

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1536001

Exhibits: 0

Dated: 24<sup>th</sup> 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 the GRO-B and I live at GRO-B, with my husband, GRO-B GRO-B, and our daughter, GRO-B. I also have a daughter, GRO-B GRO-B. GRO-B: H I do not work.
2. This witness statement is made in relation to H who died of AIDS, after being infected with Human Immunodeficiency Virus (HIV) as a result of being treated with blood products.
3. This statement was prepared without the benefit of access to H medical records.

**Section 2. How affected**

4. [H] suffered from severe Haemophilia A. We met in [GRO-B] when he was around [GRO-B] and we married in [GRO-B] of the same year. I recall that he was receiving Factor VIII at the time as a treatment for his Haemophilia.
5. He was treated at the [GRO-B] by [GRO-B]  
[GRO-B]
6. I am not sure when he started receiving blood products; however, I am aware that he was diagnosed with Haemophilia when he was a baby. I am aware that Factor VIII was not available when [H] was a born, but I believe that once it became available, he started receiving it. When we were together he received Factor VIII treatment about three times per week.
7. I am certain that [H] (or his parents to my knowledge) were not informed about any risks associated with being treated with blood products.
8. As a result of the treatment he received, he contracted HIV and Hepatitis C (HCV).
9. [H] found out about his HIV infection in [GRO-B]. He attended a routine check-up with [GRO-B] and he was told that he was HIV positive. When he returned home he told me about it. I was not able to attend the appointment with him as our daughter, [GRO-B] old at the time. It was a shock to us, we were not aware that he had been tested for anything in the first place, so we were not expecting the diagnosis.
10. He was not given any information about his illness, at least not at the time he was told about his HIV. He was given very basic information such as to look after his health better and how the infection could be spread. But he was certainly not informed that any treatment was available to him for the illness.

11. [H] was advised to continue his Factor VIII treatment and to carry on as normal. At that time I knew how to treat him with Factor VIII, so I continued to do it for him.
12. Looking back, I think they might have delayed informing [H] of his diagnosis because I was pregnant with [GRO-B]
13. I do not remember when exactly [H] was told about his HCV infection, but he was told of it quite a bit later after being informed about being HIV positive.
14. I recall that he returned home from a routine check-up with [H] and said that he had HCV and that he might need a liver transplant. He was given some information about HCV, but it was limited.
15. He had routine appointments every 3 or 4 months; however, after he found out about his HIV they became more regular, then after he was told he was HCV, the appointments became even more frequent.

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

16. I do not know whether [H] was exposed to any other infections.

### **Section 4. Consent**

17. At the time when [H] was tested for HIV and later for HCV, he was not informed of the purpose of the blood tests. As they took place during routine appointments he assumed they were part of the routine and that they were related to his Haemophilia.
18. However, he was suspicious that he was being tested at our local hospital due to the media coverage of HIV and haemophilia at the time and also it was highlighted through the Haemophilia community.

19. We also believed that GRO-B and I were tested for the viruses without our knowledge. This was because when she was born GRO-B and I stayed in hospital longer than normal, also the doctors kept her away from us for quite a long time and they were doing blood tests on us both, but they did not say the reason for the tests.

### Section 5. Impact

20. When H was told about his infections, he worked in maintenance at a factory. He worked for as long as he physically could, which was almost until the end of his life.

21. He suffered badly from shingles, and coughs and colds. He also contracted pneumonia not long before he passed away.

22. H was treated with a cocktail of drugs for his HIV but I can't remember what treatment he received for his HCV.

23. As a result of the treatment he received, he lost weight and his hair. He also used to have blackouts towards the end of his life. However, I am not sure whether these symptoms were caused by the treatment or his illness.

24. I do not think that he coped very well mentally with his condition. I know that he was very upset and annoyed by the whole situation; he did not think that it was fair. We had just got married and had a baby, it was meant to be a very exciting and happy time for us, but it was horrendous, miserable, stressful and full of uncertainty. GRO-B was GRO-B years old when H died, he died two weeks after her GRO-B birthday.

25. We also chose not to tell anyone about his condition because of the stigma attached, particularly to HIV. This was also because these were the early days of HIV and AIDS in the UK, and there were disturbing advertisements on the TV

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warning people about it. We did not know how people would treat us if they knew of [H] condition.

26. The only people who knew about [H] condition initially were his parents and his two sisters. It took me a while longer to tell my family about [H] condition. This was because I was worried about how they were going to react. This in itself was exhausting for us. No one knew much about it and there was speculation in the media as to how HIV spread.

27. I don't know if [H] employers knew he had been treated with infected blood, certainly they knew he had haemophilia and they may have put two and two together.

28. I felt that I could not rely on our friends' support because I could never tell them about his condition, in case they judged us and turned away from us.

29. It also impacted on our social life, as it is fair to say that we did not have much social life at all. We only used to go out, if we could, on special occasions.

30. Once [H] was diagnosed with Acquired Immune Deficiency Syndrome (AIDS) in 1987 he became unwell very quickly and soon after there was nothing that could be done to save him. [H] lost weight. Prior to his diagnosis he was 12 or 13 stone, when he died he was barely 7 stone.

31. He was at home a lot of the time when he started getting very unwell. He had also spent some time in the [GRO-B] Hospital; however, he eventually returned home.

32. [H] passed away in [GRO-B] at home about two years after being told that he had HIV.

33. [H] illness also had a terrible effect on me I took it really badly. We had a [GRO-B] [GRO-B] old baby at the time when we found out about his HIV, and I was faced with a shock and a worry about our future.

34. I had to stop breastfeeding [GRO-B] because we did not know whether I had contracted HIV. We also had to ensure that we had safe sex. I also began to gain a lot of weight as a result of the stress.

35. [H] condition also affected my work. I was a [GRO-B] and I worked in the [GRO-B] while [H] looked after [GRO-B]. I managed to work until the [GRO-B] before he passed away in the [GRO-B]; by then [H] was unable to cope looking after [GRO-B] so I had to give up my job.

36. His death has also affected [GRO-B]. He passed away when she was just [GRO-B] years old, so that she missed out on having her Dad around throughout her life particularly in her formative years. [GRO-B] developed a sty on her eye after he died it took a long time to get rid of it.

37. [H] died on the settee at home. For a year afterwards [GRO-B] drew an out-line of him lying on the settee both when she was at home and at play school which was heart-breaking.

38. [GRO-B] found it very difficult and always felt cheated not having her Dad around. She was never offered any counselling to help her to deal with her loss.

#### **Section 6. Treatment/Care/Support**

39. I do not think that he had any difficulty accessing treatment, although I am not certain. I am also not aware as to whether there was any other treatment that ought to be made available to him at the time.

40. Neither [H] nor I received any counselling during his illness but after he died I had counselling once a week for a year.

**Section 7. Financial Assistance**

41. I received £20,000 from the government about a month after [H] passed away. I cannot remember if I had to apply for it.

42. As a result of the litigation in the 90's, I received £44,000 and £16,000 was held in trust for [GRO-B] until she was 18.

43. I applied for financial assistance in relation to [H] HCV. I received the 1<sup>st</sup> stage payment of £20,000 around 8-10 years ago, a long time after he died. I also wanted to apply for the 2<sup>nd</sup> stage payment; however, I did not receive his medical records to support the application. I applied for his medical records; however it was around the time when [GRO-B] retired and [GRO-B] replaced him. I tried to contact the hospital, but I was always ignored. I have heard later in the media that some records were destroyed, so I gave up trying.

44. I found the application process difficult, the wording used was complicated and the need for proof of [H] illness was onerous, bearing in mind that his medical records were impossible to obtain.

**Section 8. Other Issues**

45. I am concerned that the Inquiry has taken so long to set up, someone is to blame and they should be held liable.

**Anonymity, disclosure and redaction**

46. I confirm that I wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

47. I do not wish to be called to give oral evidence.

**Statement of Truth**

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

Signed

**GRO-B**

**GRO-B**

Dated 24/1/19 January 2019