

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1400001

Exhibits: WITN1400002-3

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B**, DOB **GRO-B** and I live at **GRO-B**, **GRO-B** with my husband.
2. I was infected with Hepatitis C in 1984 after receiving contaminated Factor VIII.
3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I am a carrier of the gene for Haemophilia A and unusually for a female, I am also a bleeder myself.

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5. I received Factor VIII when I was sterilised on 03.04.1984, six months after the birth of my second daughter. This was because my Factor VIII level was very low when I was tested.
6. The procedure was carried out at the GRO-B. I was given Factor VIII pre operatively and on the first and second post operative days.
7. I was not really given my own say in the sterilisation; it was very much encouraged and pushed upon me. This is not reflected in my medical records which suggest I was keen to have the procedure done.
8. I was not offered any other possible treatment other than Factor VIII and I was not told any information about possible risks associated with this treatment.
9. In or around 1994, ten years after I received Factor VIII, I was called to the hospital by Dr GRO-B for what I thought was a factor level check. It was at this appointment that I was tested for Hepatitis C, unbeknownst to me. I believe that Dr GRO-B knew what he was looking for although he never informed me of why he was testing me. It was unforgivable and a clear breach of medical ethics.
10. I was not told that I had been infected with a virus until May/June 1996. I recall that I was sent a letter stating that I had been infected with a virus but it would pass. I was given no explanation and no support; I was not even told what virus they were referring to. I cannot trace a copy of this letter in my medical records. There is now shown to me marked **WITN1400002** a copy of the letter from Dr GRO-B that confirms my test results.
11. It was only when I later went to GRO-B hospital that I was actually told about Hepatitis C and given more information regarding the infection.
12. My husband also had to be tested for Hepatitis C. Luckily this test came back negative.
13. I was later tested for HIV. Fortunately, this test also came back negative.

14. My medical records contain a letter dated 14 September 1989 which states that the Factor VIII I received in 1984 was all NHS British material and that any risk would be negligible. I cannot recall the circumstances in which this letter arose. A copy of the letter is shown to me marked **WITN1400003**.

Section 3. Other Infections

15. I was told that I may have been exposed to vCJD, but I cannot remember much about this.

Section 4. Consent

16. I had no knowledge that I had been tested for Hepatitis C and therefore could not have consented to this test.

17. Given the conversation with Dr **GRO-B** in or about 1994 (which is not detailed in my records which leads me to believe the records are incomplete) I believe that I should have been tested for Hepatitis C earlier. There was a 2 year delay between it being suggested I had a virus and me being tested.

18. I did consent to be tested for HIV after my Hepatitis C diagnosis.

Section 5. Impact of the Infection

19. The effect of being given contaminated blood products has had a devastating effect on not only my life but that of my family, and my life has never been the same since my infection.

20. After my operation in 1984 I was always feeling tired and fatigued. I went to the doctors who ran blood tests and looked into the matter, but they had no explanation for my chronic, debilitating tiredness.

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21. One of my daughters was born in 1980 and the other in 1983 so I had two young children to look after at this time. Fortunately, my mother-in-law and my mum were very supportive which really helped me cope.
22. I had suffered from depression before I was infected. I had tried counselling and medication but nothing was particularly effective. I found I could not tolerate antidepressants. After my infection my mental health worsened and caused me more significant problems.
23. I was told by one doctor that living with Hepatitis C is no different than living with depression, which I considered to be extremely naïve and disrespectful.
24. My nephew, [GRO-B: N] was a haemophiliac who was infected with HIV through contaminated blood products. I was only told six months before he died that he had been infected. My sister did not tell me before because of the stigma associated with AIDS. I saw him the night before he died; he was in a horrific state. He died in 1994. This was very difficult for me as I looked after [GRO-B: N] a lot when he was a boy.
25. My sister has produced a statement for the Inquiry regarding [GRO-B: N]
[GRO-B: N]
26. [GRO-B: N] died on my wedding anniversary and he had been a page boy at my wedding. That date has now been tarnished for me as it is a constant reminder of losing him.
27. After I found out about [GRO-B: N] illness I asked the hospital if I may also be infected, as we had both been treated with Factor VIII. I was told not to worry about it because I had apparently been treated with UK products.
28. My physical and mental health has never let me enjoy life as I should. This has impacted on my marriage and on my husband's life as he has also had to be tested for the infection. The fear about infecting my husband was always at the back of my mind.

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29. My daughters have lived with this all of their lives and have never had the mother they should have had. They know about the Inquiry and what is happening but it isn't something that we talk about. I don't know whether it's them that don't want to bring it up or me.
30. I have two grandchildren now, but as my life is so impaired I cannot enjoy them as I should. I won't kiss them on the face or cuddle them too much as I am so worried about infecting them. My daughter is a nurse and is very understanding of my infection and my contact with her children, but the stigma around the infection has left me so worried.
31. There is still a stigma attached to Hepatitis C and I am wary of the impact this has had on my family. As a result I am always extremely conscious of my infection; I have my own cups, my own plates and my own cutlery. If I had cancer people would be sympathetic but a lot of people don't understand about Hepatitis C.
32. I get very self conscious about other people finding out about my infection; it's always in the back of my mind. My hands sometimes get very red and covered in a rash and I worry about people making comments or finding out about my infection.
33. Physically, I am chronically tired and sometimes not able to motivate myself to do the simplest of tasks such as cooking and shopping for essentials. The tiredness and fatigue is there all of the time. I also suffer from brain fog and struggle with my concentration and memory.
34. I've just been diagnosed with an underactive thyroid and osteoarthritis. My list of problems is getting bigger and bigger, and I don't know whether this is due to the Hepatitis or just me. I am permanently anxious, frustrated with my condition and angry as to why I was given infected Factor VIII, which has completely ruined my life.

35. My husband has to do a lot of things for me. The infection has therefore taken over his life as well, at a time when his father is very ill and he has to spend a lot of time with him whilst also caring for me.
36. Once or twice a year I visit the hospital in GRO-B where they perform liver function tests, and I live with the worry of possibly having to undergo a future liver transplant.
37. Years ago I went to see a liver specialist to perform a biopsy. I asked if he had ever performed one on a haemophiliac, to which he replied 'I think you're being very rude Ms GRO-B'. As he couldn't give me more of a positive answer I decided I did not want to go ahead with it. I did see a professor at Cambridge Hospital who advised me not to have a liver biopsy because of the bleeding.
38. I have a new GP who is lovely and very supportive. I had to ask her to change my information in my records to make it easier for medical professionals to see that I have Hepatitis C and *how* I became infected with it, because I was so tired of answering the question at every new appointment.
39. I had one dentist who I told about my infection but he started asking loads of questions about my infection and how I got it. I got so fed up with this that I had to go to a different dentist.
40. I was offered treatment for my Hepatitis C from GRO-B hospital but I was warned there may be bad side effects for six months. I was offered a later course of treatment which I was told may or may not clear the virus. I decided against taking the risk of having treatment.
41. My infection is like a death sentence; you don't know when it will kill you but you know it will.

Section 6. Treatment/care/support

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42. I feel like I need more support. People don't understand how I am feeling or what is going on in my mind. My GP is trying to arrange more support for me but it is proving difficult to arrange.

Section 7. Financial Assistance

43. I don't deal with the financial assistance schemes; my husband deals with all of the financial side of it.

44. I receive monthly payments from EIBSS.

45. I received the Stage One Skipton Payment.

Section 8. Other Issues

46. I want to know why the blood products were imported from America instead of being sourced from the UK.

47. I want the pharmaceutical companies to be investigated and I want to know whether contaminated blood products were also given to American people or whether it was all exported.

48. I also want to know why I was given the treatment when it was known that that batch had been infected. The people who were involved in that decision should be held accountable and should face prison as so many people have died and I have had to live with a potential death sentence.

Anonymity

49. I would like to apply for anonymity.

50. I would have liked to give oral evidence to the Inquiry but I don't think my health will permit me to do that.

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Statement of Truth

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

Signed..

GRO-B

Dated

21/3/19