals working within it, have been at fault'

Section 8. Other Issues

21. [H] has recently had to undergo treatment for skin cancer which was every day for almost three weeks. We await the all clear for this April. I love my husband very much and I am proud of the way he has come through all these trials with such courage. I hope these few insights show what it was like to care for someone with both haemophilia and Hep.C. We are so glad that this Inquiry will make this public as so many people have suffered just like us and someone needs to be held accountable.

22. Thank you for reading this and your time. PS. Due to [H]'s continued ill health and my own health issues I am now working three days a week. We manage but what would life have held for us had [H] been able to continue his job as a Master Tailor, the holidays we may have had. But least we have each other.

Statement of Truth

I believe that the facts stated in this witness statement are true.

GRO-B

Signed _____

Dated 6.03-2019.