

# ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN1415001

Exhibits: WITN1415002-6

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** My date of birth is **GRO-B** and I live at **GRO-B**
2. My husband, **GRO-B: H** date of birth **GRO-B**, passed away on **GRO-B** after being infected with Hepatitis C and HIV from contaminated blood products **H** and I married in **GRO-B**
3. This witness statement has been prepared without the benefit of access to my late husband's 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.
4. When I inquired about obtaining **H**'s medical records for the purposes of the Inquiry I was initially told that **GRO-B** still had copies of his records on microfilm. However, on 5 December 2018 I was then told this was not the case. A copy of the hospital's email is exhibited at "WITN1415002".

Section 2. How Affected

5. [H] suffered from severe Haemophilia A.
6. He was treated at [GRO-B] under [GRO-B], and at the [GRO-B] under Dr [GRO-B].
7. When we married we lived in [GRO-B] but [GRO-B]  
[GRO-B] [GRO-B]  
[GRO-B]  
[GRO-B]
8. [GRO-B]  
[GRO-B]
9. A copy of [H]'s treatment record from the UK National Haemophilia Database (UKHDO) is exhibited at "WITN1415003". This is incomplete and inaccurate. I have also been provided with a copy of [H]'s MDT records from the QEH which detail some of the treatments [H] was given. This list shows that he was treated multiple times in 1978 and 1979 whereas there is only one treatment listed for each year in his UKHDO record. Furthermore, his UKHDO record does not refer to him being treated with Lister manufactured products whereas his [GRO-B] notes state he was treated with Lister Factor VIII throughout 1978 and 1979.
10. [H] was informed that he may have been exposed to HIV in a letter received from Dr [GRO-B] in 1985. Although this letter is undated, I know we received it in 1985 and a copy is included at "WITN1415004".
11. When we received the letter [H] immediately made an appointment to be tested. I believe we waited three months to receive the results, which was an agonising wait. It was a nightmare. When we were finally told to go to the hospital for the test results, I drove [H] to the entrance and told him I couldn't go in with him; I was just too frightened. I regret not being able to go in. When

[H] came back out he told me he was HIV positive. I asked him not to tell me anything else until we were home because I had to drive us ten miles back home.

12. I don't believe [H] was told much about the prognosis of his infection other than it was a death sentence. We had received some very basic information regarding transmission in the earlier letter from Dr [GRO-B]

13. We were not told that [H] had Hepatitis C, but it was later assumed that he had been infected with this as well.

### **Section 3. Other Infections**

14. I am not aware of any other infections that [H] may have been exposed to.

### **Section 4. Consent**

15. I was not aware of [H] being tested for HIV or Hepatitis before we received the letter from Dr [GRO-B] which was the first that either of us had heard about the risks of infection.

16. However, I note from the UKHDO records that [H] first tested positive for HIV on 18 January 1985 which was before Dr [GRO-B] wrote to us. The UKHDO records give [H]'s date of diagnosis as 12 October 1989 which is clearly incorrect. This is the date he was admitted to hospital just before his death.

### **Section 5. Impact of the Infection**

17. Before [H] was diagnosed with HIV we underwent years of fertility treatment. We were both very keen to have a family. I had three rounds of IVF treatment after which I unsuccessfully attempted artificial insemination from a donor. When [H] was diagnosed we had to give up any further hope of fertility treatment and we were ultimately unable to have a child which was a great source of sadness to us both.

18. [H]'s health wasn't too bad until shortly before his death in 1989. [H] became very breathless shortly after starting his AZT treatment, which was still in its early stages.
19. I remember having to call the GP out because [H] was poorly in bed. The GP said that he had a virus and suggested that [H] should be checked out by the hospital.
20. [H] went to the Haemophilia Clinic [GRO-B] on [GRO-B] for them to check his condition. He was admitted and remained in the hospital until his death two weeks later.
21. I now believe that the dose of AZT [H] was given was too high and may have contributed to his sudden deterioration.
22. I was told over the phone that my husband had died. I was told not to go to the hospital because I wouldn't be able to see him as a result of his infection. I was later told that I actually had to go and identify him.
23. I was made to identify my husband in a dirty, horrible mortuary in the hospital. His body was just in a bag. It was a completely undignified and unacceptable way to treat a grieving person. This was the last time I saw [H] as I was never given the opportunity to see his body again. I wasn't even given the opportunity to bury him; [H] had to be cremated due to his infection.
24. The causes of death stated on [H]'s death certificate are 1(a) bronchopneumonia 1(b) Acquired Immune Deficiency Syndrome; 2 Haemophilia A; 3 Accident. A copy of the certificate is exhibited at "WITN1415005".
25. There was an inquest into [H]'s death, which I did not want to be a part of because I couldn't face going through it all so soon after his death and I worried about the press finding out his HIV status. Despite this, I was summonsed to give evidence at the inquest and was made to attend.



26. I was told by the coroner that the inquest would start at 1:30pm but the press wouldn't be there until 2:00pm, so I could get my part done before they arrived. However, when I arrived at the inquest the press were already there. The coroner told me to leave through the side door at the end of the hearing so that I could try and avoid the press.

27. The next day I had a knock on the door from a journalist from the **GRO-B**

**GRO-B** Initially I denied that I was **GRO-B** as I just wanted him to leave.

**GRO-B**

**GRO-B**

**GRO-B**

**GRO-B**

28. **GRO-B**

**GRO-B**

**GRO-B**

29. **GRO-B**

**GRO-B**

**GRO-B**

30. During his life **H** suffered from the stigma surrounding HIV despite not really telling people about his infection. I recall on one occasion he was due to have an operation at **GRO-B**. The treatment he received was appalling - he was kept in a bed surrounded by sharps bins to emphasise the fact he was HIV positive. When he was due to go into surgery, he saw all of the surgeons in their 'space suits', before they ultimately refused to operate on him due to the fear around his infection. I had to take **H** home in his pyjamas because he didn't have any clothes to be discharged in and reorganise the operation for several weeks later. It was a horrible experience for us both - **H** was an intelligent, quiet man who was devastated by the impact of his illness and the stigma surrounding it. He felt ashamed by his diagnosis.

31. As a result of incidents such as this and the general fear of the infection, [H] struggled a lot. I remember one day when my great-nieces were visiting us, and when they went to say goodbye, [H] stood up so they couldn't kiss him.

32. I was the youngest of [GRO-B] siblings. I did tell my family about [H]'s diagnosis but that brought its own difficulties for me. My sister spoke to her doctor and asked how safe it was to be around [H]. None of my siblings told their children the truth about [H]'s illness.

33. After [H] died my mental health was terrible. I saw a clinical psychologist for a while because I wasn't in a good state. I suffered from agoraphobia when I was a child which came back after [H] passed away.

34. I recall when I was made to identify [H]'s body at the hospital. I was given a coffee and just found myself unable to drink it. [GRO-B]

[GRO-B]  
[GRO-B]

35. I find it very difficult to talk about my late husband and freeze whenever I have to.

#### Section 6. Treatment/care/support

36. [H] was given AZT for his HIV. He never really had to fight for his treatment as this was a time when little was known about the disease and there were not many treatments available.

37. [H] was never offered any kind of psychological support when he was diagnosed. We saw a psychologist together at the Haemophilia Unit in or about 1989 when he started to get breathless on the AZT treatment but that was only just before he died.

38. I spoke to a clinical psychologist after [H] passed away as already referred to in Paragraph 33 above.

**Section 7. Financial Assistance**

39. I was a party to the 1991 HIV litigation, during which I was told I had to sign a waiver to receive any money. I was the only person in the room who objected to signing the waiver, however the solicitor told me that if I didn't sign it no one would receive anything; I therefore had no option than to sign it. I have retained some of the paperwork relating to this litigation and it is exhibited at "WITN1415006".

40. I also received both the Stage 1 and Stage 2 lump sum payments from the Skipton Fund; however this was a difficult process. I had to contact my local MP who got involved and it was only after this that the Fund agreed to pay.

41. I was previously given monthly payments of £100 from the MacFarlane Trust. However, one day these payments were stopped without any prior warning. When I contacted the Trust for more information I was just told that I no longer qualified for the payments.

42. I found out through the support group Tainted Blood that I was eligible for a top-up payment from the MacFarlane Trust. When I asked the Trust why they hadn't informed me about this, I was told that they were unable to as they didn't know my address; this was incorrect as they had send me letters during that time so clearly had my address on file.

43. I currently receive monthly payments from EIBSS.

**Section 8. Other Issues**

44. I want to know why the medical records of so many people infected by contaminated blood are missing.

**Anonymity**

45. I wish to remain anonymous.

46. 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 18.1.2019.