ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3133001
Exhibits: WITN3133002
Dated: 19 October 2019

Infected Blood Inquiry

WRITTEN STATEMENT OF GRO-B

I, GRO-B, will say as follows:

Section 1: Introduction

1. My name is GRO-B and my date of birth is GRO-B 1942. I live at an address known to the Inquiry.

2. I am the widow of the late GRO-B:H who sadly died on GRO-B 1989.

3. I have a daughter, who lives close by and two grandchildren. For many years I worked as a carer and prior to that I worked in a local factory. I chose to retire at the age of 57 so that I could care for my grandchildren, whilst my daughter worked.

4. The content of this statement is made from memory. I no longer have access to my husband's medical records as I disposed of these shortly after his death, save for his death certificate (**WITN3133002**). I do not wish to obtain a copy of his medical records.

Section 2: How Affected

5. H was born on GRO-B 1940. He lived with his parents and nine siblings. He was diagnosed as having severe haemophilia at a young age. As I understand it, two of his brothers were also diagnosed with haemophilia.

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6. My daughter is a carrier of the haemophilia gene. My grandson has also been diagnosed as having haemophilia and when he was younger, he also had epileptic seizures but he no longer suffers from these.

7. I met H when I was 15 years of age. He was 17 and had been just released from hospital where he had received treatment for serious internal bleeding, affecting his kidneys. I am told that he was lucky to survive. I am not aware of whether he was given blood products during his recovery.

8. H did not find employment until he was 20 years of age. His father wanted him to get a job in a disability factory so he had to wait for a vacancy.

9. As far as I am aware, his family did not discuss their children's haemophilia diagnosis. I knew very little about the condition when we got married. I was 21 years of age and did not ask questions about the condition or symptoms. In hindsight I was naïve.

10. H has always struggled with his health, linked to his haemophilia but there were periods when he was in good health, up until he contracted HIV. If H sustained an injury, he would receive blood products. I cannot recall the name of the blood products that he received; it may have been Factor VIII or Cryoprecipitate. He used to receive them intravenously through a drip at hospital. H was only ever treated in hospital, on demand. I am unaware if he was taught to self-administer at home, I did not see him do this.

11. Initially H was under the care of the Royal Infirmary Sunderland ("RIS") but this was later changed to Royal Victoria Infirmary in Newcastle ("RVI"), where he attended for most, if not all, of his medical appointments.

12. I recall that H was treated by Dr Peter Jones at the RVI. In or around 1986, at a medical appointment, Dr Jones informed H that he had tested positive for HIV antibodies. He was told that there was an issue with the blood products he had been administered to treat his haemophilia. I was not present during this appointment but H came home and told me his news. H was not

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open about what was discussed and did not repeat, in any great detail what he had been told by Dr Jones. I understood the word antibodies to be positive, but have since learnt that it is anything but.

13. At the time I did not understand the significance of the news so I decided to speak with Dr Jones directly to obtain further information. I was told that H had tested positive for HIV, a virus which he had contracted from contaminated blood products. Dr Jones gave information on risks of cross-infection including sexual transmission and blood contact. I am not aware whether H had received the same information.

Section 3: Other Infections

14. After H had died, I found out that he had also contracted Hepatitis C.

Section 4: Consent and testing for other infections

15. H always attended medical appointments on his own so I am not aware whether he consented to testing for HIV or Hepatitis C.

16. Dr Jones did attempt to carry out a liver biopsy when H was alive but was unsuccessful so this was carried out when he died.

17. I am not aware whether H consented to be part of clinical trials.

Section 5: Impact

Mental and physical impact on H

18. H was angry at being infected with HIV from contaminated blood. Prior to his death he had not been diagnosed with Hepatitis C. He could never understand why the medical profession had exposed him to such life-threatening risks.

19. I did not ask H questions and he would not talk about his condition or emotions but his moods began to change. H had always been quick tempered but this increased in severity in 1988.

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20. It was not until 1988, when there was a sudden decline in H health, that we knew his condition was much more serious than we had previously understood. He had lost weight and was all skin and bones. We were told at the end of 1988 that H condition could be life threatening. H was angry for not receiving this information sooner and that his life was going to change so dramatically.

21. In March 1989, H health continued to decline. I recall speaking to Dr Jones who stated that H condition was terminal and that he would not survive. At that stage H had developed AIDS. I asked Dr Jones not to tell H. I am not aware whether he abided by my wishes. I recall Dr Jones stating that if H asked, he would have to be honest with him.

22. H had worked at the same factory for many years and was eventually promoted to Chargehand, which led to an increase in pay. He worked throughout his illness but was unable to work when he was in hospital or recovering from HIV related symptoms at home. He had long periods in hospital between March and October 1989. H would have weeks and months off work which meant that we were financially struggling. Up until this point we both had jobs and were financially comfortable.

23. H only decided to leave his job, on the grounds of ill-health, a month before he died. H had previously told his employer he was a haemophiliac and had contracted HIV. H employer encouraged him to try and work at least one day a week, so that he would be paid and could receive maximum benefits such as his pension. I am aware that H received a lump sum from his pension after he left.

24. Towards the end of his life H spent most of his time in bed. When he was able to he would play bowls and darts with friends. We had always liked to go on holiday. When we were first married we went on holiday in the UK, staying in caravans around coastal areas. As we became more financially secure, we began to travel abroad, mainly to Jersey and Malta. I recall that we had planned to go to Italy before H had died but he was unable to go. Dr Jones

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recommended a break so instead we went to Jersey for a few days in September 1989. He was frail but we enjoyed our time together there.

25. On GRO-B 1989, H complained that he was feeling unwell. A taxi ambulance came to collect him at 11.30am for an appointment at the hospital and I encouraged him to go. I assume the appointment was for treatment but cannot recall what for. At 14:00 I received a telephone call from the hospital informing that due to his health H had been admitted. I received another phone call at 16:00 during which the doctors informed me that H death was imminent. My daughter and I had to wait for her partner to collect us and later arrived at the hospital at 17:40 H sadly died at 20:00.

26. H death certificate (**WITN31330001**) does not refer to the cause of death as HIV. I did not ask the Coroner or doctors to record another cause of death instead of HIV and was not aware that this was an option. H brother dealt with matters after he died so he may have asked, although it is unlikely. I understood that H died of AIDS and a liver disease.

Impact on family life

27. Our daughter initially did not know the cause of her father's ill-health. She was young and was in a serious long term relationship. H did not want the illness to affect her future so he was reluctant to tell our daughter and her long-term partner.

28. One day H had cut his hand and our daughter went to put a plaster on him, without wearing gloves. H reacted in such a way which resulted in her asking questions. Initially H refused to tell her but then eventually said that he had contracted HIV from contaminated blood. She then admitted to using his razors but thankfully she was not cross-infected. She was 22 years of age when she found out and the seriousness of her father's condition did not immediately register.

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29. She later told her partner as they were due to be married and we did not think she could keep this from him. We were worried that he would reject her when he found out, due to the stigma related to HIV at the time. However, he did not.

30. In September 1989, our daughter was engaged and decide to have a party. H was able to attend part of it but left after a few hours. She had planned to get married a year later and we all struggled with the reality that H would not be alive to walk her down the aisle. H was alive to see her choose her wedding dress but unfortunately died before she was married. The wedding took place 10 months after H death.

31. H health condition and subsequent death has had a profound effect on the family. His death devastated the whole family. My daughter was a daddy's girl and she had lost her father. He did not see our daughter get married or the birth of our grandchildren.

32. Our granddaughter has recently married and our grandson has graduated from university. We all miss him terribly and are sad that he has missed these important milestones.

Personal Impact

33. In 1988 H health rapidly declined and he was regularly admitted to the RVI. In the same year, my mother had had a stroke and was admitted to RIS. I struggled to visit both, so my daughter offered to help. I was an only child and we had a small family so there was no one else to help with my mother, other than my cousin, with whom I had, and continue to have, a close relationship with.

34. In 1989, my mother was transferred to a nursing home. I felt constant guilt about not being able to see my mother as I had been told that for my own mental health, I needed to reduce the visits to her.

35. Due to limited financial means, I continued to work as well as visit my husband and mother in hospital. I did not drive so had to use public transport to get to and from the different hospitals.

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36. Around the same time, I developed an eating disorder, which was linked to the anxiety and upset I was suffering. I began eating large quantities of lettuce and cucumber, which I had not done previously. It was a distressing and upsetting period in my life. I then developed anaemia which was said to be caused by stress. This was initially treated with iron tablets. After H had died, I began to receive injections to control the condition.

37. During H illness, I tried to have a social life and went to bingo with my sister-in-law. I was still working but continued to support him.

38. After H death I felt numb. My life was turned upside down. When the realisation that H had died eventually came to the fore, I was incredibly angry.

39. I now live on my own and often get lonely. I used to have dogs as companions but have not had one for over three years. After H death I continued to go on holiday to Jersey and Italy with friends and now have the confidence to go alone on coach trips in the UK. I am rarely at home, instead I prefer to go shopping, visit family or go out for coffee.

40. I did not get tested for HIV until after my husband had died. Thankfully I have not been cross-infected. The experience was embarrassing as I had to go to a sexual health clinic in Sunderland for the test.

41. Since H death, I have confidence to ask questions about treatment I am offered from doctors. I used to be shy and quiet but now I stand up for myself.

Stigma

42. H was not affected by the stigma surrounding HIV at the time as we decided not to tell family or friends until he was terminally ill. Even then, we only told a select few including his brother, my cousin and eventually our daughter and her partner. Despite not being affected by the stigma, we were aware of the

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negative media coverage and that other haemophiliacs had been subject to harassment. As a result of this we were scared to tell anyone.

43. We agreed not to lie when asked if H had HIV but we agreed not to voluntarily reveal the information.

44. In or around March 1989, we decided to tell H elder brother that he had contracted HIV and that he was terminally ill. He reacted with sympathy but when I offered him and his wife a cup of tea, both of them declined. H and I were hurt by this.

45. H decided not to tell his haemophiliac brother to avoid causing him distress, as he too could have been infected. As far as I am aware, H is the only sibling in his family to have contracted HIV. Since H died in GRO-B 1989, his family have not stayed in touch with me.

46. I also told my cousin who both H and me were close to that H was terminally ill and that he had contracted HIV. My cousin was understanding and devastated.

47. My brother-in-law organised the funeral. We were not allowed to see H in the coffin as it was sealed. H sister was not aware that he had HIV and caused trouble prior to the funeral as she was not allowed to see him so she complained to the undertakers. She asked why but I did not tell her and neither did the undertakers, who were very understanding.

48. I recall that my son-in-law's sister asked if H had haemophilia after he had died. I confirmed that he had but did not go into further detail.

49. To this day, I do not discuss what we went through as a family. Our grandchildren know that H was a haemophiliac but we have not told them that he had HIV. They have been through enough and I do not want to burden them with this upsetting information.

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Section 6: Treatment/Care/Support

50. As far as I am aware, H did not receive treatment for HIV or Hepatitis C but he continued to receive blood products to treat his haemophilia.

51. As set out above, H went to all medical appointments alone so I cannot comment on whether he had been given information and support by medical professionals. I tried to speak to him about his condition but was under the impression he did not want to discuss it, possibly because he was embarrassed.

52. H was not denied medical or dental treatment, either as a result of being haemophiliac or having HIV. H had to go to the hospital for dental treatment.

53. I am not aware whether my husband was offered counselling, if he had been, I suspect he would have declined the offer of help.

54. After H death, I was offered counselling by The Haemophilia Society and attended sessions at the RVI for approximately four months after H death. The sessions were helpful and my mental health improved afterwards.

Section 7: Financial Assistance

55. I cannot recall how I became aware of the Macfarlane Trust but I believe it was The Haemophilia Society who wrote to me and made me aware of it. I made an application and received a lump sum of, I believe, £50,000. I also received regular monthly payments.

56. I also applied to the Skipton Fund and received £20,000. I did not encounter any difficulties in completing the application forms or receiving money. Dr Jones and Nurse Maureen Fearns helped with the process.

57. I continue to receive monthly payments from EIBSS.

58. We did not claim disability benefits only sick pay when H was unable to work. H had to be off work for 3 days before he was able to claim sick pay.

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Section 8: Other Issues

59. I hope that the Inquiry answers questioned that for years have been left unanswered. I blame the government more than the doctors administering the blood products, as they only administered products that were available. Contaminated blood has affected so many lives and I would like to understand why H was infected.

Statement of Truth

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

Signed GRO-B

Dated 19/10/19