

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1428001

Exhibits: WITN1428002 - 3

Dated: January 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN WITNESS STATEMENT OF **GRO-B**

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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** I am a widow and I have one son, **GRO-B** I am currently employed as a part-time team leader by **GRO-B** **GRO-B**
2. I write this statement on behalf of my late son, **GRO-B: S** born on **GRO-B** He died at the age of **GRO-B** on the **GRO-B** as a result of **GRO-B** **GRO-B**
3. This witness statement has been prepared without the benefit of access to my late son'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.

### Section 2. How Affected

4. **GRO-B: S** was diagnosed with severe Haemophilia A just after birth when had a bleed around his ear as a result of catching it on a brooch.

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5. As a young child [GRO-B :S] suffered from severe knee bleeds and lip bleeds and therefore required treatment regularly. He was initially treated with Cryoprecipitate and I believe in the late 70s/early 80s he was treated with Factor VIII (FVIII). A copy of [GRO-B :S] National Haemophilia Database (NHD) is exhibited at "WITN1428002". However, the NHD only shows treatment that he received from 1985.
6. Initially all his treatment was administered at the North Devon District Hospital (NDDH). The hospital trained me to administer FVIII, so I was able to treat [GRO-B :S] at home without travelling to the hospital all the time.
7. He also attended the [GRO-B] where he had a tooth extraction and I believe he also received FVIII.
8. At the age of 9 he had an offer and a placement at [GRO-B] [GRO-B]. We did not make an application to the school we just received a letter stating that they would like to offer [GRO-B :S] a place. They had a Haemophilia Centre and therefore were able to administer FVIII and attend to [GRO-B :S] medical needs. Prior to this he went to a normal state school, where he had a supportive worker that looked after him.
9. The Haemophilia Centre at [GRO-B] became [GRO-B :S] main centre where he had FVII treatment. He would live in the [GRO-B] for most of the time and return home for holidays. When he was at home, he would be treated at the NDDH.
10. Overall [GRO-B :S] told me that he was happy at [GRO-B] and he was satisfied with the level of care that he received at the centre. He told me that he had a very close relationship with the doctors and nurses at the centre.
11. I was not provided with any information beforehand about the risks involved in using FVIII. I understood it to be a miracle drug to the haemophilia community. I only found out about the potential risks because of the media coverage.

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12. I recall in the late 1980s that I was contacted by the NDDH, and asked to return a batch of FVIII which I had at home. No explanation was given. I returned the batch that I had and was given a new batch. I believe it was because the batch we had was contaminated. However, this was never confirmed by the hospital or any of the doctors.
13. As a result of being treated with FVIII, [GRO-B :S] contracted HIV and Hepatitis C (Hep C).
14. From the best of my memory of the version of the events, in November 1988 I received a telephone call from the NDDH to attend the hospital. I was told by [GRO-B] that [GRO-B :S] had HIV. [GRO-B :S] was only [GR O-B] at the time and I was not sure how he would take the news. However, the doctor asked me for my permission to tell [GRO-B :S] at [GRO-B] and I agreed and I believe he was told in [GRO-B]
15. [GRO-B :S] was first tested for HIV on the [GRO-B]. This is stated in the NHD exhibited at "WITN1428002". I was shocked when I received his NHD to see that I was told about his HIV status [GRO-B] years after he was tested. The doctors put [GRO-B :S] and others around him at risk.
16. When I was first told about the HIV status I was shocked and in disbelief. I was not accepting this completely beyond our comprehension with the stigma already taken over our lives. We did not have comprehensive practical knowledge about HIV. We believed the doctors at the time and we took normal precautions. We never thought to question them.
17. I only recall being told to be careful when dealing with his blood and to keep it to ourselves. I do not recall any further information given about the infection. I am not sure if [GRO-B :S] was given any information about it at [GRO-B]
18. Unfortunately, I do not know when [GRO-B :S] was told about his HCV.
19. I do not believe I was provided with adequate information or information about how to manage it. I believe we should have been given one-to-one support for guidance from day one.



20. I was never told by the medical staff about the risks of others being infected. I was only told to take reasonable precautions, such as not to share toothbrushes and taking care of any blood loss when administering FVIII.

21. Looking at it retrospectively, I believe that the real risks ought to have been pointed out to us. It was a very serious infection that [GRO-B: S] had and we were not given any information about it.

22. I believe that I should have been told about both of the infections a lot earlier, as the doctors were clearly aware that [GRO-B: S] was HIV positive in [GRO-B]

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

23. I am not aware that [GRO-B: S] had contracted any other infections other than HIV and Hep C. I believe his HIV developed into AIDS near to the end of his life.

### **Section 4. Consent**

24. I believe that [GRO-B: S] was tested and treated without our knowledge, as the NHD confirms that he was tested in 1984 for HIV and I was not told in 1984 that he was being tested for HIV. [GRO-B: S] had regular blood tests and I always thought it was in relation to his haemophilia.

25. I therefore believe that he was tested and treated without my consent and without being provided with adequate information.

26. I cannot say if [GRO-B: S] was tested or treated for the purposes of research, but I believe he was, as he was in a school with other boys in a similar situation within a controlled environment being a convert placement to assess and observe the treatment of FVIII and allowing their findings to be hidden in the public domain and the parents.

### **Section 5. Impact**

27. [GRO-B: S] infections had a great negative impact on his life. He lost a lot of friends and his girlfriend, at the time, because of the stigma that was associated with

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it. I recall that the media at the time portrayed HIV in an awful way, calling it the 'gay' disease. It had horrible adverts with gravestones falling. This sort of publicity caused revulsion towards people who were affected by the infection.

28. I recall [GRO-B: S] was given a pen pal, [GRO-B] by his care manager. [GRO-B] had coffee with him and listened to him. I recall one specific letter, which is exhibited at 'WITN1428003' where he had expressed his feeling about the infections to [GRO-B]. He suffered greatly and was rather lonely. He said that it was extremely hard for him to live with HIV, listening to his friends speak about it in a mocking way without having any idea of the realities of the infections. He was extremely angry about being infected and felt the whole situation that he was in was unfair.
29. [GRO-B: S] developed serious paranoia and I believe it was because of the infections. He walked around carrying a camera, taking pictures of people. He used to say that he had to take pictures of people because they were following us.
30. He also became obsessed with the news, especially when the Contaminated Blood Scandal was broadcast. He was terrified of it.
31. A lot of [GRO-B: S] friends died as a result of the infection and that also had a massive strain on his mental health. Because [GRO-B: S] lost a lot of friends and hated being infected he attempted suicide on the 01/11/1990.
32. He was also affected physically. He had hair loss and he lost a lot weight. He had several viral infections and he was given a lot of pain relief medication for it.
33. [GRO-B: S] was expelled from school at the age of [GRO-B]. I was told by the school that [GRO-B: S] was found in a girl's room and it was not allowed. [GRO-B: S] later told me that he did not do anything and he was just talking to her. I do not believe it was fair for the school to expel him because he was in a girl's room. I believe the reason why [GRO-B: S] was expelled was because of his HIV infection and the school was terrified of the potential danger that [GRO-B: S] posed to other students.

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34. When I picked him up from school to take him home, I recall being treated badly by the school. I got the impression that they really wanted us to leave as soon as possible.
35. I believe that [GRO-B: S] would have had a good education had he not been infected.
36. [GRO-B: S] found it difficult to get a job. He wanted to live a normal life. He did apply for a job in a factory that produced glass; however, he was not successful. I believe it was because of his infected status.
37. I recall that [GRO-B: S] was given a treatment for HIV; however, I do not recall the name of the treatment. The treatment affected him mentally. I recall an instance when he became very frustrated because the treatment was not working and therefore threw the medication out of the window.
38. [GRO-B: S] was given strong pain killers for his Hep C, but still required to attend the hospital for further treatment.
39. I am not aware of any other treatment that could have been made available to him. I believe that he was given the treatment that was available at the time.
40. I worked at a special care facility for the elderly and I was afraid of losing my job because of [GRO-B: S] infections. I was afraid that they would assume that contracted the infections from [GRO-B: S]. I therefore did not tell anyone at work.
41. I recall the doctor telling me about [GRO-B: S] life expectancy and it caused a lot of stress and uncertainty in the household. [GRO-B: S] was never told, but he did ask me if he was going to die because of the infections and I did not know what to say. I felt very isolated and only told my mother and sister in the beginning.
42. [GRO-B: S] stopped socialising with his friends because [GRO-B: S] was too poorly to go and see his friends and because he was too poorly, his friends eventually stopped seeing him all together. I did not have a social life. I was his main career and I found it difficult to balance my job and care for [GRO-B: S]. There was an immense amount of pressure on me. I had to reduce my working hours in order to care



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for [GRO-B:S] I went part-time, but I was unable to deal with it mentally. Looking after elderly people was a massive strain, and I felt like I had no rest.

43. There were times that I was scared because [GRO-B:S] was very angry and frustrated. There were times that he would take it out at home by breaking things. A lot of the times I felt heart broken watching [GRO-B:S] facing his death.

44. I feel that I slightly neglected my second son, [GRO-B] because I gave a lot of my attention to [GRO-B:S]. [GRO-B] was also affected as he often heard his friends make jokes about HIV, which made him very angry.

45. Near to the end of [GRO-B:S] life he was unable to eat normal food. He was about [GRO-B] years old and he was provided with the necessary nutrition in a liquid form.

46. It was heart breaking seeing [GRO-B:S] turn from a loving boy to a sick man at only 22. [GRO-B] was so devastated when he lost his brother. They were very close.

### Section 6. Treatment/Care/Support

47. We were not provided with any care or support and we were left to deal with it on our own.

48. As previously stated, he had a care manager who arranged for a [GRO-B] [GRO-B] to visit him and offer him support. However, I believe that he should have been offered more psychological support as it would have helped him, as he really struggled to come to terms that he was infected, knowing some his friends from [GRO-B] were dying.

49. I do not believe that [GRO-B:S] was offered any counselling. I was not offered any counselling or psychological support.

**Section 7. Financial Assistance**

50. I believe [GRO-B: S] received approximately £22,000 in the early 1990s from the Macfarlane Trust. I do know what the application process was or if any preconditions were imposed as a result.

51. After [GRO-B: S] death I received a sum of £1,000 towards his funeral and I believe it was from the Macfarlane Trust.

52. In or about 2012, I received a Stage 1 payment in the sum of £20,000 from the Skipton Fund. I also received a Stage 2 payment in the sum of £50,000.

53. Applying for the Stage 1 payment was straightforward. However, I found the process of applying for the Stage 2 payment to be difficult. I recall the doctor at the hospital had to intervene for the Stage 2 payment to confirm [GRO-B: S] status. I believe they simply did not want to grant the payment.

54. I do not recall any preconditions imposed on the applications.

55. I am very disappointed with the fact that the NHS Business Authority provides monthly payments to people that are infected and there is no support for the parents of children who have passed away as a direct result of contracting the infections. I believe that parents should be supported financially.

**Section 8. Other Issues**

56. I recall a very unpleasant situation which I was a part of in relation to [GRO-B: S] death and the payments which I have received as a result of it. The MP in our area, [GRO-B] stated that I have "done very well" with the above payments. I found it extremely inappropriate and painful, as no amount of money could compensate a loss of my child.



**Anonymity, disclosure and redaction**

57. I confirm that I do wish to apply for anonymity.

58. I do not wish to give oral evidence.

**Statement of Truth**

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

Signed.. GRO-B .....

Dated 29 / 1 / 2019

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## Medical Summary

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

### Virology Results

26/07/1985          Anti HTLV III Positive

### Significant Entries/Absent Entries

23/02/1994          Clinical Data Summary – Other chronic Nonalcoholic Liver Disease