Witness Name: GRO-B
Statement No.: WITN0950001
Exhibits: **WITN0950002 - 014**
Dated: 13th August 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 16 May 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B and my address is known to the Inquiry. I am retired and I intend to speak about my son Richard, who sadly died due to a chronic brain infection contracted from infected blood products. I will speak, in particular, about the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together.

2. I have lived in Sussex for around 30 years and worked for a large company for 25 years in a variey of different roles within the call centre. I am now retired. I enjoy travelling and have travelled extensively in North

American and Canada. I have also worked for The Royal Overseas League in London. I am a mother and granny to four children.

3. I am not legally represented, the investigator has explained the anonymity process to me and I have chosen to be anonymous, in so far as I would like my name redacted from the statement. I would like my story to be shared but am conscious of having my name published on the Inquiry website. I would also like to put my story forward so that others who have had a similar experience to my son know that they are not alone.

4. The investigator has explained the 'Right to Reply' procedure to me. I understand that any doctors criticised in my statement will have the right to reply to any criticism.

5. The events documented in this statement happened over 30 years ago. Understandably, my memory has faded over time. I have tried my best to recall my experience to the best of my ability, by anchoring memories to significant events in my life. Therefore, all dates in this statement should be treated as an approximation and not as a definitive.

Section 2. How Affected

6. My son Richard was born prematurely on GRO-B at Mount Alvernia Hospital, a private maternity hospital in Guildford. He was born at 33 weeks, weighing 4 pounds. Shortly after birth, he was transferred to the St Luke's Hospital, Guilford which is now closed.

7. We were discharged from the hospital with no issues and life continued as normal for the first year. When Richard was around 12-18 months old, I began to notice that he would regularly contract ear infections and have

'sticky eyes'. This was the first indicator that he may not be as well as he seemed. Richard was treated for these infections at St Luke's Hospital, Guilford by Dr David Wright. Grommets were inserted in his ears at around the age of 12-18 months.

8. Richard suffered from frequent ear infections which over time weakened his immune system. As a consequence of this he suffered a bout of pneumonia. This was the only time in Richard's life that I considered him to be critically ill. Whilst Richard was being treated for pneumonia at St Luke's Hospital Guildford, I had a consultation with Dr Neil Walker who was a doctor on the paediatric ward. Dr. Walker suggested that we should look at Richard's over all condition.

9. He gave me two choices for Richard's treatment; he could be treated at the Westminster Children's Hospital, London or the Northwick Park Hospital, Middlesex. I asked him what he suggested; and consequently the decision was made for Richard to be examined at Northwick Park Hospital, Middlesex. This option was chosen, as in Dr Walker's opinion, this was a more proactive hospital.

10. After an initial consultation, it was decided that Richard was to be treated under Dr A.D.W Webster, Consultant Physician, and Specialist of Clinical Immunology at Northwick Park Hospital. This took place around 1974 when Richard was around 22 months old. Dr Webster was in charge of the Clinical Research Centre at Northwick Park Hospital. Under the care of Dr Webster, Richard had numerous blood tests; as a result, he was diagnosed with Hypogammaglobulinemia, an immune system disorder. The condition is characterised by sufferers having an impaired immune system, meaning that their bodies are unable to fight off infections.

11. It was agreed that as treatment for this Richard would have injections of Gamma globulin, a mix of blood plasma proteins. People often commented that Richard may grow out of the condition and with hindsight

I think that he may have done. I believe that the treatment for the condition is what, at least in part, caused his death.

12. Dr Webster suggested weekly injections, of gamma globulin. He organised a district nurse to come to our house and administer these injections. Physically and mentally at this point, Richard was fine. Richard stayed under the care of Dr David Webster for the entirety of his 19 years. Richard would only be treated by local hospitals in an emergency and his GP would treat minor ailments. Hypogammaglobulinemia is a rare condition and as such most GP's had not come across the condition; therefore treatment needed to be administered to Richard by specialists.

13. Richard started these injections at the age of 22 months old and they continued until Dr Webster suggested a clinical trial of fresh frozen plasma in 1978. Richard would have check ups with Dr David Webster at Northwick Park Hospital, they would check his blood and we would stay overnight, the results of these checks were that Richard was fine.

14. On 9 November 1978, Richard has his first consultation with Dr Webster about a fresh frozen plasma ('FFP') clinical trial that he was running. He wanted to put Richard on this trial. He believed that this would give Richard more freedom, as it would be every three weeks as opposed to weekly. He said treatment with FFP would provide a better result for Richard and hopefully eliminate problems such as recurring ear infections.

15. Dr David Webster did not tell me any more about the trial; he did not explain any of the potential risks. I trusted Dr Webster to act in the best interests of my son, so I allowed Richard to be treated with FFP. However, I cannot remember expressly consenting to Richard's participation in the trial or signing any documentation to this effect.

16. In September of 1978 Dr Webster wrote to Dr Robins at St Luke's Hospital asking if Richard's FFP treatment could be carried out at St

Luke's Hospital, nearer to our home. Towards the end of 1978, after two or three infusions of FFP at Northwick Park Hospital, Dr Webster gave permission for the treatment to be carried at St Luke's Hospital, Guildford.

17. I can vividly remember the FFP treatment. I recall the FFP itself looking like a thick, sticky, urine coloured liquid. It was administered in a blood bag, which was hooked onto a drip stand. The bag was cold to the touch. I remember on one occasion the bag of plasma was thick and creamy. When I asked about the unusual colour, the nurse said that the donation came from someone who ate a lot of chips. I asked for it to be changed but the nurse told me she could not change the bag. I thought this because it was probably too expensive!

18. Although treatment was now administered closer to our home, I would still have to travel to Northwick Park for Richard to be monitored by Dr Webster. Dr Webster monitored Richard through a series of blood tests. He told me that Richard was doing fine and that all was ok. In hindsight I should have asked more questions. I did not do so as I trusted Dr Webster. I had no idea how long the clinical trial would last for, however, it was an unspoken assumption that Richard would be on this treatment indefinitely.

19. During this time, I was frequently visiting Northwick Park Hospital. Richard's appointments would entail hours of waiting around for me. On one occaion, I asked Dr Webster if I could look around the Clinical Research Centre that was located in the grounds of Northwick Park Hospital. He agreed, on the condition that I did not tell anyone what I had seen. Once inside I saw goats and monkeys that were being tested on. One goat had a tag on his neck dislaying the words 'Dr Asherson' who was Dr Websters superior. They were injecting drugs into all kinds of animals including dogs and cats, however I was not allowed to see these animals.

20. Throughout the treatment Richard would suffer episodes of blood rashes in his legs. These were on his lower leg, they were a large rash around the size of a grapefruit. The rash would appear and disappear suddenly. I took Richard to see Dr Webster concerning these rashes, but I was told not to be concerned. Richard also suffered from frequent nosebleeds and diarrhoea.

21. Significant issues started arising for Richard from around 1981 onwards. The first issue I noticed was that his speech was becoming slurred and he occasionally had balance problems. He was a very bright child but this was slowly changing. He became increasingly frustrated with his own abilities.

22. His education began to suffer as it was becoming impacted by these difficulties. At school little things started happening, his capabilities started reducing and as a consequence he started getting bullied. He had behavioural issues; he wasn't as quick off the mark any more as his memory was failing. His cognitive abilities deteriorated significantly between the ages of 9-13. Throughout this time the plasma therapy continued. On 16 November 1982 when Richard was aged 10 years and 7 months, his school organised an intelligence test using the 'Wechsler Intelligence Scale for Children'. The results of which showed that he was a few years behind where he should be academically.

23. A letter **WITN0950002** dated 30 April 1984 to Professor Roger Robinson at Guys hospital from an unknown individual stated that a second 'Wechsler Intelligence Scale for Children' test was later carried out, the letter commented on the evidence of deterioration between the two results. *'On the verbal scale he had fallen from 79 in December 1983 to 67. On the performance scale he had dropped from 57 to 45, it really does look as though progressive deteriorate were indeed taking place. All the figures on the 'Wechsler Intelligence Scale for Children' have fallen progressively since 1982.'*

24. At this time I was visiting Northwick Park Hospital around every 6 Months for check ups. Dr Webster performed several lumbar punctures over the following years to collect samples of his spinal cord fluid. I have a letter **WITN0950003** dated 2 March 1983 from Dr Webster to myself saying that he would like to get a lumbar puncture done on Richard on Monday 28 March 1983. These procedures were carried out in an effort to establish what was causing Richard's mental deterioration, these became a regular part of Richard's treatment he had around 5/6 of the procedures.

25. From 1978 to 1983 Richard attended the Fernden School, an independent fee paying boarding school. However towards the end of the 1983 Richard had to move to Chelmsford Hall Preparatory School, Eastbourne, as they could best cope with Richard's educational needs. However, his attendance at the Chelmsford School came to an abrupt end when I approached the headmaster at the school carol concert to wish him a Merry Christmas. He refused to look at me and with his gaze fixed on his feet he instructed me to return Richard's uniform to the second hand shop.

26. This was his way of telling me that Richard was no longer welcome at his school. In around 1984 when this incident occurred there were rumours about HIV infecting, blood products. The Headmaster knew that Richard was receiving treatment with such products so, it is my opinion that part of the reason we were asked to leave was because of the risk of Richard being infected. I believe Richard was removed from the school because of the uninformed opinion of people at the time. The school was worried about the stigma attached to HIV and the safety of staff and other pupils with regards to HIV spreading.

27. After this on 26 February 1985, Richard was moved to St Mary's School, Bexhill, which is a residential boarding school for children with special educational needs. At this point Richard was continuing to deteriorate further. St Marys fitted Richard with a safety helmet to prevent injury if he fell over due to his balance and coordination issues. However he was still

walking and talking but just a little unsteady on his feet. He could not control his hand movements and he started shaking. This lead to him eventually becoming wheelchair bound. He went from drinking out of a glass to drinking out of a beaker.

28. A consultation on 4 April 1985 lead to Dr Webster referring Richard to Dr Robinson at Guy's Hospital Paediatric Neurology Department. There, Richard underwent scans of his brain in summer 1985. At the first appointment we were transferred to the Royal Marsden Hospital, London as the Scanning equipment at Guy's Hospital was broken. The results of this scan were never communicated to me.

29. In 1986 after we had moved to GRO-B as a family, Richard had to leave St Mary's school. The School informed me that they were very sorry to see him go but they could no longer cope with Richard's advancing needs. With brain deterioration people go from being awkward to having special needs to being physically handicapped. As a result of this Richard had to move schools again, this time to a specialist day school, Downs View School Brighton. This school was very well equipped to deal with Richard's needs they had lots of children with these needs and could cope with this. Throughout this time Richard continued to live at home with me.

30. In 1986 Dr Webster was still unsure what was happening in terms of Richard's deterioration. He suggested a brain biopsy, but at this point it did not happen. Instead, Dr Webster performed lumbar punctures, from which sufficient results of Richard's brain function could be obtained. I have a letter **WITN0950004** dated 7 October 1986, from Professor Roger Robinson of Guys Hospital to myself stating that Dr Webster had spoken to his neurosurgeon colleague Mr Strong. He states that Mr Strong was not keen to do a brain biopsy unless '*there are clear reasons for thinking that this would be helpful to Richard*'.

31. After my conversations with Dr Webster, I felt that there was never a positive outcome, he promised results but they never came to fruition. They were still doing the blood tests but I was never informed of the results.

32. In terms of treatment at this point, in around 1986 there was a change driven by Dr Webster away from FFP towards a new manufactured Swiss product named Sandoglobulin. He informed me that he was no longer prescribing FFP as there was a new manufactured product available. I was completely in the dark about the reasons for this sudden change.

33. With hindsight I believe that this switch was because FFP was a dangerous product, which had risks attached. With FFP, I believe that there were never any checks on where the product was made. I think the FFP was disease ridden, it was dangerous and contaminated. I believe that the use of this diseased product on my son, resulted in his mental deterioration.

34. One morning in late 1987, I was preparing Richard for school when he fell down the stairs and landed on top of me. At this point Richard was around 16; after this accident, I thought one of us would get killed if I continued to care for Richard at home. I had no support and was caring for Richard alone; I decided to make the difficult decision to find him a residential placement. He moved to Ceres House, Brighton, a children's home, which cares for disabled children. He lived at Ceres House and continued to attend day school. He was never sickly but he was in a poor state of health in terms of his motor neuron skills. Despite these issues he was always very smiley and retained his sense of humour.

35. Dr Webster continued to perform tests on Richard, there was a muscle biopsy and other various tests carried out until around October 1988. Dr Webster then suggested in one of our routine visits, that a brain biopsy should be conducted to find out the reasons for Richard's deterioration. Dr Webster informed me that he could put a shunt into Richard's brain, which

could reverse the damage. He then wrote to me on 12 October 1988 WITN0950005 confirming this. Staff at Ceres House were worried about Richard having the procedure mainly because of the aftercare that it would entail.

36. In this letter **WITN0950005** Dr Webster suggested the brain biopsy to test for the presence of the 'JC' Virus. Towards the end of the letter the procedure is explained and is detailed in the following extract.

> *'Unfortunately, the only way on diagnosing this infection is to do a brain biopsy, which of course we considered doing many years ago when he was being seen at Guys hospital. Although we would not have known what to look for then. The procedure is very safe nowadays, with only an incredibly small risk of side effects.*
>
> *He would have to be admitted for two of three days to the neurological centre in London, and after various x ray scans a small hole would be made in the skull and a tiny piece of brain tissue removed. This is a routine procedure nowadays in anybody with unexplained brain disease, and the piece of brain removed has no detrimental effect, since it is taken from a 'silent' area of the brain'.*

37. The procedure was carried out at the National Hospital, Maida Vale, London in November 1988. This involved drilling a hole through Richard's skull on the side of his head. Following this, a letter arrived **WITN0950006** from Dr Webster on 20 December 1988, stating that results were not yet available but initial results are surprising. The disease was far advanced and had caused severe damage to the brain.

> *'We thought that this may have been caused by a recently recognised virus which causes a similar clinical problem in other immunodeficiency diseases, however the initial findings are not*

consistent with such an infection and look like the sort of changes we have seen before with echovirus.'

38. Richard continued to deteriorate mentally, Ceres House called me to a meeting in early 1991 to talk about Richard's future care. Before I attended this meeting I received a letter **WITN0950007** dated 27 February 1991 from Dr Webster informing me of Dr Gillian McCarthy's opinion on the continuation of Richard's treatment. Dr McCarthy was a doctor associated with Ceres House and the Royal Alexandra Children's Hospital. I was completely shocked and devastated to read that the letter suggested removal of all treatment.

39. I went to the meeting at Ceres House on 7 March 1991 and I was incredibly angry. I knew what the meeting was about as I had received the letter, however, the staff at the home did not know I had been informed. I completely lost my temper at what they were suggesting. I think that with hindsight, Dr MacCarthy suggested action of terminating treatment was somewhat driven by cost.

40. Things continued as normal for the following weeks. On 21 May 1991, my ex husband, Richard's father, was going on a business trip, he rang me at work asking if he could take Richard out for a meal. I confirmed this was allowed. For Richard's 18th Birthday I had taken Richard to a restaurant in Hove, Topolinos. I told my ex husband to take Richard to Topolinos as they were familiar with Richard's needs.

41. Unusually, I met Richard and his father at the restaurant; I did not usually attend Richard's outings with his father. Richard enjoyed a meal comprising of a prawn cocktail, cannelloni and ice cream, we all sat outside at the restaurant. His father took Richard back to the Ceres House; I said good-bye and told Richard that I would see him tomorrow.

42. At 6 am morning of the 22 May 1991, I had a phone call which I ignored. The phone rang again and it was Roy Holman owner of the Children's home he said *"Roy here, Richard's dead".*

43. There was then an autopsy as it was a legal requirement. I called Dr Webster the same morning and informed him that Richard had died and that he could take any samples that he wanted from Richard's body. This permission was given verbally and at a time of great emotional distress, previously I had decided against any intervention with Richards body as I felt he had suffered enough. He took Richard's Brain and Spinal Cord to investigate what had caused his brain deterioration. Other specimens of Richard's organs were also stored by the hospital in case a histopathology (a study of changes in tissue caused by disease) was needed.

44. The cause of Richard's death was stated on his death certificate **WITN0950008** as 'Chronic menigo-encephalitis and Congential agammoglobulin anemia'.

45. On 4 June 1991 I received a letter **WITN0950009** from Dr Webster to myself, expressing sympathies for Richard's death. The letter contains troubling themes such as Dr Webster describing Richard as 'physically good looking'. It also thanked me for allowing Webster to 'influence the autopsy'

'Dear Mrs GRO-B

Just a note to offer my sympathies over the death of Richard. It's been a very long haul for you, and particularly distressing because Richard was such a physically good-looking boy. I am very grateful to you for allowing us to influence the post mortem, and I can tell you that the arrangements went well and they were very cooperative at the Royal Sussex Brighton.

It will take some time before the specimens obtained will tell us anything new about Richard's disease, but early information strongly suggests he was suffering from a similar chronic viral infection, which has been seen in other children and young adults with hypogammaglobulinaemia. If we can prove this then it will help us considerably in our understanding of this problem. I will write to you again when I have some more news, but this probably won't be for 3-6 months.

Best wishes for the future,

Dr Webster'

46. I have a letter **WITN0950010** dated 7 October 1991 from Dr Webster to myself stating that *'autopsy specimens are still being investigated and so far we have no definitive information that he suffered from a chronic virus infection. However there is still a lot of work to be done and I will not forget to let you know when we come to a final conclusion'.*

47. I never got any answers from Dr Webster or any other medical professionals. I recall one day seeing Richard's former GP in the local churchyard. I asked him about the risk CJD may have posed to Richard. However instead of talking to me in his normal caring way he walked away very quickly. I can only assume that he did not want to discuss this possibility with me.

48. After Richard's death I continued to receive newsletters from the Primary Immunodeficiency Association (formerly the Hyopgammaglobulinaemia Society). This was charity set up by Dr Webster which operated as a support group for patients suffering from these conditions. I received two letters one in 1997 and one in 1998 both discussing the hypothetical risk to members posed by Creutzfeldt Jacob Disease ('CJD').

49. The letter **WITN0950011** dated 17 November 1997 states that

> *'The key point for PiA members is that, while there is a theoretical risk, there is no evidence at the moment that CJD can be transmitted by an infusion of immunoglobulin'.*

50. The second letter **WITN09500012,** a news letter, dated 4 March 1998 states that the

> *'Department of Health, with the expert advice available to it has signalled a review of the use of UK sourced plasma and decided to permit UK manufactures of Immunoglobulins to import plasma and decide to permit UK manufacturers of Immunoglobulins to import plasma from elsewhere for the production of blood products. The secretary of state Frank Dobson, said 'if there is even a hypothetical risk and there are available safe alternatives sources of products, then it makes sense to use them.*

51. After the above communication with Dr Webster I never received any further information regarding Dr Webster's conclusions about Richard's death. On 29 August 1999 **WITN0950013** some 8 years after Richard's death, motivated in part by the news letters I received from PiA. I wrote to Dr Webster. I covered a number of issues but in particular I asked the question:

> *'Did Richard have CJD or a form of NV CJD?' 'With the immense amount of research, which has been done into illnesses, since Richard's death would it be possible for you to re-examine his medical histories?'*

52. I received a reply dated 7 September 1999 **WITN0950014** from Dr Webster who, at that point, was a Consultant a The Royal Free Hospital. In particular I would like to draw you attention to two paragraphs.

> *'Richard had classical features of Enteroviral Encephalitis. These viruses are common and frequently cause minor illnesses in 'healthy' people. It is now well known that patients with agammaglobulinaemia are particularly prone to infection with these viruses in the brain. He would have caught the virus in from his activities in everyday life and the virus would not have been contaminating any of the plasma or gamma globulin that he was given as treatment. He certainly did not have CJD, so you can put your mind at rest about this.*
>
> *I hope you find this info reassuring. Richard was unlucky. All I can say is that his suffering, and that of a few other who died of this infection in my clinic, did lead us to find a cure so something positive has come from this long and distressing illness.'*

53. Richard was never formally identified as having an infectious disease contracted through infected blood products and as such we were never told about any infection. Whenever I raised any issues with Richard's consultant, Dr Webster he would just tell me everything was fine and not to worry. As such no information was made available to me to help to manage Richard's condition. I believe that information should have been available to me from the very beginning of the process.

54. I was never given information about the clinical trials Dr Webster proposed. I was never informed of the possible side effects. I believed that Dr Webster was acting in the best interests of my son. Nothing was ever communicated to me; I was very much in the dark about my son's treatment.

Section 3. Other Infections

55. I believe that Richard did receive other infections as a result of his treatment with blood products. I believe that the blood rashes he suffered were symptomatic of other infections.

Section 4. Consent

56. I believe that Richard was treated and tested without my knowledge and therefore without my consent. I could not consent to treatment that I did not know about. Richard also took part in clinical trials, which, I verbally consented to during the course of Richards check-ups. However the details of these trials were never fully explained to me. I was never given the results of these trials.

57. I believe that Richard was treated without adequate and full information. I feel as if I was just dismissed when I attempted to ask about treatments. I believe that Richard was treated for the purposes of research as he participated in a clinical trial. I gave my verbal consent to the trial, as I believed that it was in Richard's best interests.

Section 5. Impact

58. Not having a definitive answer has put me under tremendous strain. When things started to go wrong with Richard's health I believe that he was scared and confused. He had bouts of anger and confusion. Richard saw a psychologist aged 10 or 11 and asked if he was going to die. It must have been a great worry for him. My situation was very difficult as I was a single parent, living on my own trying to raise an ill child. During this period, I had very little support. I had to fight in the face of a total lack of answers.

59. Richard suffered from a severe brain disease, I believe, as a result of the FFP treatment. The infection affected his mobility, speech and ultimately lead to his death. Richard was never critically ill; his deterioration was gradual and happened over many years.

60. Richard never experienced any difficulties or obstacles in accessing treatments. Dr Webster took control of everything, he even arranged for Richard to be treated in a different centre when we were on holiday in Scotland.

61. In the very early days a Bone Marrow transplant was discussed. However, Dr Webster said that Richards was not ill enough for that treatment. This disscussion was prompted by the creation, at the time, of the Antony Nolan Charity. I thought that this treatment may be applicable to Richard's condition.

62. We had no problems accessing dental treatment. The dentist knew us well and we had no issues.

63. It was particularly difficult for Richard to maintain friends as he was always declining physically and mentally. However he was always happy and smiling.

64. Richard's illness had a huge impact on me; I found it very difficult. I was angry at the situation, I was angry with Richard's father for not helping me enough. My elder son had to help with Richard's care including helping with his feeding and personal hygiene. Richard was physically strong although he couldn't walk. He would lock his legs and refuse to get out of the car on occasions. Looking after him was a very physically demanding task.

65. My elder son found it very difficult to remember Richard as a well child. I know that he feels as if Richard's whole life was defined by this decline.

66. Richard's education suffered due to his condition, it ceased to be a priority from the age of 11 onwards.

appointments. I also had to invest a lot of time trying to get Richard into different schools. I had to apply for disabled badges etc. these tasks sucked up a lot of my time and energy. I felt I had no choice so I just had to get on and do it; I was not getting any financial support. My social worker at the time was excellent and did offer support.

Section 6: Treatment/Care/Support

68. It was suggested to me that I saw a bereavement counsellor but this only happened once after Richard's death. It is hard to say if I would have benefitted from additional psychological support. My social worker was a great source of support for me.

69. The investigator has informed me about the Red Cross support service and I will consider if using this service would benefit me.

Section 7: Financial Assistance

70. I have never received any financial assistance.

Section 8: Other Issues

71. I want to know why this has been covered up for over 20 years. I know the government accepted blood from America. I want to know why this blood was not vetted? As a consequence of the Inquiry, I hope that products will be safer today.

72. I find the lack of willingness on the part of doctors to enquire as to possible causes of Richard's brain disease shocking. There was no effort to diagnose or reassure me. I want to know why Richard's treatment switched to Sandoglobulin. Why did it change to this synthetic product? Was this an acknowledgement that this product was safer than before? This switch raised questions for me, questions that we will never know the answer to.

73. I think that there must be other patients who have suffered in the same way. Richard could not have been Dr Webster's only patient. I would like closure and someone from the government to accept responsibility. The government needs to make sure that this will not happen again. I want to be informed of the actual practical steps to ensure that this will never happen again.

Statement of Truth

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

Signed GRO-B

Dated 13th August 2019