ANONYMOUS

Witness Name GRO-B
Statement No.: WITN5745001
Exhibits: WITN5745002 - 005
Dated: 6 8 2021.

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 15 June 2021.

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1940, and I have lived at my current address in GRO-B for the last 44 years. I used to work in insurance, but I retired at the age of 62. I have been married and widowed a couple of times, and I have three grown-up children, my daughter, who is 55 and my twin sons, who are 47 years old.

2. I have three siblings, two sisters and one brother. My brother GRO-B GRO-B was born on GRO-B 1939. He used to work in classic car restoration but has been retired for about 15 years. He has been married to his wife GRO-B for nearly 54 years.

3. My brother GRO-B: B was born on GRO-B 1936 and passed away on GRO-B 1987. B was diagnosed with severe Haemophilia A from a very young age. His death certificate states that his cause of death was cirrhosis of the liver, Non-A - Non-B Hepatitis, Haemophilia A, and HIV infection. I exhibit the death certificate as **WITN5745002**.

4. I intend to speak about my brother B Haemophilia A and subsequent infection with Hepatitis C ("HCV") and HIV. In particular, the nature of his illness, how the illness affected him, the treatment received, and the impact it had on his and our family's lives.

5. I make this statement with support from my brother GRO-B and his wife GRO-B.

6. I have made the decision to be anonymous as I wish for my personal and private family matters to be kept confidential.

Section 2. How Affected

7. My siblings and I were born and raised in India until we moved to the UK in 1952. B was diagnosed with severe haemophilia A from a very young age. I remember my parent's coming home to tell us that it meant that B bruised easily. His joints used to swell up, which meant that he could not play with GRO-B and me. B never received any treatment for his Haemophilia in India and was never given a blood transfusion or blood products.

8. B was 15 years old when we moved to GRO-B in the UK but still could not play outside with us. By the time GRO-B and GRO-B were together, and GRO-B met the family, B was under the care of Churchill Hospital in Oxford, as this was the closest hospital to us that could deal with blood disorders.

later plasma. Finally, in 1971, he moved to London to be closer to the hospital and began working for Remploy.

9. At the time, the Royal Free was believed to be one of the best facilities to help care for people with Haemophilia A, and B was under the care of Professor Kernoff and Professor Tuddenham.

10. When Recombinant Factor VIII became available B was offered this as a treatment for his haemophilia. He accepted it because it was promised that it would make his life easier. I remember how happy he was that he could move freely and be independent due to the treatment.

11. Nothing was explained to us about the risks associated with receiving Factor VIII. They may or may not have been explained to B but he never said anything about that to us.

12. In 1985, GRO-B oldest son was having GRO-C, and the family arranged a meeting at the Royal Free Hospital with Dr Natasha Burkhart. We were asked if there were other issues that we were concerned about with regard to the whole family, to which we mentioned that we were worried about B because his health seemed to be in decline. He was withdrawn and was deteriorating quickly.

13. We were also concerned about the possibility that he may have contracted AIDS because this was when AIDS was rife in the country. Dr Natasha Burkhart said to us at the meeting, "*Haven't they told you he might have AIDS?*". She then wrote a letter to the Royal Free Hospital on our behalf seeking information regarding GRO-B health.

14. As a result of that letter, Dr Kernoff at the Royal Free arranged a meeting with the whole family, and a social worker connected to the Royal Free was also present at the meeting. The social worker and Dr

Kernoff said, "*just to put your mind at rest; He does not have AIDS*". They were very Insistent and yelled at us, "*He does not have AIDS, have you got that?*".

15. B health was really poor by this time; he was confused, and we were concerned about his mental health deteriorating. By the time he realised he had an infection, it was too late.

16. One day I was sitting at home, and B called me on the phone and said GRO-B *I have AIDS*". I said, don't be silly, but I went into a state of panic. I think I must have rushed down to console him. This was long after we met with those doctors in 1985.

17. No officials or doctors told us B had AIDS. Most of the family, like GRO-B and GRO-B did not realise until B had passed away and came across this information upon reading the death certificate.

18. We were vaguely aware that he had some sort of hepatitis, because his eyes had been clearly jaundiced at one stage in the late 1970s to early 1980s. Then again, no one gave us much information about this or ever came out to say that it was hepatitis.

19. Between 1985 and 1987, his health rapidly deteriorated. He lost a lot of weight, could no longer move about independently, and was forced to quit working. He was also experiencing hallucinations and paranoia. He would sometimes say that there was someone out there waiting for him. We thought that his deteriorating mental state was due to the stress of living alone in London.

20. Aside from his haemophilia, he had no other health issues before. By the end, he was spending more and more time in hospital. He was bedridden and needed help to feed himself. We all used to come down from GRO-B to London to see him, but it was very hard to watch.

21. B passed away on GRO-B 1987. It was very hard for everyone in the family, especially our parents. We were only relieved that he had finally stopped suffering.

Section 3. Other Infections

22. We only became aware that B had contracted HIV due to being given infected blood products after he had passed away and received the death certificate.

23. Recently, we have come to believe that B also contracted HBV in the 1970s, when he was receiving treatment at the Oxford Haemophilia Centre. See exhibit **WITN5745003**.

Section 4. Consent

24. We are not sure if B was ever treated or tested without his knowledge, consent, or for research purposes. However, we know that B trusted the team at the Royal Free Hospital and would probably have said yes to treatments because it was the only way he could be mobile.

25. We can only imagine that B did not give full and informed consent, if he was being treated towards the end. When we attended the meeting at the Royal Free, nobody told us about the risk of the blood being contaminated.

Section 5. Impact

26. We were a very close-knit family, so it had an impact on the entire family. My parents are a very old fashioned, sweet and a lovely couple, so B illness took over their whole life. After B moved to London and began deteriorating, they would travel down to London regularly and spend nights with him at the hospital. The trip to London

was very complicated; they had to get multiple trains and buses, and then the tube, but my parents would always do it. My dad had retired at this point, and my mum had always been a housewife, so it did not affect their careers.

27. It was quite an ordeal for everyone. For GRO-B and me, our brother was dying, but we were also watching our parents lose their son.

28 B had always been an upbeat person. He was very intelligent, artistic, and he had big ambitions. He had an independent streak despite his severe haemophilia restricting him. In his teenage years, he had a job as a tailor, and he loved the girls.

29 GRO-B and B were very close, and B tried to keep up with GRO-B but would end up being black, blue, and bruised. He had regular nosebleeds, and sometimes, if he had a nosebleed, he would have to stop being active for days. Most of the time, he had to stay indoors and so could not attend school regularly like us.

30. He could not ride a bike, but as he got older and once he started getting treatment at the Oxford haemophilia centre, he was able to have a car adapted for his needs. Once he moved to London, he used to drive up to GRO-B to see the family. He would stay with us, and we would go down to London and visit him too.

31 GRO-B remembers him travelling abroad to Ibiza on his own and him being proud of that. He always wanted to be independent, and his car was a way for him to mix with society. I believe that when he lost the ability to drive, he lost his lifeline, and it would have contributed to the decline of his mental health.

32. He began talking to himself from a very young age when we lived in India. This was most likely because he spent a lot of time on his own indoors. After he moved to London, he did not have any relationships

or dates. He wanted so much to be like "normal" people, but as his health deteriorated, he started believing he had a girlfriend or a wife named GRO-B and also believed he had a son.

33. It did not bother us to take time out to travel to London to care for B even though we now had our own families to raise. I had been widowed a couple times, so I went to see him whenever I could.

34. We accepted it as part of our lives to care for him as much as we could. We were all very close and all loved music. We used to sing a lot and we lost all of that when his health began to deteriorate. He could no longer talk on the phone, and he could no longer drive down to see us.

35. When B passed away, my parents took it badly. My mum became depressed. I think that she had always suffered from guilt about B haemophilia because it is a genetic condition. They wanted to do everything they could for B while he was alive. They put themselves through so much trauma, driving down to visit him, and sleeping over in uncomfortable hospital beds or sleeping on the floor in B one bed flat.

36. My mum had asthma, and all the stress and worry about B seemed to make it worse. She was an introverted lady who spent most of her time looking after her family, a sweet, inoffensive lady, so being unable to do anything for her son was very difficult.

37. I think my parents never got over B passing. They both became withdrawn, and I know my mum felt guilty for bringing him into this world and for him experiencing so much pain. It's quite an old-fashioned attitude, but that was their belief.

38. Knowing that haemophilia was a genetic condition was also very scary for my siblings and I when we got married. When my sister had her

children, a girl and a boy, I know that she was concerned about whether her son could have it.

39. When I married for the second time, I was sweating about the sex of the child because, in those days, you could not tell. After I had twin boys, my husband and I cried because we were devastated and worried. The boys were tested at the Oxford Haemophilia centre when they were around six months old, and we were relieved to find out they did not have haemophilia.

40. GRO-B stated that the last time he saw B he looked like a shell of himself. He was gaunt, and he looked as though he was dying. After he passed and we saw him, we were all heartbroken. For GRO-B it was infuriating that the hospital had yanked the gold medallion of B St Christopher pendant, as GRO-B bought him that when he was in Italy several years before. B used to wear it everywhere and would never take it off. St Christopher is the patron saint of protection; which keeps people safe on their travels, and B loved that medallion. GRO-B was so incensed that he stormed out of the hospital and drove home to GRO-B

41. For me, watching B deteriorate affected me a lot. He was such a fastidious and clean person, and even after he moved to London, he would always keep his house clean. After he started to deteriorate and I would visit his apartment, it looked like a mess. I was heartbroken for him. He was spending so much time in the hospital and could no longer do all the things he used to do whilst at home.

42. He used to be a person so full of life, but by the end, he looked so emaciated. He had a hollow-eyed look which gave us the shivers. The last time I saw him I thought he looked like a ghost, like he had died a month before.

Section 6. Treatment/Care/Support

43. I don't know if B was officially informed of any of his diagnoses by the doctors. However, I know that B thought Dr Kernoff was like a saint. He worshipped the ground he walked on. Dr Kernoff was a short man with dark hair who always had time to talk to B I believe he was really good for him.

44. Dr Kernoff was B primary point of contact at the Royal Free, and I believe he was getting one-to-one care, although I don't know how often. He was a saviour for B initially, as B was suffering from pains in his joints as a result of his severe bleeds, he could not walk. I know that B was not self-administering Factor VIII because he had to go to the hospital quite frequently. I am not sure if there were set times though.

45. Nobody ever spoke to us about transmission risks because we were kept in the dark concerning B diagnosis. It seemed as though everyone did not want to engage and were actively dodging us. I never saw Dr Kernoff again after that meeting with him in 1985. I would phone him to ask about B and all I would get in response is that B seemed fine.

46. I know that B received treatment for his pain. He used to take dihydrocodeine for the pains. We looked the medication up because we were worried it might be contributing to his depression, but were reassured that they were just pain killers. B was also prescribed antidepressants and seeing psychiatrists at the Royal Free.

47. As a family, we were never offered any counselling or psychological support. Even after B passed, we were not offered grief counselling. We were just left alone. Luckily, we were young enough to pick up the pieces, and I had been through some grief in my life as a widow.

Section 7. Financial Assistance

48. We have never received financial assistance from any of the Trusts or Funds. No doctors or medical professionals have ever informed us about any avenues for financial support. They may have spoken to my parents, but we cannot know for sure, but they have definitely not spoken to any of us about it. We have never thought about seeking financial compensation.

Section 8. Other Issues

49. I think the NHS is wonderful in general, however, when I think about what happened to B and the secrecy involved, it was awful. We ended up being so engrossed in our own grief, that we didn't realise that there were plenty of other people impacted.

50. I think there was a problem with a shortage of blood donors, and they tried to do the next best thing. They had a good idea years before that there was a problem, but they did not stop doing it. I think the earliest point when they had the slightest idea that something was wrong, they should have stopped, but perhaps because they were not aware of the exact consequences or scale of it, they did not.

51. Money can be a token, but it can never compensate for the loss and the trauma. Thinking about that period and what happened to B still brings us so much pain and agony. We are not interested in money.

52. I think they tried to keep it hush, but so many people died as a consequence of receiving infected blood. I think they would have been happy for it to fade away, but people were dying and the doctors were still giving them infected blood. This is what infuriates me. There are too many discrepancies and they have tried to sweep it under the carpet.

53. I have attached four documents below as exhibits;

- **WITN5745002**. This is B death certificate which lists the cause of death as (a) Cirrhosis of the liver; (b) Non A Non B Hepatitis; (c) Haemophilia A; (ii) HIV Infection
- **WITN5745003**. A document from the Oxford Haemophilia Centre, subheading Hepatitis Follow Up Study. showing follow up investigations done in 1977 and 1978
- **WITN5745004**. The detailed handwritten notes I made in response to the questions in the IBI Rule 9
- **WITN5745005**. GRO-B handwritten notes in response to the Rule 9

Statement of Truth

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

Signed GRO-B

Dated 6. 8. 2021.