Witness Name: Neil Long
Statement No: WITN7506001
Exhibits: WITN7506002
Dated: November 2022

INFECTED BLOOD INQUIRY

EXHIBIT WITN7506002

ANONYMOUS

Witness Name: GRO-B
Statement No: WITN0194001
Exhibits: **WITN0194002 - 10**
Dated: 22 May 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. My name is GRO-B. My date of birth is GRO-B 1951 and I live by myself at my home in the West Midlands. I have been retired since 2012, after being made redundant and I have two sons who live nearby. I intend to speak about my late husband, GRO-B: H. In particular, the nature of his illnesses, how his illnesses affected him, the treatment he received and the impact it had on him and our lives together.

2. I confirm that I am not legally represented and that I am content for the Inquiry team to assist me with my statement. I have provided the Inquiry

with some of H's medical records and documents relating to litigation, and exhibit these with my statement.

3. My two sons, GRO-B and GRO-B have contributed some detail of how their dad's illnesses affected them, which is included in this statement.

4. Due to the stigma associated with HIV, I wish for my statement to remain anonymous. I do not wish to give oral evidence to the Inquiry.

Section 2. How Affected

5. H and I met when I was 16 and he was 18. We got married a couple of years later, on GRO-B 1970 and had two boys within the next five years. We were a happy family; H was employed for a long time, but later on, we also ran his business together.

6. H was born on GRO-B 1949. When he was born, his navel wouldn't stop bleeding, and he was diagnosed with severe haemophilia A, having a clotting factor of 0%. Unbeknownst to the family, his mum had been a carrier of the gene. After he was diagnosed, it was revealed that his grandmother had had a son who was a haemophiliac, but who had already died.

7. As a child, there were no treatments available for H's haemophilia. If he had a bleed, he would have to stay in bed until it subsided and he frequently had to spend time in hospital after a bad bleed. He would receive blood transfusions and was given Fresh Frozen Plasma, but after 1968, he was treated with cryoprecipitate. In 1977, he was switched on to various Factor VIII products.

8. His haemophilia affected his knees and elbows the worst, and he would at times be unable to bend and flex them fully. As he got older, he would also occasionally walk with sticks or crutches.

9. H was initially under the care of GRO-B hospital, before being moved to the Queen Elizabeth Hospital Birmingham (QEH), where he remained until he died. His primary physician was Dr Franklin, but he was also treated by Drs Wilde, Boughton and Mainell.

10. We heard about QEH from GRO-B's mum, who received the Haemophilia Society Newsletters. Once H was under their care, I was taught how to prepare and administer the cryoprecipitate and later, the Factor VIII. It was relatively simple. I would phone and order whatever H needed and we would then help ourselves to equipment and supplies out of the freezer at the hospital.

11. The cryoprecipitate came in a frozen bag, which we defrosted and ensured was the correct temperature. We would use about eight bags for one treatment. We didn't use preventative measures to stop H bleeding, we would only administer treatment once a bleed began.

12. H was very reluctant to move from the cryoprecipitate to Factor VIII. He was eventually talked on to using Factor VIII, after being told that they were keeping the other drugs for children. I do suspect that they had an idea that there was a problem with Factor VIII, even then, but I think they wanted to move him on to Factor VIII as it was cheaper.

13. I am shown now **(WITN0194002)**, which is a client questionnaire, filled in by H prior to his death. In that, he states that he was told by Drs Hill and Boughton that Factor VIII was easier to use and a better treatment than cryoprecipitate.

14. He was really against switching to Factor VIII as he had seen an article in the Mail on Sunday in May 1983, which said that Factor VIII presented a risk of HIV transmission. He took that newspaper cutting to Dr Boughton

who said that it was "blown out of proportion" and that he had two options: one was to use the Factor VIII or to die of a haemorrhage.

15. H received Factor VIII manufactured by Lister, Hemofil, Armour and Alpha. He wasn't given a choice of treatment, he just had to take what he was told to, and what was available.

16. H never administered the Factor VIII himself; I was shown how to prepare and inject him by the QEH. I would warm it in a bowl, mix the mixture together and draw it into a syringe. I would inject it in to the back of his hand. I would often miss a vein and would have to make several attempts at injecting him. Our eldest son GRO-B now has a phobia of needles after watching me inject his dad so many times.

17. We were never given any official warnings about the risk of infection, but H never blamed the doctors for his illnesses. I don't think they fully knew about it or what might happen.

18. As a result of receiving contaminated blood products, H was infected with HIV and hepatitis C.

19. A letter from Dr Ian Franklin, a Consultant Haematologist in the Department of Haematology at QEH shown to me as **(WITN0194003)** states that H s medical notes suggest that he contracted non-A, non-B hepatitis following his first exposure to Factor VIII on 29 June 1977, following an episode of bleeding in the urine.

20. H s first test for HTLV3 antibodies was on 13th December 1984, but the results weren't reported until 10th April 1985, when H was 34 and he was informed at some point before 21st February 1986. Throughout his life, he did not wish to know about the details of his infection. At first H was told that he was to behave as if he was HIV positive.

21. At his next appointment, H was told 'we're sorry but several haemophiliacs have been infected with HIV and we don't know how it's going to work out'.

22. The doctors seemed to think it was connected to Factor VIII, but they weren't sure and as such, we were advised to carry on using it.

23. We weren't given any guidance on how to manage the HIV, but I think that's because they didn't know how to manage it. We were told to use protection if we had sex and I was told to use gloves when I was administering his treatment. However, I refused to do this, as I didn't want H to think I didn't want to touch him. I wasn't afraid to get his blood on my hands. I just made sure I washed them properly afterwards.

24. H found out about his hepatitis C infection by accident. He was admitted to QEH either for an ear infection or a bleed in his ear. I'd already tried to treat him at home (we had been told, if in doubt, treat) and it hadn't worked.

25. In hospital, one of the junior doctors said very casually 'well you've got HIV and hepatitis C'. H replied 'no I haven't', to which the doctor replied 'well you said you didn't want to know any more, so that's why you haven't been told. I have no recollection of H saying that, but there are some references to something similar in some of H s notes.

26. I think H was told in 1994 or 1995 that he had hepatitis C. We weren't given any information or guidance about the virus, nor were we offered any counselling as a result of the diagnosis.

Section 3. Other Infections

27. I do not believe H was infected with anything other than HIV and hepatitis C. However, communication with our hospitals was very minimal, with little engagement from us. We didn't question them, they just told us

what would happen. Therefore, I cannot be certain that H didn't have any other infections.

28. After providing the Inquiry team with a bundle of documents, they have now shown to me **(WITN0194004)**, which is a Preliminary Medico-Legal Report, prepared by Dr Timothy Tilsey. In it is stated that H was also found to have hepatitis B surface antibodies and core antibodies. I was unaware that he had been infected with Hepatitis B and that's a bit of a shock.

Section 4. Consent

29. **(WITN0194002)** para 34, also states tha H was first tested for AIDS in approximately 1984. He was told what he was being tested for AIDS at the time. Latterly, I don't think he was aware that he was also tested for HCV.

Section 5. Impact

30. H did lose a lot of weight, but you couldn't really tell that he was ill, other than him having lost weight. The illnesses did age him prematurely too. He couldn't walk well, but that had been true even before he was infected with HIV and HCV.

31. As time went on, his eyes and pallor did begin to look quite yellow and we were told that he had some liver damage. His eyesight also began to fail. He didn't have cirrhosis, but was close to it. There was no chance of him ever having a liver transplant, as his HIV medication would have interfered with the anti-rejection drugs.

32. The biggest effect of the illnesses was mentally. H wasn't a big drinker, but he definitely began drinking more after he was diagnosed with HIV. Neither the boys nor me would describe him as a drunk but Dr Franklin did refer him to All Saints, to help address his drinking.

33. I remember going vividly. It was attended by drug addicts and ex-prisoners, one of which was shouting about AIDS. We left immediately. Dr Franklin told us we shouldn't have left. Thereafter, The Dr's at All Saints must have realised we felt uncomfortable waiting with the rest of the patients and they let us wait in our car, the Doctor would then come and get us when he was ready.

34. We went to All Saints for about 18 months but it had no effect on his drinking. He only seemed to talk about football. I think he knew that drinking wasn't going to kill him, so he didn't care about how much he drank. It did get to a point where he would have a whisky when he got up in the morning but I thought that if it helped him cope, it was fine. We never held his drinking against him. He was given Librium, but he didn't keep up with his medication regimen.

35. He was quite depressed, particularly towards the end. I am shown now (**WITN0194005**), which is a proof of evidence drafted by H for our solicitors. It sums up H s attitude clearly, He says, 'There is of course no real sense of planning for the future, since I do not see that I have a future'. I find that very sad. (see page 4)

36. He was prescribed Amitriptyline to help him feel better, but I don't know that it worked. I did worry that he might be suicidal but I was never certain that he would actually kill himself. It had an effect on our marriage and our sex life. He didn't want to be near me for fear of infecting me; his infections created a big wedge in our marriage.

37. He kept having vivid dreams, which were triggered by the adverts on TV. One of them was a train rattling down the track with the headline, 'it's coming to get you' H couldn't sleep properly as a result.

38. He also became very irritable. He went to the hospital and asked if it was the drugs making him so, as he had always been a jolly person previously. They confirmed that they could make him irritable.

39. Dr Franklin once said to me that he didn't think H was coping very well. I asked him, 'would you?' and he replied 'but he's got to face the facts and learn to cope'. It wasn't said in a nasty way, but did seem to show a lack of understanding by him.

40. At one stage, H suffered with haematuria, which is bleeding of the kidneys, causing kidney stones. He was taken to QEH and argued with them, saying that Factor VIII wasn't as good as cryoprecipitate for his treatment. His comments were ignored. No one was nasty about it but it was plain to us that there was nothing any of them could do.

41. H was in and out of hospital a lot throughout his life and particularly in the last year of his life. He would vomit frequently and he couldn't eat a lot, which meant he lost a lot of weight. When he went to hospital for check ups, he would keep his keys in his trouser pockets when they weighed him, just to make himself seem heavier.

42. He developed vasculitis, which thinned his blood vessels, and would regularly suffer with headaches, which made him drowsy and as such, would spend a lot of time sleeping. In the last few days of his life, he was very obviously not well and I think he knew there was something wrong. He was sleeping in our bedroom and I would check on him frequently. On the Thursday night, he woke up in the night vomiting, it was like he couldn't quite clear his throat of it. Eventually, however, he dozed off back to sleep.

43. When he woke in the morning, he asked me to phone an ambulance for him, which I did. However, I had to wait for one to come from within our area to take him to QEH. When he arrived, they took him to neurology

after which, one surgeon told us there was a bleed on his brain but that they could perform surgery on him to fix it.

44. Dr Wilde then called us in. They had thought he had had a stroke, as he was displaying many of the same symptoms, he couldn't talk or move his arms.

45. He wasn't kept on life support, but he was hooked up to a blood pressure machine and was being infused with Factor VIII. I think he must have spoken to a doctor previously about not using extraordinary measures, as he couldn't speak when he was admitted. They took the blood pressure monitor off first and then a sister asked if she could remove the Factor VIII. He then slipped in to a coma and died on Sunday evening. It transpired that he had had a bleed on his brain.

46. H lived for 15 years from the time of his diagnosis to the time of his death in QEH on GRO-B 1998. His death certificate **(WITN0194006)** lists (1) intracerebral haemorrhage and (2) severe haemophilia A as causes of death. We asked for HIV to be withheld from the certificate, as we wanted him to be buried and we were worried that if HIV were listed, then H would have to be cremated. Additionally, we didn't tell the undertakers about his infections so that they didn't insist on him being cremated either.

47. For his HIV, H was given AZT but he couldn't tolerate it and would frequently be sick, which in turn meant that he lost a lot of weight. He went from being around 16 stone to only 9 to 9 and a half stone at the time of his death.

48. At one point H was on 10 tablets a day, but he wouldn't take them regularly. After he died, we found pills hidden all over the house, including stuffed down the side of the bed and GRO-B even found some in the middle of the garden umbrella. H took what he thought was essential to

manage his symptoms, but didn't take anything that made him feel more unwell.

49. H had to fight for treatment initially. He even wrote to our MP, but got the response that treatment wasn't available in our area. Eventually, however, they offered to fund it for him and one other person.

50. I used to be a regular blood donor. The last time I went to give blood in around 1985, I asked if it was ok for me to give, because of H s illnesses. The person said, 'oh god no, haven't you been tested?' I told him I hadn't and was later booked in for an HIV test at QEH. H was devastated at the thought that he might have given it to me but thankfully it was negative. I have never been tested for hepatitis C. I have, however, had numerous blood tests over the years and I think it would've shown on one of these, though I have never been told I have been tested for hepatitis C.

51. We never told anyone about H s illness. His parents didn't even know, as H was worried that his mum would tell people. Even to this day we don't tell people about his illness or how he died.

52. Over time, AIDS was more prominently reported in the news. We began to realise that it was more serious that what we'd previously been lead to believe. Dr Boundan had previously told us that H s "risk of developing AIDS as a result of using American product were...a million to one" **(WITN0194007)**. Page 4.

53. H used to say he felt dirty; he had never been with other women, and had good morals. He felt that people were tying haemophiliacs with homosexuals and drug addicts and he didn't like the association.

54. I do think a lot of people would put two and two together, but nobody knew for certain. They knew he was a haemophiliac and then after seeing us with nice cars, they thought we must have had a pay out for

something, even though H's business was coincidentally doing very well at the time we received the money.

55. We used to go down to the local pub, but people would sit and pointedly make jokes about AIDS, I think to see if they got a reaction from us, and I was just supposed to sit there and laugh. After a while it got too hard and we just stopped going.

56. H was a smart guy, but was pretty much self-educated, due to missing lots of school whilst he received haemophilia treatment in hospital as a child. That being said, he was always up to date on current affairs, enjoyed crosswords and would play chess in an evening.

57. H carried on working full time as an inspector for GKN. Some smaller companies wouldn't allow for time off with the haemophilia, but they mostly understood why he needed the time off. When they offered him redundancy, he took it.

58. Immediately after that, he ran a market stall for a year, trading in pretty much anything and everything, which eventually lead to him starting his own business doing transport and industrial painting. Eventually though, his illnesses made him so fatigued that he couldn't drive much, which was something on which his business depended.

59. Nowadays, I am not in the best of health, having required multiple operations on my hips. As such, my mobility is slightly impaired and being on my own without my husband has affected my life considerably.

Section 6. Treatment/Care/Support

60. H had trouble with his teeth throughout his life. As he had haemophilia, he often received dental treatment in hospital. When he was younger, if he needed an extraction, it would mean spending a week in

hospital to deal with the bleeding. However, once he moved on to cryoprecipitate, it meant only spending one day in hospital.

61. H's GP, Dr GRO-B was useless. They never really cared about him and frequently moaned at him for requesting medical sick notes for work. One time, I went in to pick a doctor's note up for him and he tore a strip off me, saying 'I'm breaking the law doing this! He should come himself!' He didn't have any kind of relationship with H otherwise he would know why he couldn't go himself. When H died, he had the audacity to send a condolence card.

62. Counselling or psychological support was never made available to H while he was alive. Nor have I received any counselling related to H's illnesses. I did receive a few weeks of bereavement counselling after he died, where a woman would come around to the house once a week and we would talk about H. My sons have not received any counselling either.

63. I was put on antidepressants after H died and am still on them now some 20 years later. I think I am addicted but no one has really questioned it. I don't go out a lot and have never wanted to find another partner, despite being widowed at a young age.

Section 7. Financial Assistance

64. We were made aware of the MacFarlane Trust by the Haemophilia Society. They advised us to instruct McGrath & Co solicitors in Birmingham, to represent us throughout litigation against Central Birmingham Health Authority and Others. Initially, we were not deemed eligible for legal aid, as we were both working. However, at some point, the position changed and we were allowed legal aid.

65. As a result of the litigation, we received £80,000, which I believe was administered by the MacFarlane Trust.

66. We also received an ex-gratia payment of £20,000 from the MacFarlane Special Payments Trust on 16th February 1990 (**WITN0194008**).

67. After H died, a lady by the name of April who worked at QEH contacted me and told me about the Skipton Fund. My understanding is that the hospital supplied H's medical records to the fund. I received £10,000 from the Skipton due to him being infected with hepatitis C.

68. Since H died, I have received a monthly payment of £750 from MacFarlane, though it is now administered by EIBSS. A few weeks ago, I received a letter saying that the Prime Minister had announced additional money was going to be made available and as such, the payments would be going up in July. I had originally thought that the letter would be one informing me that the payments would be stopping, so this was a relief.

69. In order to receive the money, we had to sign a waiver, agreeing not to bring further litigation against the Health Authority. It was also made clear to us that the money we received was not an admission of liability.

70. We had a good experience with the MacFarlane Trust, I think they were very good and came out and visited H at home.

71. However, when I look back, the amount that was paid was a pittance. John Major allocated the money, but people who got dismissed from work got more money than people who had been given these illnesses.

72. We received as much as we did because H was married with children. However, those who were single only got about £20,000, which was a disgraceful amount. Their lives were ruined and they didn't even have the option to have children, and yet that was all they got.

Section 8. Other Issues

73. My eldest son, GRO-B thinks it unacceptable that there has been no acceptance of liability. They knew the drugs weren't safe and that they were buying them cheap, but they continued giving them to people, even children. He recalls it 'kicking off' – he remembers Freddie Mercury dying and people asking questions about H He thought 'if a bloke with that much money dies of AIDS, then we have no chance'.

74. GRO-B doesn't remember too much else, there are massive chunks of his life where he draws a blank. I think that it was probably his mind's way of coping with his dad's death. He recalls now, 'One minute dad was here, the next he wasn't. That was it'.

75. GRO-B recalls GRO-B going off on his own a lot of the time. Some of his friends would ask him if his dad was ill, but he felt like it was their parents asking via their children. No one would ask outright if H had AIDS, they would always ask around it. After H's death, GRO-B found a lot of comfort in his granddad, but he died only a year after H did. H's dad changed after H's death and shouldn't have outlived his son.

76. H loved children and desperately wanted to live to see his grandchildren born. However, he never lived to see them. I remember on one occasion H was asked to be the local Father Christmas, he initially accepted the offer and was exited about it, he then reflected and realised that if the parents of the children he would come into contact with found out there would be an uproar, he then had to decline which made him sad.

77. We were involved in litigation for some time. We instructed McGrath & Co solicitors, who spent a lot of time preparing our case and researching

similar cases from around the world. I have adduced numerous papers with my statement relating to this litigation.

78. We brought a case (**WITN0194009**): GRO-B v (1) Central Birmingham Health Authority; (2) West Midlands Regional Health Authority; (3) The Attorney General on behalf of the Committee on Safety of Medicines; (4) The Attorney General on behalf of the Licensing Authority pursuant to the Medicines Act 1968; (5) Department of Health; (6) North West Thames Regional Health Authority; (7) Central Blood Laboratories Authority GRO-B GRO-B

79. We also made enquiries about bringing a case against Armour Pharmaceuticals, though were advised that we would be unlikely to succeed in our claim (**WITN0194010**).

80. I hereby give the Inquiry the requisite authority to make enquiries with these solicitors on my behalf, in order to establish if they have retained any further documentation, which may be relevant to my evidence or the Terms of Reference.

81. From the inquiry I would like to know who was responsible for allowing the contaminated blood into the country and why it was allowed to continue. I also think Kenneth Clarke was very blasé about this and his comments were disgraceful.

Schedule of Exhibits

WITN0194002	Questionnaire in the name of H Para 17 indicates he did not want to change his treatment; Para 32 newspaper cutting; Para 35 Junior Doctor informing him of HIV.

WITN0194003	Letter from Ian M Franklin, Consultant Haematologist (Dept of Haematology Queen Elizabeth Hospital), in answer to questions asked by Mr H re. HCV & HIV. Dated 04/10/1989.
WITN0194004	Copy Preliminary Medico Legal Report H H Signed Dr T.M. Tilsey. Dated 24/01/1990.
WITN0194005	Proof of Evidence for H Dated 16/02/1990.
WITN0194006	Death Certificate for H Dated GRO-B
WITN0194007	Further Proof of Evidence, dated 09/06/1990: "risk of my developing AIDS as a result of using American Products were "a million to one".
WITN0194008	Macfarlane Special Payments Letter. Dated 16/02/1990.
WITN0194009	Letter from McGrath & Co re. HIV litigation and enclosing Individual Statement of Claim. Dated 28/02/1990.
WITN0194010	Letter from McGrath & Co re. Armour Pharmaceuticals. Dated 04/01/1991.

Statement of Truth

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

Signed: **GRO-B**

Dated: 22nd May 2019.