

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN3392001

Exhibits: WITN3392002-007

Dated: July 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** and I live at **GRO-B**.
My date of birth is **GRO-B**.
2. I live with my husband **GRO-B** and I have **GRO-B** children from a previous marriage.
3. I write this statement on behalf of my late husband **GRO-B: H** who was born on **GRO-B** and died on **GRO-B** as a result of HIV.
4. This witness statement has been prepared without the benefit of access to my late husband's full hospital records. The relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. **H** had severe Haemophilia A. I am not sure when he was diagnosed.
6. I believe that **H** received Factor VIII concentrates (FVIII) (Factorate and Hemofil) from **GRO-B**. Prior to this, I believe he received Cryoprecipitate. After

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reviewing the medical records I have received, I have found records which detail batch numbers that [H] received from [GRO-B]. Copies of these medical records with the batch numbers are exhibited at 'WITN3392002'.

7. [H] was treated at [GRO-B] and was under the overall care of [GRO-B], director of the Haemophilia Unit.
8. I am not sure when [H] was infected with HIV. As stated above, I have exhibited medical records with batch numbers that he received. The first positive test for HIV evident in [H]'s medical records is [GRO-B]. A copy of the above blood test is exhibited at 'WITN3392003'.
9. I do not believe that [H] was provided with any information beforehand about the risk of being exposed to infection when using FVIII.
10. [H] was infected with HIV and Hepatitis B (Hep B) as a result of receiving FVIII. There is also evidence in [H]'s medical records that he had Hepatitis A (Hep A) and pulmonary TB and I believe it was as a result of the contaminated blood products.
11. A Hep B blood test was carried out on [GRO-B]. On [GRO-B] [GRO-B] told [H]'s parents, by letter, that he was suffering from a 'mild attack of jaundice'. However, on the same day [GRO-B] informed [H]'s GP, also by letter that [H] was suffering from "mild Hepatitis", and that it was probably due to the fact that he had a lot of treatment. Copies of these letters are exhibited at 'WITN3392004'.
12. I believe that [H] and his family were never formally notified of the HIV infection; there are no letters to his parents regarding this matter in his records. However, there is a letter from [GRO-B] to [GRO-B] dated [GRO-B] [GRO-B] stating that "...presumably you have already done it, but I just thought I would check that you had looked for the relevant AIDS tests in view of his rather complicated history two years ago. Presumably you are doing

this on all your haemophiliacs and I would be interested to hear the answer". A response was provided to [GRO-B] from [GRO-B], dated [GRO-B] confirming that [H] had the relevant HTLV III test and he tested positive "like the majority of heavy users of FVIII". Copies of the above letters are exhibited at 'WITN3392005'. There is no evidence that [H] was informed of this at that time. [H] told me that he found about his HIV status in passing at the hospital from a doctor after he was admitted. This was the first time that he was told that he had HIV. I do not know if he had a follow-up consultation about the infection.

13. In relation to the Hep B, [H] was initially told to rest at home and then visit the doctor again in a week's time to have further bloods test. As [H] was not formally informed of the HIV status, there are no medical records to confirm what information, advice or treatment was given.

14. I believe that [H] should have been informed about his infections as soon as the doctors had a positive result, particularly with HIV when he tested positive in [GRO-B].

15. Given the serious nature of the HIV, both for long term health and the possibility of infecting others, it is almost unbelievable that no formal communication was made or detailed advice given to [H] at the time. I am not aware, if any, informal information was provided to [H] about the risks of others being infected as a result of the infection.

Section 3. Other Infections

16. As previously stated, there is evidence in [H]'s medical records that he also had Hep A and Pulmonary tuberculosis (TB). The TB was first diagnosed in [GRO-B] and I believe that the first diagnosis of Hep A was on the [GRO-B], with evidence of past infection with Hep A. A copy of this letter is exhibited at 'WITN3392006'.

Section 4. Consent

17. There is no evidence in [H]'s medical records in forms or letters indicating that he had any prior knowledge or gave his consent in relation to being tested for HIV. There is also no evidence or any formal communication of the results afterwards.

18. I do not know if [H] was treated or tested for the purposes of research. However, there is a medical record dated [GRO-B] from [GRO-B] [GRO-B] at the Armour Pharmaceutical Company Ltd to [GRO-B] responding to [GRO-B]'s letter dated [GRO-B] 'reporting a case of jaundice in a patient who had received Factorate and Cryoprecipitate'. Dr [GRO-B] was asked to provide the batch number of the treatment that [H] was given, which he believes had the infection. The letter dated [GRO-B] and another letter dated [GRO-B] (cover letter for report on suspected toxicity or side-effects and hepatitis survey) have been exhibited at 'WITN3392007'.

Section 5. Impact

19. When I first met [H] in around [GRO-B] or [GRO-B], he was in relatively good health, despite having HIV. I already knew he had HIV as we attended the same church. He was a happy, confident person and enjoyed life. He had many friends and enjoyed spending time with his friends who had young families. We had regular trips to the east coast, days out with friends and we were actively involved at our local church. In [GRO-B], shortly after my sister's wedding and not long before our own wedding in [GRO-B], [H] became unwell and was admitted to the hospital. He was released on the day of our wedding, but went back into hospital for several days after. [H]'s mental and physical health started to deteriorate after this time. We were married for [GRO-B] months before he passed away.

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20. I think what strikes me as I write this was the lack of support given at such a young age, for a couple facing such a terrible time. No counselling was offered and [H]'s AIDS treatment was managed by his haemophilia doctor. [H] was convinced that his mood swings were as a result of the AZT medication that he was having. I am not sure what information was provided in relation to the treatment that [H] received or when he started it.
21. It is hard to look back at this time even now, and remember the pain and suffering [H] endured, and the loss of those things he would have loved; a family.
22. On [H]'s death certificate, it states that he had a Septicemic shock and pneumonia, as well as AIDS and haemophilia. He previously had several bouts of life-threatening pneumonia/pneumocystis pneumonia, persistent laryngitis and coughing, and respiratory tract infections and TB.
23. [H] was treated with AZT, Fluconazole, Erythromycin, Acyclovir, Pyrimethamine, Dapsone, Zidovudine, MST and steroids.
24. I do not know if [H] faced any difficulties or obstacles in accessing treatment.
25. I do not know if there were treatments which I consider ought to have been made available to him.
26. It is difficult to say what symptoms were as a result of the treatment and what symptoms were as a result of the infection/s. However, I do recall [H] saying that he believed that the AZT treatment that he had caused mood swings and depression.
27. I do not know if [H]'s infected status impacted upon his treatment, medical or dental care for any other conditions.

28. It is difficult to describe how being infected with HIV impacted [H] at the time. [H] loved life and people. Not only did he have to learn to live with having an illness that would kill him, but he had to also watch his friends and some of his family members die before him because of the cruel disease. I remember attending a funeral of a friend (also a haemophiliac who had contracted HIV through contaminated blood products), knowing that one day it would be our story. [H] was such a kind, loving and generous person. We spent a lot of time with family and friends, had lots of adventures, and tried to live a normal life as possible. I think one of the hardest things for [H] was that he knew we could never have a family of our own.

29. It is hard to look back and remember these details, as you just want to remember the good times and block out the pain, sadness, exhaustion and fear that was such a huge part of our life at that time. When we became engaged, [H]'s health was stable and we led a normal, happy life. Sadly, by the time we were getting married, [H]'s health had started to deteriorate and he never really recovered. On the day of our wedding he was allowed out of hospital to get married, [GRO-B] months later, in the same church, we had his funeral. It's only when I look back [GRO-B] years later) that I realise that the feelings I have are really not too far buried in the past, and that I can easily recall the pain.

30. I can remember the many trips to [GRO-B] for appointments and when [H] was admitted just before our wedding. I can remember the pain I had watching him deteriorate and unable to enjoy his life. I particularly remember him telling me not to buy him Christmas presents as he wouldn't be here (he died on the [GRO-B]). His funeral was on [GRO-B] Christmas to this day is a difficult time for me. I didn't put up any Christmas decorations until I had children. Following [H]'s death, I had counselling for panic attacks, and I had a sense of fear of losing other people close to me. Grieving is always a long and difficult process, for it to be in such tragic circumstances just added

to it. [H]'s picture remains on our lounge wall and he will always be part of our lives.

31. My family initially really struggled with me being in a relationship with someone who had HIV. However, once my family got to know [H], their attitude towards him changed and they all had a really close relationship with him. My mother cared for him whilst I was at work, and my brother became his best friend.

32. [H]'s mother died a year after him. His father is now elderly. I do not think you ever get over losing a child. However, I'd rather not speak on their behalf other than to say that this was a devastating loss for them.

33. [H] had to give up work as his symptoms got worse, which also had an impact on his mental health. I continued to work full-time in childcare, as we lived next door to my mother and father who were very supportive in helping and providing care for [H].

Section 6. Treatment/Care/Support

34. [H] always used to tell me that his haemophilia and HIV were always treated by the same doctor and felt that the HIV should have been treated by a specialist.

Section 7. Financial Assistance

35. I believe that [H] was involved in the HIV litigation. I do not know what financial assistance he received from the litigation.

36. I did not receive any financial assistance from any of the Trusts and Funds that were set up. I do remember getting newsletters from the Macfarlane Trust, but nothing else.

Anonymity, disclosure and redaction

37. I wish to remain anonymous.

38. I don't 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 17/7/19

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MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Significant Entries

[GRO-B] letter from [GRO-B] to [GRO-B] – problem: pulmonary TB