

ANONYMOUS

Witness Name: [GRO-B]

Statement No: WITN1547001

Exhibits: WITN1547002

Dated: June 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]. I was born on [GRO-B] and I live at [GRO-B].
2. I make this statement on behalf of my late husband, [GRO-B: H]. He was born on the [GRO-B] and died on the [GRO-B] aged [GRO-B] as a result of Cerebral Toxoplasmosis caused by HIV. Together we have a daughter, [GRO-B].
3. My daughter, [GRO-B] has also produced a witness statement ([GRO-B]) for the Inquiry.
4. I am married and have [GRO-B] altogether. I look after my [GRO-B] while my daughter goes to University.
5. This witness statement has been prepared without the benefit of access to my late husband's full medical records. My daughter and I made a request for [H] medical records at the [GRO-B], London and we were told that he was never treated at the [GRO-B] which was not true because

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he was always treated at the [GRO-B] for his haemophilia and he died at the [GRO-B].
A copy of his death certificate is exhibited at 'WITN1547002'.

Section 2. How Affected

6. [H] was diagnosed with severe Haemophilia A and as a result, received Factor VIII Concentrate (FVIII). I believe he was diagnosed when he was a child. [H]'s mother was a Haemophilia carrier.
7. I believe he was infected at the [GRO-B] where he was mainly treated. His treating doctor was [GRO-B]. When we moved to [GRO-B], he went to [GRO-B] [GRO-B] for some treatment.
8. I know [H] went to Treloar's school but I do not have any further information about it.
9. I met [H] in 1975 and from then I know he was treated with Cryoprecipitate as I remember he had treatment bags in a freezer which had to be defrosted before he used it. I don't know when he started using Cryoprecipitate. In the late 1970s/ early 1980s, I believe he was given FVIII. He was self-administering for most of the time unless the bleed was severe and it could not be controlled in which case he would go to the [GRO-B] to be treated.
10. [H] was not provided with any information beforehand about the risk of being exposed to infections from the FVIII blood products. If he had been told, I know he would not have taken it and asked for an alternative treatment.
11. As a result of the contaminated FVIII blood products, [H] was infected with HIV and possibly Hepatitis C (Hep C).
12. [H] found out that he had HIV when [GRO-B] was a [GRO-B] probably at the end of 1985 or beginning of 1986. From what I remember, [H] was called in for something else and then had some blood tests done. After he had blood test we were then called into hospital and had a face to face meeting and we were told by the doctor that [H] tested positive for HIV.

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13. [GRO-B] and I were tested after [H] and was told that we both tested negative. [GRO-B] was just a baby at the time. It was quite shocking to hear the news and very shocking that both [GRO-B] and I had to be tested.
14. At the time when [H] was diagnosed, I was quite young and naïve and did not understand that HIV was such a major thing. I suppose they gave us the information they had at the time to help us understand and manage the infection, but I can't remember the conversation. [GRO-B] was quite a good hospital at the time and were quite good in relation to treatment.
15. I believe information about the infection should have been provided earlier if the [GRO-B] thought there was any chance that [H] was infected.
16. [H] and I were provided with some information about the risks of others being infected as a result of the HIV.

Section 3. Other Infections

17. To my knowledge, I do not know if [H] had any other infections other than HIV and possibly Hep C.

Section 4. Consent

18. I believe that [H] was probably treated and tested without his knowledge. It is also possible that he was treated and tested without his consent. The hospital did a lot of blood tests and we assumed it was all for his haemophilia and nothing else.
19. I believe he was probably also treated and tested without being given adequate or full information and for the purposes of research.

Section 5. Impact of the Infection

20. [H] suffered mental and physical effects as a result of the HIV. We had to move away from [GRO-B] as some of the neighbours knew that [H] had haemophilia and there was media connecting haemophiliacs with HIV. Back

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- then HIV was known as a death sentence and a lot of people did not understand the infection much.
- 21 [H] became an aggressive person and became violent towards me as I was the closest person to him. He took his anger and frustrations out on me. He became angry when the doctors would come to visit him to tell him about the diagnosis and he always thought to himself "why me?". It was totally out of character for him. He also became very depressed.
22. As a result of the infection [H] lost a lot of weight. It became worse near to the end of his life.
23. The last 3-4 months of [H]'s life was very difficult, he was bedridden. We were living in [GRO-B] at the time and in his last two weeks, we travelled down to the [GRO-B] where he died. We travelled to the [GRO-B] because he was treated there and they had all his medical records there.
- 24 [H] received AZT treatment for the HIV. I think he was probably given it approximately a year after he was diagnosed.
25. We assumed that [H] was given the only available treatment at the time. We just trusted the doctors and followed their advice.
26. I believe that [H] suffered mental effects as a result of the treatment that he received for the HIV. I do not know if it was the treatment or the HIV itself but he was very frustrated and he knew he was going to die and that he could not do anything about it.
- 27 [H]'s HIV impacted on his private, family and social life massively. We were forced to move to [GRO-B] in 1987 due to neighbours finding out about [H] being diagnosed with HIV and the subsequent abuse we received because of this. When we moved to [GRO-B] he was unable to work and therefore the finances were affected. I worked part-time because we were having financial problems and I had a young child. When I went to work it really upset me that I had to leave [GRO-B] with [H] when he was quite violent. He did not physically hurt [GRO-B] but that thought had always crossed my mind and I

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would worry when I was at work. I didn't have a choice but to work and leave **GRO-B** with him. As previously stated, **H** was never like that. All his anger and frustration came after he was diagnosed. I did not have a social life as moving to **GRO-B** isolated us from all our friends and family. We didn't really make any friends in the short time **H** was alive due to his deteriorating general health and his severe depression and mood swings. Sometimes when we had family and friends visiting us, **H** would have an outburst and act out so they tended not to come very often.

28. **H**'s HIV as well as his subsequent death impacted on me physically, mentally and emotionally for quite a long time. I could not sleep properly when he was alive and after he died. He left me alone with a young daughter and in a lot of debt.

29. At the time when **H** was diagnosed with HIV, there was a lot of bad media and advertisements. We did not want to suffer any stigma so we decided to move to a new location where nobody knew of **H**'s haemophilia and HIV. HIV was seen as dirty back then and that was because of the way the media portrayed it. A lot of the time people thought only gay men had HIV. People did not even know what Haemophilia was back then. They thought that by sharing a cup or shaking hands, you could catch HIV.

30. This stigma continued into my new relationship some years later, whereby I was forced to undergo testing for HIV due to my husband's ex-wife discovering **H** had died of HIV. She refused to allow me to have any contact with my stepson because she thought I could infect him.

31. I did not tell **GRO-B** that her father died from the infection until she was about **GRO-B** old because I was worried that she would innocently tell people. I did not want her growing up with that stigma hanging over her and being bullied at school. The stigma affected us then but now it is not a problem, friends know and generally people are much more understanding of it now.

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32. As previously stated we were financial impact. The mortgage on our property was not paid off when he died. It really affected me as he left me in a lot of debt as he had a lot of credit cards which I had to pay off.

33. I was working in [GRO-B] prior to when [H] was told he had HIV. I was doing secretarial work. I had to give that up to move to [GRO-B]. I could not work full-time but only part-time due to his sickness and because I had to look after [GRO-B]. [H] was a tailor when we were in [GRO-B]. When we moved down to [GRO-B] he did not work.

Section 6. Treatment/care/support

34. [H] was not offered any counselling or psychological support from what I remember. I believe it might have helped him if it was offered to him. I was not offered any counselling and I think it would have helped me as I did not know anything about HIV then.

Section 7. Financial Assistance

35. [H] began legal proceedings when he was alive but I am unsure what, if any documentation he signed before he died. I believe it was the 1991 litigation and he went to solicitors in [GRO-B]. He died before receiving any monies.

36. I remember they said if we took the payment, we could never make any future litigation claims against them.

37. I received a lump sum payment about a year after [H]'s death, but I can't remember how much it was.

38. I also received a widow's allowance from the government and unfortunately I cannot remember the amount that I received.

Anonymity, disclosure and redaction

39. I wish to remain anonymous.

40. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-B

Dated 14/6/19 .