Witness Name: GRO-B

Statement No: WITN1042001

Exhibit: None

Dated: May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS 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 GRO-B and I live at GRO-B GRO-B where I live with my wife, GRO-B. We have a daughter, GRO-B I have retired as a GRO-B due to GRO-B

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 and am aware that my wife has also provided a statement. This is in respect of our late son, GRO-B: S, born on GRO-B, who sadly passed away on GRO-B, aged GRO-B as a result of Human Immunodeficiency Virus (HIV) which he contracted through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my son's full medical records, as Salisbury District Hospital have said that they don't hold any notes.

Section 2. How affected

4. S was born with severe haemophilia A. We started to realise that he bruised very easily when he began to crawl. The authorities initially thought that we were knocking the baby about because he had lots of bruises. He was tested when he was very little and he was eventually diagnosed with haemophilia.

5. In 1979 he had his first Factor VIII concentrate at the Odstock Hospital, Salisbury, which was used instead of Cryoprecipitate, as the hospital had none left. S's UKHCDO records show that he was treated with Travenol, Hyland, Hemofil and Factor VIII during his first year alone. After we were told that he had been infected they kept him on American factor rather than transferring him over to heat treated BPL, as they told us that they would give heat treated to other to people who weren't infected. During his lifetime he also received Factorate, Kryoblin, Cutter Factor VIII (Koate), Profilate, Oxford Factor VIII and Factor VIII (BPL).

6. S was mostly treated at the Children's Unit clinic at Odstock Hospital, Salisbury. He was also seen 3 times at GRO-B Haemophilia Centre, once at the GRO-B and once at GRO-B when we were on holiday in GRO-B.

7. When he was 3, he kept on developing problems with stiff elbow, but the doctors did not treat it, because they said that it was not a bleed. We later found out at GRO-B that it was indeed a bleed, and due to the lack of treatment there was severe damage caused to it so he could not fully use his arm. He started to receive prophylactic Factor VIII. This meant that he received huge amounts of Factor VIII for the rest of his life and we believe this was when he was infected.

8. My wife took S to all his hospital appointments and she was not told about any risks about being given Factor VIII concentrate. I was not aware of any risks either.

9. S was diagnosed with HIV on GRO-B, at the age of GRO-B. At that time my wife and I completely dedicated our whole lives to supporting S. My wife took him to the hospital for his Factor VIII treatment and she was told about it by GRO-B.

10. The way in which my wife was told about his HIV was appalling, because the doctor just came out with saying it is positive then left her without any further explanation or what was to follow. She was not even asked if she needed help after such devastating news. She was left in total shock. I think what he did was callous. She then rang me with the devastating news.

11. At that point, we were not given any information about the infection or how to manage it. He was diagnosed at the beginning of the HIV scare and I don't think that the doctors had enough information at that stage to give us.

12. We were given no information regarding any risk of infection from taking Factor VIII. Had we had that information we would probably not have agreed to S having that treatment.

13. We were told sometime later about the precautions to take regarding HIV contamination, such as wearing gloves to handle blood spills. We were told by S's GP when I went to see him and S's condition came up in conversation.

14. S may also have been infected with Hepatitis C but it was never confirmed to us, however, GRO-B said he was bound to have it.

Section 3. Other Infections

15. I am not aware of S contracting any other infections, as a result of being treated with contaminated blood products.

Section 4. Consent

16. We were aware of and consented to S s HIV test.

Section 5. Impact

17. My wife attended all S 's appointments with him, so I feel that she has explained his treatment better in her statement.

18. S 's appearance and abilities changed completely over the past few years of his life. He was an active, healthy-looking boy, but in the end he ended up being wheelchair bound. In the last GRO-B weeks of his life his appearance changed completely; he was very thin, had a protruding stomach, could not walk, was incontinent, his hair got very thin and he had a yellow appearance. He also had repeated pneumonia, and he was also not able to eat much during his last year of life.

19. Towards the end of his life, S developed dementia-like symptoms. He constantly kept on forgetting things that he had just asked about. We had to watch as his memory got worse until near the end it was completely gone and he would repeatedly ask the same question over and over. He kept on repeatedly asking for a drink, to clean his teeth, and when we put him in a bath he kept saying that it was either too cold or too hot. We argued with GRO-B about telling S about his illness, as we believed either he would not have understood, or he would not have remembered and it wasn't going to make him better.

20. When his bouts of pneumonia started, he became worse. He spent his last GRO-B weeks in the hospital under the care of McMillian nurses, as well as Dr Parry and GRO-B. He then slipped into a coma. He was put onto a morphine driver to help with the pain. He died on GRO-B aged GRO-B.

21. He had several attempts at taking Azidothymidine (AZT), but that made him more ill. He took Septrin for about a year, until he had a bad reaction to it – he was covered in a rash.

22. S's HIV affected the way in which his treatments took place. Whenever S had to have any treatment or had to have any appointment with a doctor, everything had to be perfectly cleaned and sterilised. This was because since his immune system was so weak and they did not want him to catch anything.

23. When S first had pneumonia, he had to have a camera put down his throat at GRO-B to check what it was. It was a very unpleasant experience. The procedure was meant to take an hour, but it only lasted for a couple of minutes; the doctors did not have to look very far, as there was so much mucus in his lungs.

24. I also recall having a heated argument with one of the nurses at the hospital towards the end of S's life; my wife and I kept on swapping at the hospital to be with him. We were there all the time, until we were told by one of the nurses that we needed to get some rest. Eventually we agreed and both went back home after being assured that there would always be someone with him. But on returning home I felt something was just not right, and returned to the hospital. The ward was unlocked which was unusual. On entering the ward, I found S was alone in his room which we had been assured would not happen. I went mad and expressed my disappointment and anger to the nurse, who apologised. I said that we would get our own nursing staff in to look after S if they couldn't cope but she said that they would arrange to get extra staff in.

25. We never told S about his infection. He was only GRO-B when he died and we did not believe that he would be able to understand. However, my wife and I were affected by this knowledge.

26. We were physically and mentally drained right from the outset of his diagnosis. I had to try and continue to work to support the family, which put an intolerable amount of strain on GRO-B as she had to deal with everything while I was away working. It was very difficult to focus on work, as I was constantly worrying about how GRO-B and S were, and I wanted to be with them. It was unbearable, but I had to work. My work performance suffered, as a result of the whole situation.

27. We were not offered any support from any quarter; our parents I believe were just not able to cope with the situation and were probably afraid. The stigma associated with HIV meant that we were not able to tell our friends what was wrong; therefore we were not able to seek help from them.

28. I recall an instance when I went to see a GP at our surgery, I do not recall whether it was for me or for S, but S's infection came up in the conversation. The GP said that he wanted to inform everybody at the surgery about S's infection, in order to prevent cross-contamination. I refused and said that S was not the problem; instead the medical staff should take appropriate precautions with all their patients. I did not want everybody to know about his infection, as the majority of the staff would have no involvement with him, and I was afraid of the potential stigma.

29. Overall, our GPs were good, but they had very little involvement with S. As soon as we had S's diagnosis, the hospital took over his treatment. Dr Hugh Parry was our main point of contact.

30. After S died, Dr Parry told us to sue him and said that he would not contest it. However, we decided not sue him, as we believed that he did his best.

31. We looked after S 24 hours a day, 7 days a week patient, so our life stopped completely as everything had to be dedicated to him. There was no normal family life available to us, as a result of his deteriorating health caused directly by his illness.

32. We have never informed S s school about his illness; however, I believe that the Head Mistress, GRO-B, probably suspected what was happening, especially since there was a lot of press coverage on HIV and haemophilia. When he was too ill to go into school, a home tutor was arranged for S which worked quite well. When S had a slightly better day he wanted to go to school and GRO-B would take him in a wheelchair. His friends were always pleased to see him and everyone wanted to be with him. On one occasion I remember hearing that the children were taking bets on whether S or another girl in a wheelchair could go down the corridors faster.

33. However, S became more ill and I had to go to a meeting at school, and inform them that S only had a few weeks to live. The tuition was then stopped.

34. Financially we were fine as I continued to work up to the last 6 weeks of S's life. I had to work to provide for our family, as GRO-B was a full-time carer for S. I wanted to be with her and S, but I had to work, whist at the same time I felt guilty for being away from home. I also had a very responsible job, whereby I had 25 people under me. I had to focus on my work and shut it off, but it was very difficult.

35. My office was based in GRO-B and I had to drive all around the UK to see clients, so I had no choice but to think about it all the time. My work varied but I would sometimes leave on Sunday night and come back Friday night, and even if I was home during the week I would have to leave at 5am the following morning. I always avoided anybody who had an illness at work, and I remember one time I

went out with a 'rep' I had the windows down the whole time as I was petrified of catching his cold and giving it to S. Our life was dominated by his illness.

36. I won a holiday at work in around GRO-B and we wanted to go on a GRO-B but they would not take us due to S's haemophilia. In the end we went to GRO-B for a 2 week holiday in early GRO-B because the travel agents WH Smith helped us to secure £2 million travel insurance.

37. During the last 6 weeks of S's life, GRO-B and I devoted our time to being with him in the hospital. I believe that I managed to get around 3 weeks of a paid leave during that time. GRO-B would be with him during the day and I spent the nights with him. GRO-B would arrive in the morning and we would have breakfast together and I would return home, returning in the evening when we would have a meal at the hospital and GRO-B would return home.

38. After S died things were different. We were told that they had to handle his body differently and once he was taken from hospital he wouldn't be touched.

39. I found it very difficult to cope after S's death and still do to this day. I returned to work but found it very difficult, as my work would take me away and staying in hotels alone just left me time to think about nothing else. I wanted to be home with GRO-B who was also suffering from being on her own at such a time. I blamed myself and still do for the death of my son, it was my job as his father to protect him and I failed.

Section 6. Treatment/Care/Support

40. The only problem with accessing any of his treatment was that the hospital wanted us to get his AZT and drugs from the GP to help with their budget. That would have meant that all the people in the surgery would have known, as AZT was the treatment for HIV and with the stigma associated with HIV we did not want that to happen, so the hospital provided it.

41. We were offered 4 counselling sessions at the hospital after S passed away. I did not find them of great help; they were not proper counselling sessions like my wife had recently for about 2 years. After these 4 sessions, all the support and contact stopped.

Section 7. Financial Assistance

42. S was involved in the litigation in the 1990s. We accepted a £20,000 award on his behalf.

43. We also received money from the Macfarlane Trust for a washing machine and a dishwasher, while S was still alive. I recall that we were re-doing our entire kitchen and we were told that since S's immune system was so weak, we needed to keep everything very clean.

44. I believe that when he died the Macfarlane Trust also made a lump sum contribution towards his funeral. We have had no contact from anyone since his death.

45. I believe that the way in which we have found out about the financial help was by receiving a letter from the Macfarlane Trust. I am not sure how they knew about us. I was involved in fundraisers for the Haemophilia Society, so this might have been another way through which the Trust found out about us.

46. I do not remember much about the application process, but I do recall that it was only an application form, which was quite straightforward.

Section 8. Other Issues

47. I am completely devastated by the whole situation which I believe should never have happened, as people were aware of the risk, but did nothing to put a stop to it. There has been a cover up and I hope the Inquiry will uncover the truth.

48. I would also like to draw Chair's attention to the fact that there was no information provided about the risks of the blood products, not even from the haemophilia society, so people could not make informed decisions. There was no indication of anything being wrong for a very long time.

Anonymity, disclosure and redaction

49. I confirm that I wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

50. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed.... GRO-B ....

Dated........13/5/19........