Witness Name: GRO-B
Statement No: WITN2984001
Exhibit: WITN2984002- WITN2984006
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 and I live at GRO-B GRO-B with my husband, GRO-B. We have a daughter, GRO-B, who was born in GRO-B after our son GRO-B: S died. I spent GRO-B years as a carer for my son, S, who was diagnosed with haemophilia. I am now retired.

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 and I am aware that my husband will also provide a statement. This is in respect of our late son, S, born on the GRO-B, who sadly passed away on the GRO-B, aged GRO-B from Acquired Immune Deficiency Syndrome (AIDS) which developed from 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.

Section 2. How affected

4. S was born with severe haemophilia A, with less than 1% clotting factor. We were not aware of it when he was first born, as he was the first haemophiliac in the family for GRO-B years. We only started to realise that he bruised very easily when he began to crawl and bump into things. When he started to crawl I put special protection on his knees and elbows made out of foam and later we bought him a helmet.

5. S was treated at Salisbury Haemophilia Centre under the care of GRO-B GRO-B, Consultant Haematologist, until approximately GRO-B years of age. However, during this time GRO-B had no input into his treatment; everything was dealt with by GRO-B, Consultant Paediatrician. Dr Hugh Parry took over from GRO-B and this was when we had more involvement from the haematology department.

6. At the time we did not have a lot of information about haemophilia or what to do in general. We took it upon ourselves to take him to the children's unit at the Odstock Hospital in Salisbury where we went quite often. He was seen there by the consultant GRO-B if he went to the hospital during day time hours. Sometimes he needed a treatment and sometimes it was not required. He was often seen by registrars or junior doctors if we went there out of hours.

7. In GRO-B when he was around GRO-B he had his first Factor VIII concentrate. The junior doctor on call told us that S should have Cryoprecipitate but there was none available, so he was given Factor VIII instead. I was reassured that it was going to be fine. S's UKHCDO records show that he was treated with Travenol, Hyland, Hemofil Factor VIII during that year alone. He was

subsequently given Oxford Factor VIII, Factorate, Kryobulin, Factor VIII (BPL), Cutter Factor VIII (Koate) and Profilate. I exhibit the UKHCDO Patient annual treatment record showing the blood products that he received at exhibit WITN2984002.

8. At around the age of GRO-B, S kept on developing problems with a stiff elbow. We took him to the hospital whenever he had a problem, but the doctors kept on saying that it was not a bleed and that it did not need to be treated. Looking back at this now, I realise that a lot of the time when we went to the hospital to have S's elbow treated there were often junior doctors around. It was their decision as to whether to give S Factor VIII or not, however, they did not have enough knowledge.

9. His elbow became worse and the hospital provided a splint for when he could not move it although Factor VIII was given when it was very stiff. The doctors did not realise for a long time that elbows do not behave the same way as knees. The hospital later realised that the problem with S's elbow was due to bleeds.

10. S was eventually referred to the haemophilia centre at GRO-B for his elbow and went there about 3 times. Around this time he also had an appointment for his elbow at GRO-B. Following these appointments S received massive amounts of Factor VIII, which was about 3 times the amount of Factor VIII that an adult would have had and he was put on prophylactic Factor VIII for the rest of his life.

11. From about the age of GRO-B years old I injected him with Factor VIII at home on a prophylactic basis every couple of days. I had to first practice on an orange and then on myself before I treated S. This was to keep his elbow stable and also because we were planning a trip to GRO-B around GRO-B and I wanted to be able to give S his treatment so that we would not need to attend a hospital in GRO-B.

12. S was also treated at GRO-B Haemophilia Centre once when we were on holiday in GRO-B before he started to get ill.

13. We were never fully informed about anything to do with Factor VIII. Neither I nor my husband, were ever told about the risks of infection associated with the treatment with blood products. If we had known about the risks, we would certainly have not allowed S to be given so much Factor VIII to treat his elbow, as we would have weighed up the benefits and possible negative effects.

14. As a result of being treated with infected blood products, S was infected with HIV. He was tested for Hep C at Salisbury once and I was told it was negative, however, I remember when we had the appointment at GRO-B a doctor there said there was no way he would not have had it.

15. The first we knew of HIV was from an article in the Mail on Sunday, regarding two men who had the infection. I got worried so I took S to the hospital and asked GRO-B to have him tested. There was no test available at that time but as soon as one became available, GRO-B had him tested. I was not called in to get the results. The results were given to me during a routine treatment appointment. I was therefore aware of the tests for HIV taking place.

16. S was diagnosed with HIV on the GRO-B, at the age of about GRO-B years old as seen in the UKHCDO Patient HIV data which I exhibit at WITN2984003.

17. I can clearly remember when the HIV results were given to me. S and I were in the treatment room with a doctor and nurse, who were giving him his usual Factor VIII concentrate. GRO-B came in and said to me "*I've got the test results back and it's positive*". Then he walked out of the room. That was it; nothing else was said. We were given no more information at that point.

18. I was in total shock and I was distressed but I could not say anything in front of S and had to hide it all from him. S was unaware of what was going on. In

fact, we never told him what was wrong. I remember when I was driving home I tried not to cry and I tried to talk to S normally. Then I had to ring GRO-B and tell him. I can't even describe it; it was awful. GRO-B had given me no information and I didn't know what they were going to do.

19. A couple of weeks later I was called in by GRO-B for another appointment. This was when I was told about the precautions to take, such as to wear gloves, how to handle blood spills and how the infection can be spread. Prior to that all I knew was from the information that was given in newspapers. At the time S was tested, we really only knew what had been reported in the press. There were no computers or easy access to information on the internet, so newspapers were all that I could rely on.

20. I do believe that we should have been told about the risks of contamination when S started having huge amounts of Factor VIII, so that we could have weighed up the benefits and possible negative effects.

21. I do not believe that the way in which I was informed about S's infection was appropriate. What the doctor should have done was to take me to one side, in a private room and prepare me for the information. I needed more privacy to be told about it and I certainly needed it to be broken to me more gently. At the same time, GRO-B might have said it in the way he did and left so abruptly because he was also upset. Regardless of this, I do not think that it excuses his behaviour.

Section 3. Other Infections

22. I am not aware if S contracted any other infections, as a result of being treated with contaminated blood products, however, GRO-B said he was certain to have Hep C although he tested negative at Salisbury.

Section 4. Consent

23. We were never asked for our consent to give S Factor VIII as a treatment in the first place.

24. I gave my consent to S s HIV test, as I had voluntarily gone to the hospital and asked for it.

25. We were also never asked for our consent when it came to Azidothymidine (AZT) treatment for HIV. We were informed by the doctors that they were going to put him on it, without being given the space to refuse it. We were simply told AZT was the treatment they had to give him.

26. I do not know whether he was ever used for the purposes of research but his details were passed to the UKHCDO for their survey of patients with AIDS or AIDS-related illnesses, copy of which correspondence I exhibit at WITN2984004.

Section 5. Impact

27. S was a fairly active boy; he looked well and had a head of thick curly hair. He was well until he was about GRO-B years old until he suffered from his first pneumonia in around GRO-B. From that point on, he kept on becoming worse. By the time he got to his last GRO-B weeks of his life his physical appearance had changed dramatically. He was very thin, had a protruding stomach, his skin turned yellow he could not walk, so he was wheelchair-bound, was doubly incontinent and his hair was very thin. Three comparison photographs have been exhibited with this statement as WITN2984005.

28. S 's main problems were due to the repeated pneumonia infections. Once he started getting it, it took longer and longer to get over it. He was not able to eat much and he had great difficulty breathing. He couldn't walk and became wheelchair bound.

29. S 's illnesses affected him greatly on the physical level. It is difficult to say how it affected him on the mental level, as we never told him about HIV / AIDS. He knew that he was unwell, but he never asked what was wrong with him.

30. He spent the last GRO-B weeks of his life in the hospital, under the care of Macmillan nurses, as well as Dr Parry and GRO-B , GRO-B and other medical staff insisted they should tell S that he was dying and what he was dying from, but GRO-B and I did not believe that it was necessary and he was too young to comprehend it or mentally cope with it. We felt that it would have not have benefitted him to know. On one occasion I remember a nurse asked us what they should do if we were not there and S asked them if he was dying, to which GRO-B and I replied that they should lie to him and tell us. S just carried on in total oblivion, which we felt was the best course of action.

31. When Dr Parry started working at Salisbury Hospital he was devastated to learn of S 's condition. Towards the end of S 's life, he gave us his home telephone number so that we could ring him at any time. He went to visit S every day he was an inpatient and the nurses told us that once he would leave the ward he would cry his eyes out, because he was so upset. Dr Parry did a lot for us and he came to S 's funeral. When Dr Parry retired some years later, he informed GRO-B (his replacement) about S 's medical history and how devastated he was as he did not want it happening to anyone else.

32. By far the worst effect that HIV had on S is the fact that it developed into AIDS which eventually resulted in his death, as stated on his death certificate, which I exhibit at WITN2984006.

33. It was some time before he was offered any treatment for HIV as there was none available. We believe he was offered AZT as soon as it became available. He was put on the AZT treatment twice. I first heard about the treatment in the press and I asked Dr Parry about it. He said that he would get hold of some to try it out on S . His first course of AZT started in December 1990. It made him very ill.

He experienced horrible side-effects, such as a complete loss of appetite, lethargy and it was apparent that he was generally getting worse. Eventually, it was GRO-B and I who stopped it.

34. The HIV also caused him several recurring pneumonia infections, as well as haemophilus influenza. He had his first pneumonia when he was around GRO-B years old. He was given Septrin, which is an antibiotic, to treat the pneumonia. He had this intravenously at first and then took this for about a year in tablet form until he had a bad reaction to it, when he was covered in an awful allergic rash.

35. The last time he was in the hospital the doctors insisted they put him back on AZT, which they did in the end, regardless of the fact that I was not happy with it and that it was going to make him feel worse. Eventually it did make him feel worse, so we had to stop it again.

36. Having thought about it, I think it is possible they gave him DDI but I can't be certain. Towards the end of his life, S was given an inhaler made by DeVilbiss. I do not know what exactly it was, but the doctors advised that it was good for his chest as he had a very bad cough. We were not provided any more information about it. I recall that I had to wear a mask whenever he used it and there was an exhaust pipe coming from it to the outside of the window, as it was toxic. He only used this inhaler at home. Eventually, it started to make him worse. Once again, I refused to give it to him, seeing the effect it had on him.

37. S originally went to a local dentist and had good teeth. As a direct result of his HIV infections he was no longer able to attend the local dentist and had to go to the hospital for his dental appointments.

Impact on S's private, family and social life

38. S was a very sociable child; he loved to socialise with other children. He was also very smart and he liked to learn. He went on a school adventure holiday to

GRO-B once. GRO-B and I rented a flat nearby to be close in case S needed treatment. I recall seeing him with his group of friends who were arguing over who was going to carry his rucksack.

39. He was liked by other children and all his friends were very devoted to him. He had a very sunny disposition. However, all this was cut short by his infection. He was not able to go out and he did not have any social life in the end. He had a couple of friends who visited him at home and there was one girl in particular, called GRO-B, who used to sit with him for hours.

40. I recall the period of time when AIDS became more prominent in the media. On one occasion one of his friends asked S if he had it. I then spoke to his teacher who was aware of S's haemophilia treatments. The teacher suggested that I come in to the school one day with S and show the children how I treated him with Factor VIII. We did it and it proved to be a success, as all the children were shocked that he managed to sit there so calmly. We never heard anything about it again after that.

Impact on our private, family and social life

41. I was physically and mentally drained, from the moment that I was given his diagnosis. I had to try and hold everything together, because GRO-B worked away a lot and it was down to me to deal with everything with virtually no support from anyone. I had no help from my parents, as I think they were afraid. I do believe that if it was not for my extremely hard work with S's treatment and keeping our family together, we would have fallen apart. I also kept on getting ill, as I was so worn out.

42. Our family life was affected greatly, firstly by S's haemophilia and later by his infections. In GRO-B my husband had an opportunity from work to take our family on a cruise, as a reward for his hard work as he was the top salesman of the

year. We thought that it would be a great experience and safe for S as there were medical facilities on board. However, we missed out on that opportunity, as GRO-B informed GRO-B that S was HIV positive and they refused to allow us to go. We wrote to the MD of GRO-B to complain, saying S would not be a danger to anyone, but he upheld the decision. We were angry and upset that we were precluded from the experience as a result of S s HIV and that we were so badly discriminated against. We therefore went to GRO-B instead in around GRO-B.

43. When S passed away I became a recluse. GRO-B s employers were very sympathetic when S was very ill at the end and after he died and gave him time off work. But after several weeks GRO-B had to go back to work. He threw himself into his work and I became even more isolated. Then, when I found out I was pregnant with GRO-B I could not leave the house for about GRO-B as I was so physically sick.

44. We had a few counselling sessions after S passed away; however, they stopped. I thought I would learn to accept it all over time, but my mother became very ill with dementia about GRO-B years ago and a lot of the things that I had to do and see over the course of her illness, took me back to S. Since that time, I have had GRO-B years of weekly counselling. I was originally not willing to proceed with it, but GRO-B encouraged me to go. The counselling has helped me greatly, and I am sure that without it I would not be able to write this statement.

45. The counselling made me realise the amount of baggage that I was carrying after all those years of caring for S. I was there with him 24 hours a day and there was an immense amount of pressure on me.

Stigma

46. I only had one friend who knew about S and I used to talk to her about our problems. Due to the hysteria in the press coverage and AIDS campaign: "*Don't*

die of ignorance" we never told many people what was wrong with S, as we were afraid of the consequences, even after Princess Diana shook hands un-gloved with an AIDS victim.

47. The only people who we have informed about his illness were mine and GRO-B's parents, GRO-B, a close friend of mine and S's school doctor. The school itself did not know, but they knew that he was ill and they probably had a good idea what his illness was. However, we never informed them formally.

48. We told lies and made up illnesses, to cover up his true condition. It was a terrible, unbelievably awful time.

49. During his last GRO-B weeks stay in hospital, there was one nurse who did not want to have to deal with him, but was made to by the sister on the ward. This was an example of stigma that S had to go through.

50. I have only told about GRO-B friends about S since he passed away, one of them only recently. When I told her she was devastated and in tears. Attitudes have changed for a lot of people, but I am still worried that many people still have the same ideas as before.

Impact on other family members

51. S's illness and his death have also a massive effect on GRO-B's life although she has never known S. She has grown up as an only child and she will never have the support of her brother. She has had to have counselling because she suffers from health anxiety and I believe this is due to issues with S. I think she feels like she is on her own and worries about being on her own when she is older. I think it affects her quite a lot.

Educational impact

52. S 's Head Mistress probably suspected what was wrong with him and she arranged a home tutor for S , when he was too poorly to attend school. It worked quite well, but he became more ill and his mental abilities declined rapidly, so the tuition was stopped. He had been a very intelligent boy but towards the end he couldn't even do basic maths.

Financial Impact

53. Financially we were fine as GRO-B continued to work. He was a GRO-B and was often away from home. GRO-B kept on working so we did not have any financial worries. I could not have coped with that as well.

Section 6. Treatment/Care/Support

54. I do not believe that there were any problems with accessing any of S 's treatments. I do not know of any other medication that he could have been given.

55. We were not give a disabled badge for S until the last 2 weeks of his life, by which time he was in the hospital, so it was pointless by then.

56. While S was still alive we were not offered any counselling at all. After his death we had 4 counselling sessions by a social worker attached to the children's unit at the hospital. Then all support and contact stopped.

Section 7. Financial Assistance

57. S was involved in the litigation in the 1990s, when there was an out-of-court settlement. We were approached by the Haemophilia Society who told us that they couldn't get legal aid for adults, so they wanted to do it through the infected

children as they could get legal aid. That is why they wanted to use S. We accepted a £20,000 award on his behalf.

58. We received money from the Macfarlane Trust for a washing machine and a dishwasher, while S was still alive. We have had no contact from anyone since his death and I have not heard of the Skipton Fund before making this statement.

Section 8. Other Issues

59. Originally, I did not feel strong enough to do a statement for the Inquiry, as I did not feel emotionally strong enough to do it. The 2 years of counselling have helped me to deal with revisiting a lot of painful memories. However, this experience has left me emotionally drained and depressed.

60. I feel that as parents, we have been ignored and left to get on with things after losing a child not due to a fault of ours. As a parent, having to watch your child live and die through this terrible illness is so awful, there are no words to express what it was like watching him battling through and concealing it from people – it is and will always be the most traumatic, devastating, unbelievably life-changing experience and it virtually destroyed me. We want recognition that we have lost a young child.

Anonymity, disclosure and redaction

61. 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.

62. 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....10/05/2019..................................