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Witness Name: GRO-B

Statement No.: WITN0563001

Exhibits: WITN0563002

Dated: 15th August 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4th April 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. This statement should be read in conjunction with a further statement I have made, describing the death of my Mother, GRO-B: M. My Mother was also contaminated with infected blood products and contracted Hepatitis C (see statement reference GRO-B).
2. My name is GRO-B. My date of birth is GRO-B 1962 and my address is known to the Inquiry. I felt compelled to give this statement on behalf of my brother, GRO-B: B, who received infected blood products that caused him to contract both HIV and Hepatitis C. B suffered from a very severe version of Haemophilia A. B medical number, at the Derriford Hospital in Plymouth, was GRO-B.

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3. By the time [B] was 8 years old, he had already been admitted to hospital 140 times. Throughout the course of my brother's life he required blood products to treat his haemophilia. However, despite the extent of his illness he still had a zest for life and did not let his condition hold him back. Despite the pain my brother felt, he was always making people laugh, he was not the shy, retiring type. He would always have had his picture taken with [GRO-B] when they visited the hospital wards that he was on. Some of the hospitals that he was admitted to include: St Bartholomew's Hospital, [GRO-B] Hospital Norfolk and Norwich, Great Ormond Street, Wonford Hospital, Royal Devon and Exeter Hospital (for cryoprecipitate) and [GRO-B] Hospital [GRO-B]
4. I was there for my brother when he needed me throughout his life. Although when we were both little, my mother, took him to all of his appointments. [B] did not receive treatment for his HIV or Hepatitis C infections.
5. My brother and I were supposed to grow old together but his infection with HIV prevented this.

Section 2. How Affected

6. My brother, [B] was a gregarious character, who did not let his haemophilia hold him back; he had a zest for life. We were close and had a good relationship. When my son, [GRO-] was born, [B] lived with me for quite a while. My brother received an infected batch of Factor VIII, which led to the onset of HIV and Hepatitis C infections. [B] passed away very quickly due to AIDS and other complications on the [GRO-B] 1995.
7. My brother was a 100% Haemophiliac. The Churchill Haemophiliac Centre in Oxford, commented that they had never seen anyone with such a severe form of Haemophilia A. For instance, my brother's milk teeth did not fall out and he could not go to the dentist due to the risk of

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bleeding. To prevent this, rubber bands were placed round his teeth, which slowly brought them out, so that he didn't bleed for months.

8. Another example of the extent of the severity of his haemophilia was when he bit his tongue as a baby. This led him being hospitalised for months, with a tube down his nose because they could not stop his tongue bleeding. Even for a tiny cut, he would bleed for days which could then turn into weeks.
9. Throughout the course of my brother's life he required blood products to treat his haemophilia. When [B] moved to Cornwall in 1986, and attended Derriford Hospital in Plymouth, the consultant Dr Copplestone, requested if he could use less Factor VIII as it was so expensive. At the time, my brother was very upset with this request as he needed it to survive. Although, in fairness, this hospital did not specialise in haemophilia, and therefore did not know enough about the disease.
10. [B] was first diagnosed with Haemophilia A when he was 18 months old. He therefore received different forms of treatment to mitigate the effects of his illness. The names of the treatments that I can recall, were Cryoprecipitate and Factor VIII. The Churchill Centre taught my parents how to use Factor VIII at home and this made all the difference to our family's life. Later on he learnt how to inject himself on his own.
11. My family originates from Kent. I recall that [B] GP, at the time, would comment that he would send him up to be 'experimented on' in the Great Ormond Street Hospital, London. This hospital did not specialise in haemophilia and therefore did not have the expertise to treat my brother.
12. They used to put him in plaster casts, after giving him Factor VIII, where despite its presence his joints would continue to swell under it. This led to my brother's bones being fused together, before he was even in double figures. This was a direct result of being put in the plaster casts

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with a splint. The administered Factor VIII did not stop the swelling of his joints which led to the onset of osteoarthritis.

13. Before [B] died his elbows were fused together. His legs also got stiffer and were fused later on in his life. His right leg, was quite bent. It was quite funny because the bolt in his knee, used to come undone and we would have a laugh about it.
14. Consequently, my family moved to [GRO-B] in 1971-1986, to be closer to the Churchill Haemophiliac Centre and the [GRO-B] Hospital, who provided specialist treatment to my brother. My brother mostly saw the two heads of department, Dr Matthews and on occasion Dr Rizza. It was under their care that my brother received infected blood products. I do not know if he received infected blood products on one occasion or on several.
15. [B] tried mainstream school for possibly 1 or 2 years but he was off a lot because of his illness. It was also difficult for him as he was in a wheelchair. He would want to play football with the other kids but couldn't because if he got a knock it could lead to bad bleeds.
16. In September 1975, he started to attend [GRO-B] College as a boarder and left in July 1980. At this time, I do not recall the names of any of his primary physicians. [B] was unable to sit any exams as he missed too many days of school and was further compounded by his dyslexia which was diagnosed at [GRO-B]
17. The headmaster and his wife, Mr and Mrs [GRO-B] and [GRO-B] was the chairman of the [GRO-B] during [B] time at the school.
18. In 1986, [B] moved to Cornwall to be closer to our parents, despite their wishes for him to remain in [GRO-B] He then became a patient in Derriford Hospital, in Plymouth, where he was under the care of Dr Copplestone and Dr Hammond.

19. [B] found out that he was infected with HIV when he was at the Churchill Hospital. In 1982, medical staff held a meeting where they called in all haemophiliacs under their care, who could have been exposed to infected blood products. At this meeting, they called in all haemophiliacs under their care, 694 patients were told that they were fine and that only 6 patients were infected.
20. However, not long after this, [B] went back to Churchill to get his Factor VIII. The story I was always told, by my mother and brother, was that on this occasion, [B] was pulled into a cupboard of a room, where a doctor told him that they had messed up and got it wrong, that actually 694 patients were infected with HIV and he was one of those infected. This is an horrific account. He would have been 18 years old at the time. I believe that at this meeting he was told that he was infected with American Factor VIII.
21. I recall that Churchill, were able to pin point the exact batch that infected everyone. Unfortunately, at the present moment, I cannot locate my mother's diaries which would have noted the infected batch number. I do not recall any information being given to him or my parents about the treatment of HIV.
22. I do not recall my mother or my brother ever mentioning the risk of exposure to infection due to his use of Factor VIII. The severity of my brother's haemophilia meant that he needed blood products regardless of their infected state. The only thing I remember is that you had to be careful with the needles and how you disposed of them. They never mentioned that Factor VIII could have been contaminated as I know that would have been something my mother would have been on the doctors' case about. My mother would not have sat back and let them give infected blood products to my brother; she eventually [GRO-B]
[GRO-B] infected with Hepatitis C. I really do not know if he

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was warned about the risks of Factor VIII but he never changed what he did.

23. I do not know if they warned him about safe sex after his diagnosis of his HIV infection.

24. I do not know how B was told that he was infected with Hepatitis C but that he found out in 1983. Most probably, he was told by the Churchill Centre, before he moved to Cornwall. I assume a doctor would have told him when he went to the Centre to pick up his Factor VIII.

25. I do not recall B being given any information about Hepatitis C. I imagine if any had been given, then my mother, brother and father would have discussed it in the house.

26. There was no information given to my family or my bother about the risks of spreading Hepatitis C to others.

Section 3. Other Infections

27. To the best of my knowledge, I do not believe that my brother suffered from any other illnesses as a result of being given infected blood products. Although until further infections are identified and publicised I cannot be certain.

Section 4. Consent

28. I don't think my brother was tested or treated without his knowledge. He never spoke to me about this and I felt he would have told me had he known.

29. I know from 1986 onwards that he went down to Derriford Hospital in Plymouth for blood tests every month or so, in order to keep an eye on

his white blood cell count. He would have known about these tests and would have given his consent for them.

30. I remember on one occasion, in and around the 90's, he was asked to be a 'guinea pig' for a HIV drug trial but he told them to shove it. My Mum and Dad thought it would help, but I can't blame my brother for saying no. I believe that it was an American trial, whose purpose was to slow down the effects of AIDS.
31. Even after my brother passed away, the hospital wanted to do a post-mortem, they thought that [B] would be an interesting study because of the severity of his Haemophilia A on his joints; understandably my mother refused. He was not a specimen he was my brother and my Mum's son.
32. I don't know if the Churchill Centre monitored [B] blood with or without his consent. However, I do know that they were very interested in our family because of his illness. My grandfather should have been a haemophiliac but he did not exhibit any symptoms. Both my mother and I were carriers of Haemophilia A. Although, I only received this diagnosis after [B] death. Yet, when my Mum and I would accompany [B] to the Churchill centre, they would pull us aside and ask us to take blood tests so that they could check our bloods. We did not sign a consent form for these tests to be conducted. They justified these tests on the basis of checking our clotting levels. These tests occurred from 1971 to 1984.

Section 5. Impact

33. I do recall that initially when my brother was told that he was infected with HIV that he was angry. I sometimes wonder if my brother went on a suicide hit, not that he tried to top himself but after his diagnosis it was almost as if he didn't care about whether he lived or died. For instance, he got a motorbike after he was told about the HIV infection. Even a

small motorbike crash would have killed him. I suppose he started to emanate a 'devil may care' attitude. Everything had to be done to the full.

34. The trouble is that from a young age, 4 years old, my brother was addicted to painkillers. At the age of 14, he was advised by doctors not to drink so as to protect his liver. Yet, after he found out about his HIV he would go out and get drunk regardless.

35. When he would drink he had the tendency to get a bit gobby and it almost seemed as if he was looking for a fight. On one occasion where my brother was beaten up, his leg swelled up to 51 inches which was significant giving his skinny frame. This was because he had no muscle in his right leg and his bones were already fused together. Yet, despite the swelling he did not wake anyone in the house, as he did not want to disturb anybody. He knew, the seriousness of this bleed, that it could further limit his mobility. On another occasion, I was out with him in a pub in GRO-B where he had been beaten up quite badly and had to go to John Radcliffe Hospital (please see para 47 for further information). My mother also noted that he got into a fight outside a pub in 1988 where he had to be admitted to GRO-B hospital.

36. My Dad also used to lecture my brother that he was spending his compensation money too fast, but B probably knew that he was going to die before it ran out. My brother bought a motor trike for a while and had a 125cc motorbike, just before he died. He also bought a 250cc Yamaha and was going to take his test, had he not passed away.

37. The second mental change I noticed in my brother after his diagnosis was when he was informed that his white blood cell count reduced and had full blown AIDS on 23rd November 1994. After receiving this news, he then became incredibly depressed and scared. He would visit me 4 or 5 times a week and would cry in my kitchen. I had never seen my brother cry until then, despite the severity of his haemophilia. This was

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incredibly upsetting and caused me feelings of hopelessness as there was nothing I could do or say to make it better.

38. If anything was ever spoken about his infections it was always the HIV he was most worried about, rather than the Hepatitis C. Although on his death certificate, it noted that his cause of death was a result of Septicaemia, Immune Deficiency, and Haemophilia A disease. His infection with Hepatitis C and its known effects could have further hampered his overall well-being and exacerbated the other illnesses which he suffered from.

39. I have provided a copy of [B] death certificate number [GRO-B] [GRO-B] It is dated [GRO-B] 1995 and is signed by J.J.I. Moon Registrar. The cause of death is noted as a). Septicaemia, b). Immuno Deficiency and c). Haemophilia A. Disease. I exhibit it as reference **WITN0563002.**

40. I am currently not aware of any other medical complications or conditions that resulted from his infections.

41. In general, apart from the mental strain of having HIV and going for blood tests to monitor his white blood cells, it did not affect my brother's life that much. However, once his white blood cell count reduced significantly, on 23rd November 1994, the disease progressed very quickly. I thought I would have had more time with my brother, I didn't expect it to be so quick.

42. On 22nd December 1994, he was taken into Derriford Hospital with a suspected kidney bleed but it turned out it was his liver and he was admitted to the Haematology ward. He discharged himself on the [GRO-B] [GRO-B] so that he could celebrate his 31st birthday at home which was on the [GRO-B] but because of the pain he returned to hospital at 5:30am on the [GRO-B]. He was not really aware of his birthday because he was on so much morphine to numb the pain.

43. During this stay, there was an old man in the bed next to [B] who made him feel uncomfortable. The old man implied that there was nothing wrong with [B] a response that he was quite used to because he didn't look sick. This led to [B] asking to be placed in a private room, the only thing [B] could eat was ice-cream.

44. In the short space of time between New Years Eve and his death on [GRO-B] [GRO-B] 1995, he changed a lot. From this point on you could not touch the bed that he lay on, as it would cause him excruciating pain. During this time they had him on a self-administered morphine syringe driver to try and provide some pain relief. Dr Richard Chastertly confirmed that [B] was very, very ill on 7th January 1995, to my parents.

45. It was awful because up to the 10th January, I couldn't see him because I had a cold. When I recovered, the only way I was able to recognise my brother, was because a month earlier he had dyed his hair red. He looked like somebody out of Auschwitz.

46. To my knowledge [B] did not receive any form of treatment for his HIV or Hepatitis C infection apart from the invitation to trial the HIV drugs. He received pain relief until he died. Throughout his life, he suffered more from pain, than anything else.

47. On the occasion, in [GRO-B] where I brought my brother into the John Radcliffe Hospital, because he was beaten up in a pub (probably in 1984 or 1985), he was covered in blood. When the doctor saw my brother, [B] immediately told him that he was HIV positive. This resulted in the doctor refusing to treat my brother despite having gloves on. He told [B] that he had to clean up his blood himself, before he could treat him; blood was pouring from my brother's face. This doctor justified this process because my brother was HIV positive. Obviously, I cleaned him up. This was a very traumatic process. My mother did not respond well

to these protective measures whenever she visited [B] 'as if I would mind, he is my son for goodness sake.'

48. My brother's HIV status also affected his funeral arrangements. We were led to believe that this meant that he not could be buried. My brother believed in reincarnation which required burial measures. We were also told that it had to be a closed coffin because decomposition would happen very quickly. The other thing that we were not allowed to do at my brother's funeral was to play the song, The Bright Side of Life, by Monty Python. The vicar of the Church refused to allow it to be played because there was one line at the end of it, which said that 'life is a bag of shit.' I found this very upsetting as my brother liked the song and it summed [B] up perfectly.

49. Apart from these two events, I am unaware of any other occasions where his HIV status affected his treatment.

50. My brother always had to go to hospital for dental work due to his haemophilia; he could not have an inter-muscular injection as his blood would not clot.

51. The impact of being infected on the private family and social life of my brother was probably discussed the most between my mother and brother. My Dad, being the way he was, he wouldn't have encouraged it to be spoken about. He was incredibly strict; moving up to [GRO-B] was terrible because people dropped their h's. Our childhood was mostly spent being told to sit up straight. My Dad was quite complex in a lot of ways. The relationship between my Dad and [B] was fraught. I had a better relationship, but even still I couldn't live under the same roof as him. Whereas my Mum, spent a lot of time with [B] so they had a great relationship.

52. [B] social life didn't change that much after he became aware of his infections. He didn't go around telling anyone. Although, on one

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occasion he lost a couple of friends by it being made public that he was HIV positive, but his other friends stuck with him.

53. My brother went windsurfing and horse riding. He had an adventurous spirit and he didn't let his HIV and Hepatitis C hold him back. Although, he never had a partner. I think [B] never considered having a relationship due to his knobbly elbows and his skinny frame. I don't think he ever saw HIV as something other than being in the background, so it was very hard on all of us, when his white blood cell count dropped.

54. My brother had piercings but did not have promiscuous sex or tattoos.

55. In general, it was not a good idea to tell anyone and the papers didn't help. My father was also quite homophobic and did not respect those who injected drugs therefore, he was the one mostly affected by the stigma of HIV. I worked with the lady who set up the [GRO-B] [GRO-B] in [GRO-B] so I knew a bit more about the disease. I kept trying with my parents but they did not want to understand nor speak about it. The papers just made it horrendous. My brother got an apology from The Sun newspaper because they had printed a front-page article stating that you could 'Catch AIDS.' My brother corrected them, as you cannot just catch AIDS. The Sun then had to issue a reprint with an apology because of my brother's efforts. Yet, my parents' attitude still did not change, which I could not believe.

56. On another occasion I spoke to my friend about my brother's HIV status. She subsequently told her husband who told her to throw out all of their cups and forbade [B] coming around to the house. After that, we didn't tell anyone else about it.

57. [B] death hit us really hard, it was a savage result. I moved down to Cornwall because I knew time with [B] was limited because of the HIV, but again I didn't really think; I just thought it would go on and on. It seemed to incubate for a quite a while in haemophiliacs.

58. I found it very hard, the last time I went into to see [B] in hospital. I saw him the night he died. The hospital allowed us to go in and see him when we wanted. I just wanted to spend some time with my brother. Although, when I saw him, [B] said that he was quite tired and asked me to leave. The nurses told me that he died just after I left. My parents were told that he passed away, when they arrived to visit him the following morning.

59. I didn't cope very well with [B] death. I went to my GP who prescribed me sleeping pills and arranged for me to see a bereavement counsellor. However, the lady that I saw spent the whole time looking at the clock. After that session, I decided counselling was not for me.

60. This was a very difficult time for me as my ex-husband, the father of my son [GRO-] who was 12, had just passed away unexpectedly on [GRO-B] [GRO-B] 1994, the same day as my parents' wedding anniversary. He had an undiagnosed heart problem that was inherent in his family. He was 35 years old, when he went to bed one night and didn't wake up. My father also passed away in 1998 and I lost my mother-in-law, who I was close to, between [B] and my father's death.

61. At the time of [B] death [GRO-B] my son, [GRO-C] his father's death, he was a Daddy's boy. [GRO-B] also had a good relationship with [B], so his death also affected him deeply.

62. Later, I was living with a new partner, a guy who had known [B] for some time. Unfortunately, he became fed up listening to me trying to talk about my Dad and [B]. This led to us splitting up in November 1997 and meant that [GRO-B] and myself lost what had been our home.

63. There was no one I could really speak to. I also couldn't talk to my Mum about [B] death because she would get too upset. There was

never any support system put in place nor was there any support offered to my family. This was a very traumatic time for me and my family, which took its toll.

64. My Mum was devastated even a couple of years after [B]'s death.

There was only ever the four of us. My Nan died not long after we moved to [GRO-B] 1980. My Mum fell out with her brother and I didn't meet anyone from my Dad's side for a long time. Although, I eventually met some of my cousins but it's weird, because there is no one I can reminisce with about my immediate family anymore.

65. I think [B] finished school in 1980. [B] didn't sit any exams because of his illness. Although, he did enrol in an Art course at [GRO-B] College, [GRO-B] in June 1981, he could have been infected with HIV and Hepatitis C at this stage. He could not complete the course as it was difficult for him to go up and down the stairs. [B] had restricted mobility because of the effects of the bleeds on his joints. However, he was very good according to his tutor.

66. He did get offered a job as an illustrator and he was also a car park attendant. However, he was sacked from the car park job as he took too much time off work. [B] wasn't really employable because of his illnesses.

67. One of my brother's pastimes would be to create big dioramas of particular battles in history. He took after my father, in this regard, as he was interested in past warfare. He also joined the [GRO-B] in November 1980, which he really enjoyed.

68. My brother's diagnosis didn't really impact on my life other than I just knew that I had limited time with him. It didn't affect my jobs. My brother lived with me for a bit in [GRO-B] when [GRO-B] was little and then when I moved to Cornwall. I would like to clearly state that [B] was not a burden to me, he was my brother and I didn't mind being there

for him when he needed me. I knew that if I needed something he would be there for me too.

Section 6. Treatment/Care/Support

69. Other than the difficulties that I have outlined above in para 47 and 48, to my knowledge he did not face any other difficulties in relation to obtaining treatment and care because of his HIV and Hepatitis C.

70. No support was ever made available to my brother or my family as a result of him being a recipient of infected blood products.

Section 7. Financial Assistance

71. The financial assistance my brother received as a result of being infected consisted of two lump sum payments, in the early 1990's. The first was from the Department of Social Security for being given infected Armour blood products, who gave £20,000. The second sum of £23,000 was from the government. Although on receipt of these lump sum payments he had to sign waiver of his legal rights not to pursue this further. I believe that both of these lump sum payments were organised through a solicitor.

72. I remember that my brother used to talk about a guy called GRO-B from the Macfarlane Trust, not long after he moved to Cornwall. GRO-B arranged for B to receive a waterbed which made the world of difference to him, as he could get a bleed just from rolling over in an ordinary bed. He also organised a great big chair which was comfortable for B to sit in and GRO-B also arranged carpets for his flat.

73. B also received a full mobility allowance which paid for his car, parking tickets, car tax and so forth. The only thing my brother had to pay for was his petrol due to the severity of his haemophilia.

Section 8. Other Issues

74. My brother's infection with HIV and Hepatitis C was something we just accepted, we couldn't do anything about it. Compensation does not give back what you have lost. I think that somebody needs to say sorry and note the lessons that they have learnt from this tragedy. It has left me so sad and angry.

Statement of Truth

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

Signed

GRO-B

Dated

15th August 2019