Witness Name: GRO-B
Statement No.: WITN3132001
Exhibits: WITN3132002 – WITN3132016
Dated: 18th October 2019
GRO-B

INFECTED BLOOD INQUIRY

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 1965 and I reside at GRO-B GRO-B I am married and I have a daughter. I am not currently in full-time employment.

2. I am making this statement in relation to the death of my father, GRO-B: F GRO-B GRO-B: F as a result of Hepatitis B and C contracted through contaminated blood products. I have reviewed my father's medical records from the Royal Free Hospital in London ("Royal Free") in order to clarify some of the dates of his treatment. I am awaiting the medical records from other hospitals my father attended and from his GP.

Section 2: How affected

Haemophilia

3. My father was born on GRO-B 1930 in GRO-B. My father had moderately severe haemophilia A with 2% clotting factor. I understand he was diagnosed early in his childhood, although I do not know whether this was a result of a test or a diagnosis based on his symptoms. When he was young, I believe he had a lot of operations and appointments.

4. My parents met at 16 years old. I do not believe my mother understood the severity and implications of my father's haemophilia until he had a fall on their honeymoon in around 1956. Unfortunately, this resulted in a bleed into his joint, and he spent most of their honeymoon in hospital abroad. The treatment was bed rest and a blood transfusion. I recall my mother telling me she was very worried because they were abroad and it was difficult to explain my father's condition to them. My father would have been in his mid-twenties at this point.

5. Before my parents married, my father did not need any treatment. Unfortunately, after they were married my father was in and out of hospital frequently. My mother told me it was difficult to relax around my father in case he fell, because his haemophilia was so severe. . Contrastingly, my grandma did not worry about his haemophilia; she was a very strong woman, and I think this is what made him a strong, private, and proud man.

6. My brother was born in 1962 and I was born in 1965. My brother does not have haemophilia, but I am a carrier, which I discuss further below.

7. Although my father was not embarrassed about his haemophilia he did not want to talk about it. However, I must have been told about his haemophilia when I was a child, because I knew I was not allowed to jump on him, for example. I thought that was normal. My brother and I were very aware to be careful around him.

My haemophilia and treatment

8. When I was three years old, in around 1968, I recall going to the John Radcliffe Hospital in Oxford ("the JR") and the doctor saying that they needed to test me for haemophilia. My mother and father were naïve about haemophilia and did not know that I could be a carrier of haemophilia, and the doctor explained this to them.

9. I recall this really upset my mother because she knew how severe haemophilia could be. We were fortunate that my brother did not have haemophilia. As I have referred to above, I am a carrier of haemophilia. I found out, following blood tests at the Royal Free in London in 1992, I also have mild haemophilia, with a clotting level of 5%. When I was diagnosed with mild haemophilia, I

knew I would have to deal with it when I had children, as a carrier. My husband and I wanted to be informed of any risks to our future children and we were given genetic counselling after it was discovered my clotting level was 5%.

10. My haemophilia is not as severe as my father's. My father had spontaneous bleeds, whereas I only experience difficulties clotting when I have surgery or dental treatment. My clotting factor has risen slowly over the years with age and I believe it is now near to 12%.

11. When I was 19 years old, in around 1984, I had my wisdom teeth taken out at the JR. I was given some factor cover, but I am not sure what this was. It may have been Recombinant Factor VIII, which is a synthetic product that increases Factor VIII levels.

12. In 1996 I was given DDAVP nasal spray by the Royal Free to control very heavy menstrual bleeding. This resulted in chronic sickness, which at the time I thought was due to food poisoning.

13. I recall next being treated with DDAVP at GRO-B Hospital in Hertfordshire for an appendectomy in 1999. At this time I told was that DDAVP is synthetic and cheaper than blood products. Again, it caused chronic vomiting and diarrhoea. Initially, the doctors could not think why I was reacting to the medication, but they now believe I am allergic to DDAVP. A note was made on my medical card confirming I should not be given DDAVP but Recombinant Factor VIII for all future minor or major operations. Now, if I need cover for dental treatment, I would have Tranexamic Acid, which is a medication normally used to stop nose bleeds or heavy periods.

14. I have always been treated with synthetic products namely Recombinant Factor VIII for emergency operations and during a caesarean section and hysterectomy at the Royal Free. I have had several blood tests at the Royal Free over the years and I do not know whether they tested me for HIV or Hepatitis C. Had I been tested, I would have thought I would have been told. I have a daughter and I arranged for her factor levels to be checked; the results came back normal.

My father's haemophilia treatment

15. The Luton and Dunstable Hospital ("the L&D") was the nearest hospital for my father but it did not have a haemophilia centre. I do not know what the treatment for haemophilia would have been when he was young. I was told that he had a lot of time off school because if he fell over, he was put on bed rest. He may have had blood transfusions and I have seen old photographs of him with his joints bandaged.

16. I recall, when I was a child, that my father always hobbled and appeared to be in pain but he would never complain. My mother always seemed to be on tenterhooks. We never really went abroad whilst we were children, probably because it would be difficult for my father to obtain treatment if he needed it.

17. Our mother always tried to protect us from our father being ill at home and she cared for him herself. I suspect that there is a lot they did not tell us, as they were trying to shield us.

18. My father's haemophilia centre was the JR, where he was treated by Dr Matthews. I do not know when my father started attending the JR but I recall him going for routine appointments frequently. I do not know what the appointments were about because my father was private about his medical care.

19. When I was in my early teenage years, around 1978, I recall my father requiring blood transfusions. This would have been before Factor VIII blood products were available. My father would know when a spontaneous bleed was starting. In the 1970's and early 1980's he would need to go to the JR for treatment, unless it was an emergency such as an accident. I believe my father also received Cryoprecipitate at the L&D, although I cannot recall when.

20. I do not recall when my father began receiving NHS Factor VIII blood products, although I believe it would have been in the 1980's as I was a teenager; his medical records suggest it was around 1983. I recall that my father believed it was a new and fantastic treatment because it meant he did not require blood transfusions.

21. I do not recall when my father began home treatment with Factor VIII, but it would have been in the mid-1980's. I recall he had a kit that he kept in the refrigerator at home, which he called his "box of goodies". Before home treatment was available for my father, we had only been able to go on holiday to Bournemouth. Home treatment meant we were able to go away on cruises. We were able to go anywhere that he had access to a refrigerator for his Factor VIII product. I do not recall whether my father was on prophylaxis Factor VIII treatment, or whether he would treat himself only when he had a bleed.

22. Generally, my father would not talk about his haemophilia. I think he felt ashamed that he had passed it onto me, even though it was milder than his condition. I do recall one occasion, around this time in the 1980's, when I was a teenager, where he did talk to me about treatment. He told me to insist on having British blood if either of us required treatment. I remember him saying "*I'm not having foreign blood*". He was quite a typically conservative British man and was adamant that if he was going to be treated with blood products, he wanted it to be British. He did not tell me why.

23. I do not know how my father became aware that he should insist on British blood, whether he heard it on the news or from a doctor, but he was very clear about it.

24. At some point after this conversation, although I cannot recall when, my father told me that Recombinant synthetic Factor VIII was available. He was very insistent that I needed to remember the name "Recombinant". He said to me "*if I am not there and you're asked what do you need, remember to ask for Recombinant*". This may have been because he knew that there were issues with Factor VIII blood product by this time, although I do not remember him ever discussing the risks associated with Factor VIII blood products at home.

25. There were a few weeks in the mid or late 1980's when my father was getting up frequently in the middle of the night and wandering around the house. We took him to the GP, Dr **GRO-B**, because we thought it might be a sign he was about to have a stroke. It had a real impact on me and I was frightened. It was not normal. My father seemed to be wide awake, but he was saying and doing very strange things. This lasted for two or three weeks and I recall we

had to lock his bedroom door because we were frightened he was going to fall down the stairs. We never found out what caused this behaviour.

26. In 1991 my father had a stroke, which was very sudden, and he was taken to the L&D for assessment, as this was the nearest hospital. He was then transferred to the Royal Free, as they were more confident in providing his haemophilia treatment, and they had a specialist haemophilia centre. I believe my mother and father would have insisted he was taken to the Royal Free.

27. My father was treated in the haematology department. He survived the stroke with no permanent damage but I recall he was in the hospital for a long time.

28. In 1991 or 1992, following my father's stroke, he moved his haemophilia care to the Royal Free, as it was easier for him to travel to. I recall he went to the Royal Free a lot, at some points as frequently as once a week, but I do not know why.

29. On 16 November 1992, my father's medical records note that he tested positive for Hepatitis C at the Royal Free [WITN3132002] and in June 1993, during an inpatient admission to the Royal Free it was noted he had been having abnormal liver function tests for around 10 years [WITN3132003]. I did not know this, and I do not think my mother did either.

30. My father recovered remarkably well following his stroke in 1991 and he was able to walk me down the aisle when I got married in 1994. On my wedding video, he does not look like he ever had a stroke. Psychologically, though, he was never quite the same and he got quite angry, particularly at my brother. I am not sure whether he was more angry at my brother than any other father of a teenage boy. He frequently had to "let off steam".

31. Between 1994 and 1998, my father was generally well. His knees had deteriorated, but he was never in a wheelchair unless he needed it to receive treatment. He began to use a walking stick when he was out. Haemophilia remained the main reason that he was unwell and the majority of his hospital

admissions were related to his haemophilia. Anything else seemed to fade into insignificance.

32. I do recall at his ruby wedding anniversary party in 1996, he did not look well. He seemed like he had a "worry cloud" over him and my mother knew something was wrong but he would not tell her what the problem was. I thought my father was tired from the party, but in hindsight maybe he was suffering more than we knew at the time.

33. My father died on GRO-B 1998 at the L&D. He had a brain haemorrhage and a second stroke, which was also very sudden, as he had not been unwell prior to this. He lost most of his function in his left side. My father was taken to the L&D because it was the nearest hospital but I kept asking them to transfer him to the Royal Free, where there was a haemophilia centre. I tried to speak to the Royal Free but unfortunately my father was too ill to be transferred. I remained at the L&D with him and he died later that night.

34. The cause of death was given as 1A) Aspiration Pneumonia; 1B) Cerebral Vascular Accident; 1C) Factor VIII deficiency; and 2) Cirrhosis secondary to Hepatitis B and C infection [WITN3132004]. It was not until I saw his death certificate that I learned that my father had Hepatitis B and C. Interestingly, although liver cancer is referred to in my father's medical records from the Royal Free, it is not mentioned on his death certificate.

35. My father did not have an open casket at the funeral and I do not know why. We did have an open casket for my mother, so it is something we would have wanted. I do not believe we were given a choice with my father. We had to have a church funeral, as he was such a big character and had a lot of friends. He left a big gap in our lives and the lives of lots of other people.

Section 3: Other infections

HIV

36. When I was a teenager, I recall my mother told me my father might have contracted HIV. I remember it well because it was unusual for my mother to share something like this with me and she was very upset. It was rare for my

mother to cry. Up until this point, I believe my parents had tried to shield me from any discussions about my father's health, particularly as my father was very private about it. She did not feel she could talk to me about it.

37. I recall my mother asking if I knew what was happening to my father, which I did not. She told me that my father had to be tested for HIV and AIDS. I assumed from this that the hospital had asked him to go in for a test, and he was aware of it. I also recall she said *"we cannot sleep with each other at the moment".*

38. I do not think my father knew that my mother had told me. He would have been mortified if he knew. Until reviewing my father's medical records, I did not know that the test was negative, although I knew it was not listed on his death certificate. Following this initial conversation, it was never mentioned to me again. It appears from my father's medical records he was regularly being tested for both HIV and Hepatitis B and C [WITN3132016].

Hepatitis B and C

39. As I have referred to above, I did not know about my father's Hepatitis B and C infections until it featured on his death certificate. We believed he had died from a stroke. Looking back, I recall my father had a problem with his liver whilst I was living at home but neither Cirrhosis nor Hepatitis were ever discussed. This would probably have been in the 1980's. I have memories of my father referring to his liver, but he used to joke about it rather than telling us there was a serious problem.

40. I do not recall any specific treatment my father had for his liver, but I do recall periods where he was particularly unwell. For instance, I can recall one occasion where he was in L&D and he could not attend sports day. I do not think he was in hospital for a bleed, it was something more serious than that because he was in hospital for a long time. I was at school at the time but I do not recall when this was.

41. I am sure that after my father's death I discussed the diagnosis of Hepatitis B and C with my mother. I did not get the impression my mother knew about the

diagnoses before my father died either. It made me wonder whether my father knew.

42. Since receiving my father's medical records, I am sure that he was aware because it is referred to extensively, although I am not sure whether he knew how he contracted the virus. The records contain a letter from an Associate Specialist at the Royal Free to Dr Stephens dated 26 November 1993 which states *"we discussed Hepatitis C. He had not understood that he had been exposed to Hepatitis C but did not appear to be particularly concerned after our discussion"* [WITN3132005]. It does not appear my father was aware of his exposure to Hepatitis C prior to this date.

43. However, I have also seen in my father's medical records that he did not want the doctors to tell my mother about the extent of his health conditions. For example, there is an entry during an inpatient admission to the Royal Free on 11 August 1997 which states *"he does not want wife to have full details, in particular no mention [of] Cirrhosis, cancer [or] talk about infections from clotting factor"* [WITN3132006]. I believe this indicates my father knew more than he told my mother.

44. In relation to Hepatitis C, according to his medical records, my father's genotype was taken and recorded as "1" [WITN3132007]. During an inpatient admission at the Royal Free in January 1995, it is noted that my father was *"infected probably 1976"* [WITN3132008], when I was around 11 years old.

45. The medical records suggest that the doctors were monitoring the progression of my father's Hepatitis C and any deterioration to my father's liver. The report of an ultrasound of his abdomen suggests there may have been Cirrhosis in his liver by January 1996 [WITN3132009]. In light of this, Professor Geoff Dusheiko and Professor Christine Lee were considering a liver transplant in July 1997, however they were not sure he would meet the criteria [WITN3132010]. In addition, on 25 July 1997, a report of an ultrasound of my father's liver recorded that *"there are multiple, large, mixed echoic masses, within the liver, which have the appearances of metastases"* [WITN3132011]. It was confirmed by Professor Christine Lee and Dr Prem Mistry at the Royal Free on 24 November 1997 that these were tumour masses suggestive of

hepatocellular carcinoma, but that my father did not want any further investigations or treatment [WITN3132012].

46. Additionally, the records also suggest that my father was periodically offered treatment to clear the Hepatitis C virus, but as he did not consider he was suffering the symptoms of Hepatitis C, he did not accept treatment. The records note he was offered treatment with Interferon by Professor Dusheiko at the Royal Free in June 1993. He was again offered treatment during an inpatient admission in January 1994 and in August 1994 the records state *"he says he is not looking for trouble i.e. interferon may cause him more trouble than worth! Controls alcohol now"* [WITN3132013]. I do not recall my father ever having a drink at home but he might have had something like one drink down the pub every other day. Professor Dusheiko and Professor Lee then discussed the Ribavirin and Interferon trial with him in March 1996 but my father did not want to start treatment [WITN3132014].

47. In relation to Hepatitis B, there is an entry from an inpatient admission to the Royal Free in 1991, when my father had the first stroke, which suggests he had had Hepatitis B for around 20 years [WITN3132015].

Section 4: Consent

48. I do not know whether my father was ever treated or tested without his consent, as he did not discuss his medical appointments and treatment with me.

49. From the conversation I had with my mother about HIV, I believe he was aware that he was going to have a HIV test. I do not know whether my mother was offered a HIV test at the same time but I do recall she was very panicked about it during our conversation.

50. I believe my mother was tested for Hepatitis C by the GP, Dr **GRO-B**. I do not know whether this was before or after my father died. I do not believe she knew about my father's Hepatitis C diagnosis until after his death, and so this is likely to have been following his death.

Section 5: Impact

Stigma

51. My father did not experience any stigma because he did not tell anybody about having Hepatitis C. As I have referred to throughout this statement, he was a very private man, so only close friends and family knew about his haemophilia.

Physical impact on my father

52. My father was always poorly but he always got up and out of bed when he could. Whilst I was growing up, I assumed this was related to his haemophilia. He was often fatigued and would frequently sleep on an evening, or an afternoon if he was at home, even from a young age. We used to leave him downstairs and go up to bed; it became a family joke.

53. I recall he was always limping and was quite lame by the time he died. At 60 years old, my father already looked like a very old man.

54. My father was often in hospital and I always assumed that was due to his haemophilia. However, considering it now and having access to my father's medical records from the Royal Free, the admissions could have been related to his liver. I do not know if he ever knew the severity of his Hepatitis infections, Cirrhosis or liver cancer; certainly we did not know. I only recall one occasion of my father being jaundiced, but I cannot recall when this was. It was likely to have been in the 1980's and he recovered from it.

Psychological impact on my father

55. My father had the occasional bad mood but he was generally always upbeat and positive. He felt he should have been dead long before 60 years old due to the lack of treatment for haemophilia when he was young. He lived each day as if it was his last.

56. My father was a very jovial and funny man. He did not let his haemophilia get him down. I recall my father was very flippant about his condition and once said to me "*we've all got to die of something*".

57. The only time I ever saw him cry was when I was 18 years old, in around 1983. I remember it was something very small that made him cry and I thought it was strange. It was "hushed" up quite quickly.

Impact on work and finances

58. My father's health had an impact on his working career. My father could not work to full capacity due to his haemophilia, but his liver may have also had an impact. He owned a chain of launderettes in GRO-B and rented out the rooms above them; he was the company director. He had staff working in the launderettes, which meant we could go to Bournemouth on holiday whenever we wanted. My father never had any life insurance. He was never a "career" man and he used to joke that he relied on my mother's income, which annoyed her. My mother worked for her father, my grandfather, in a hat factory in GRO-B. My father retired in 1991.

Impact of my father's death

59. My father's death was a real shock, because of the suddenness and the fact that we did not know that he was suffering from Hepatitis C. My mother could not cope and I had to look after her. She had seen him go through so much.

60. My brother was away when our father died, which meant I had to make all the arrangements. I had to inform my brother that our father had died and he was very upset. His marriage broke down shortly afterwards, although I believe this was unrelated to our father's death.

61. I was also responsible for calling all of my parents' friends to let them know that my father had died. After the first stroke, my father had recovered so well that everyone relaxed. It meant the news came as a real shock.

Section 6: Treatment, Care and Support

Difficulties with treatment

62. I do not believe my father had any difficulties obtaining treatment. He was treated at the L&D, the JR and the Royal Free throughout his life and he had

a very good GP, Dr GRO-B. My father was very close to Dr GRO-B and went out with him socially.

63. I recall that my father always had dental treatment at the JR or the Royal Free, even routine appointments. I do not think my father had any issues obtaining dental treatment. I do not know whether the dentist was aware that my father had Hepatitis C.

Counselling

64. Counselling was never offered to me. Perhaps I should have requested some counselling when my father died.

65. Even if it was offered to my mother or father, I do not think it would have been accepted. They were born in a different time; counselling was not commonplace. My mother should have had some counselling though, after all that she went through as a result of my father's ill-health.

Section 7: Financial Assistance

66. We have never received any financial assistance. Even following my father's death, when we became aware of his Hepatitis C diagnosis, neither my mother nor I made an application to the Skipton Fund. As far as I am aware, my father did not apply for financial assistance either.

Section 8: Other Issues

67. I have spent a lot of time burying my feelings about my father. My father was so private and I do not think he would have questioned how he contracted Hepatitis. It has been very eye-opening reading the accounts given to the Inquiry from those infected and affected by contaminated blood.

68. I hope that the Inquiry can establish when the authorities found out it was a possibility that Factor VIII had been contaminated and why this information was not disseminated. Would this have made the outcome different for my father?

69. It is possible my father may have been told about the risks but all my father had ever said to me was to make sure that we both received British blood. It may have been too late for him by then but it could have been that he did not want to have any more infected blood and did not want me to have any either.

Statement of Truth

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

Signed ... GRO-B ....

Dated....18th October 2019..........