Witness Name: GRO-B
Statement No.: WITN5361001
Exhibits: WITN5361002
Dated: 06.06.2022

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 22 January 2022.

GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 948 and my address is known to the Inquiry. I am the father of the late GRO-B: S who passed away on GRO-B 996. My only other son, GRO-B was with me whilst speaking to the Investigators, to support and assist me.

2. I intend to speak about my late son's infection with HIV. In particular, the nature of his illness, how the illness affected me, the treatment received and the impact it had on him and our lives together.

3. I can also confirm that I have not chosen to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. **I am seeking anonymity.**

4. I can also confirm that the Inquiry Investigator has explained to me the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate time frames to matters based on life events.

Section 2. How Affected

6. S was born on S 1975 and died on S 1996 when he was nearly 21. When he was born we thought he was healthy but when he started to crawl at about 6 months, he kept getting unexplained bruises.

7. We later found out he had Haemophilia. Haemophilia wasn't in the family before and he was the first one. It never appeared anywhere else, it seems as though it was a one off. We knew nothing about it.

8. Before being diagnosed with haemophilia, my wife was visited by a social worker from GRO-B Council when I was at work who thought we were knocking S about. My wife was most upset about this and she said I was gentler with S than she was. It was upsetting for us at the time but they were only doing their jobs.

9. S was under the care of the children's hospital in Birmingham under the care of Dr Hill. Dr Hill was very good and I couldn't say anything against him.

10. S visited the hospital on a regular basis. He had Haemophilia A with a coagulation Factor of either 2.2 or 2.4, which meant he was severe. If S got a bleed he would be treated with cryoprecipitate and then it was

Factor 8 S had an inhibitor to Factor 8 which meant he was very severe.

11 S had three massive bleeds. He had a nose bleed that they couldn't stop and I remember the nurses running around trying to stop it. He also had a massive leg bleed that affected one of his legs. His ankle also became fused and they weren't able to operate on it due to the inhibitors.

12. S was on cryoprecipitate and it wasn't working to stop the bleeding. When he was around 2 he moved to Factor 8. He had an inhibitor to the Factor 8 so neither worked. They kept giving him massive doses on a daily basis to try and stop the bleeds.

13. I wante S to have the English Factor 8 when he moved over to it from cryoprecipitate. I was told only the ones who were already on the English Factor 8 could remain on it and new people couldn't have it as there wasn't enough of the English factor. I objected to the use of foreign Factor 8 but they had no choice. I was also told that the Factor 8 was heat treated and safe, so I agreed to its use.

14. When S was 10, they had this idea to flush out the inhibitors so they gave him large amounts of Factor 8 every day or twice a day. They used 4 or 5 large syringes each time. Thankfully this procedure did work.

15. A representative for the American firm who was providing the Factor 8 would visit when they were trying to flush out the inhibitors. They would just start a general conversation and it was very strange to me at the time. They even came several times when I wasn't there. All of sudden he stopped coming and then this thing materialised, HIV.

16. The hospital held a meeting of all the children who had Factor 8. There would have been about 30 or 40+ people from all around the Midlands. Dr Hill chaired the meeting and said that there was a potential our

children could have contracted a virus but he didn't know what it meant.

17. Dr Hill didn't mention HIV, he just said it was a virus. He said that it might go away but I thought 'pigs may fly'. People were most upset and shouting at him. At this stage, I was very worried and as time progressed you were drip fed things. I started hearing things on the TV and It was referred to as the "gay plague".

18. The hospital never told us what HIV meant. I don't even recall a conversation actually saying he was HIV+. I think they were trying to be kind and nice to keep us calm. As things progressed, I knew it was becoming serious. I learnt more about HIV gradually over the years. S was okay until he was about 16 or 17, then he started getting quite ill with HIV.

19. We weren't told much about the transmission of HIV and I was very worried. I only remember one occasion in the mid-1990s when the 'bleeding doctor' told me that you would have to have an exchange of blood to catch anything of him. S never had any tattoos or any piercings or other risk factors whatsoever.

20. I remember overhearing a conversation between my mother and S when S was about 16 or 17. S was confiding in my mother saying he could not have children and couldn't get married. I think someone said something to him at Birmingham Children's Hospital before he moved to Queen Elizabeth Hospital, Birmingham.

21. When S got older he was under the treatment of Queen Elizabeth Hospital, Birmingham. He was under Dr Wilde but they didn't have a dedicated treatment room for haemophilia.

22. I wasn't told about my son's HCV until the Skipton Fund came to us. I wasn't told about the potential of infection with HCV when my son was alive. I think they assumed because of the volume of Factor 8 S received, he must have HCV. I asked for S medical record from Dr

Wilde and he had raised LFTs which was indicative that would have had HCV.

Section 3. Other Infections

23. I don't think my son received any infection or I was not told other than HIV and HCV as a result of being given infected blood products.

Section 4. Consent

24. I don't think S was treated or tested without our knowledge, or our consent or without being given adequate or full information, or for the purposes of research.

Section 5. Impact

25. There was a gap between having S and GRO-B because we didn't know whether to have another child due to the risk of them contracting Haemophilia. When GRO-B was born, they tested him straight away and he was normal.

26. We didn't really tell anyone about the infection. We never told my late wife's family as she passed when the children were young. My mum helped me bring up the children. My mother adored both of the children. She cared for S a lot and was like a mum to him.

27. S was hospitalised quite a lot and attended the hospital school. My whole life consisted of going to work and then after going to the hospital to see him. This was for years and then he had the flushing out procedure that went on for weeks. It used to make him really sick but thankfully it worked.

28. S ankle became fused and they were unable to operate due to the inhibitors. Once his inhibitor was flushed out, they operated on his

ankle. As a result, his legs were different lengths. As a result of this, I took him to a specialist shoe maker. They made him some trainers so that you couldn't tell that his legs were different lengths.

29. S had a good few years after they flushed out the inhibitor and he was on home treatment GRO-B recalls him starting snooker at about 13 or 14, and he became really good at it.

30. As the years progressed, the infection started to affect his eyesight. We went to the children's hospital and got him some glasses. He started missing simple shots and becoming increasingly unwell. He would always get ear infections and have a bad cough at times.

31. S would have terrible mood swings and lock himself in the room. He wouldn't want to talk about anything, telling me to go away. He felt really ill and would lock himself in his room alone. GRO-B used to try and go into the room to say hello or see how S was but S would scream he wanted to be alone.

32. The hospital gave S some treatment for these mood swings and low moods. It was some clear liquid, some sort of plasma. He would then be okay for a few weeks but have to go back to hospital for more. Other than this liquid, he was not given any further treatments for HIV at that time.

33. I remember wanting to have a big holiday for him when he was 17 or 18. He was incredibly ill during this holiday and spent most of the trip in his room, particularly in the second week where he had a mood swing and locked himself in his room.

34. GRO-B recalls him passing out and hitting his head on the sink. S was sick washing his face and he passed out. Thankfully, he was okay after the fall but we found out he was severely anaemic. I can't remember whether or not they gave him any transfusions for his anaemia.

35. S was about 5ft 7 or 5ft 8 and of a nice build, he weighed about 11 stone but he wasted away. I noticed a general decline of his body. He started looking gaunt and really skinny, you could tell he was very ill. He had a significant weight loss. He would also frequently be sick with blood.

36. I recall S and myself getting friendly with other patients at the hospital who were going through the same illness as S One of the patients died shortly before S I remember this hitting me hard because I knew what was coming.

37. Towards the end in mid-1996, he went into Queen Elizabeth Hospital. At first, they put him in a general ward, but he then went into a private room. He was left alone and I don't remember people coming in the room.

38. It seemed as though people were actively avoiding coming into the room. I asked the nurse for something and she wouldn't come into the room. They obviously weren't prepared to care for him so I stayed with him myself.

39. There were no basic treatments or tests done. I don't remember him having any sort of care or support from the hospital.

40. We took him home and we were all set up for him to die at home. I was never told he was going to die but I just knew. When we were at home, a nurse team started coming every day. It was all set up and the nurses would come and care for him. They looked after him quite well.

41. One day, all of a sudden, S asked to go to the hospice. He said he wanted them to try and make him better. I think he, like us all, thought he was immortal and would get better.

42. We went into the hospice at St Mary's and received the same sort of poor treatment. He was under a young lady doctor but you would never

see her. We were put in a private room and no one would come into the room. He wasn't able to look after himself and I would stay there.

43. I took GRO-B to see him when I knew the end was near. He was in the hospital for about 3 or 4 days before he died. The Investigators have taken a photograph of S Death Certificate, which I provided to them, it is produced as Exhibit **WITN5361002**

44. I didn't want him to have a stigma in his death so I asked the hospital to put pneumonia on his death certificate. They didn't agree at first and said they couldn't do this. I spoke to a social worker who came to help and convinced them to change it. I am not sure whether I was right or wrong for doing this but I didn't want the stigma to linger in death.

45. I blame myself sometimes for his death. What if I stuck to the cryoprecipitate or could have had the English Factor 8 rather than moving to Factor 8? Would S still be alive? It is a lot to digest.

46. Due to the stigma, we didn't tell my late wife's family that S was dying. When my wife's family asked me, I told them the truth and said it was HIV. I thought they must have guessed anyway. I think they were most upset that I didn't confide in them sooner. They said they would have liked to have seen him before he died but we never fell out over it. I think they must have understood.

47. GRO-B says he didn't know for many years after he died that his brother died of HIV. He thought he died from haemophilia but was too young to know any different. I told him later it was HIV/AIDS.

48. I always think if they didn't give S the infected Factor 8, he would probably still be alive.

49. Workwise, I was able to take paid leave from work to look after S in hospital as long as I had a doctor's note. My GP put it down as stress

so I didn't have to tell the employer about my son's illness. I am now retired.

50. S death had a significant impact on my mum. She died of non-hodgkin lymphoma. She was never the same after S died, it affected her terribly. She was a sensitive soul and I remember her coming home after work crying about the situation. She gave S that little bit of extra love because that's what she thought he needed. S was her entire life and she was like a mum to him.

Section 6. Treatment/Care/Support

51. I don't think S faced any difficulties in obtaining treatment. He went to the hospital dentist at Birmingham Children's Hospital. S was also on home treatment on a daily basis. They had all his records and would have known he was infected with HIV.

52. There was no counselling or psychological support ever made available to S GRO-B or myself. The children's hospital had a social worker available but this was the extent of our support.

Section 7. Financial Assistance

53. I found out about the Skipton fund as they contacted me directly. I never applied for anything and I never knew about Skipton or MacFarlane before. We received an initial payment of £20,000 from Skipton. As stated above, they wanted proof of S HCV so I asked for S medical records but informed them they were lost. So the second payment was never received.

54. We received money from the MacFarlane Trust. In order to receive this money, we had to sign some sort of Non-Disclosure Agreement, preventing us from suing the government. We were instructed by a group solicitor based in Coventry that the best thing we could do is sign

the document so we can receive the money. I just signed as advised by the solicitor this was the best he could do.

Section 8. Other Issues

55. I am open minded about the outcome of the enquiry.

Statement of Truth

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

Signed GRO-B

Dated 9 – 6 – 22.