Witness Name: GRO-B
Statement No.: WITN4691001
Exhibits: 0
Dated: X 9th December 21

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 30 October 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B. I live in GRO-B Essex. I have British nationality, my wife had British nationality and all of my children were born in Britain.

2. I am now retired, but I had a long career working in the public sector and more recently with the Court of Protection and social services based in London Borough of GRO-B for around 10 years.

3. My role was to deal with the finances of vulnerable people, such as the elderly and mentally ill. I was appointed by the London Borough of

GRO-B council to get court orders to get permission to deal with their finances in certain situations.

4. GRO-B

5. I have also been GRO-B and the GRO-B GRO-B during which GRO-B I had the privilege of supporting and raising funds for local health charities.

6. I am currently the GRO-B of the GRO-B and I volunteer with the GRO-B I'm also involved in the carer's association, which was set up for people who care for friends and relatives, whether they are paid or unpaid.

7. My wife, GRO-B passed away in GRO-B. We were married for over 40 years. It was very painful for her, seeing her only son so unwell as a result of mistreatment by the NHS. We are still grieving the loss of my wife and mother of my children.

8. Our eldest child GRO-B was born in GRO-B She is married and lives nearby. Our second child, GRO-B:S was born in GRO-B our daughter GRO-B was born in GRO-B and our youngest and final child, GRO-B was born in GRO- and lives with me. I have 3 grandchildren. S was very close with his nieces and nephew.

9. Our son S died unexpectedly last year, on GRO-B. We are still grieving his loss. S was a haemophiliac and he was infected with HIV and HCV after being mistreated with contaminated Factor VIII /blood products in the 1980's.

10. In this statement, I intend to speak about S's infection with HCV and HIV. In particular, 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.

11. My daughter, GRO-B was present with me during my meeting with the Investigator and she has also made some comments to the Investigator about S's illness and its impact on our family. She has chosen not to provide her own statement to the Inquiry.

12. This witness statement has been prepared without the benefit of access to S's full medical records. I think that looking back on the medical records will be very traumatic for us. Even though I would like to see what is contained within the medical records, I also feel that I do not want to see them as it will bring back too much pain for me having to re-live S's illness. I would however like access to his medical records.

13. I cannot recall all dates of appointments and the names of all the medical professionals S was seen by because I don't have access to the medical records.

Section 2. How Affected

14. S was born with Haemophilia, but we did not become aware of this until he was around 6 years old. This is one of the issues I have with the medical profession. From day one, he suffered pains and bleeds. We were frequent visitors to A & E. Yet, at no point did our GP, or any doctor at A & E send him for a check-up.

15. When we visited doctors, we were never told that S had Haemophilia. All they said was that he had a problem. Our family GP

was a very nice doctor, but he also let us down. We would take S to the GP as he would be experiencing pain, and the GP would just tell us to give him paracetamol or other painkillers.

16. Sometimes he would be in pain in the middle of the night so we would take him to A & E. He would often have bleeding and pain in his joints, such as the ankle, knees or groin. At no point did anyone at A & E or our GP send him to a specialist to have this checked. We were always just told to go home with pain killers. All they would do would be to put pressure on the affected part of the body to stop the bleeding, and then he would be sent home.

17. On one occasion, when S was maybe around 18 months old or so, he was eating crisps when a piece became lodged in his gum. The bleeding would not stop. I was at work, so my wife and our neighbour called an ambulance. The police arrived before the ambulance and he was taken to A & E in GRO-B Even then, the doctors were not able to figure out what was wrong.

18. When he was around 6 years old, we took him to GRO-B Hospital in Essex to have a GRO-B performed, a relatively small procedure. After the procedure, it was discovered that he was not healing because the bleeding would not stop.

19. Following the GRO-B, he was sent to Great Ormond Street Hospital in London. He was referred to Great Ormond Street in around 1981/1982. They carried out some tests and diagnosed him with Haemophilia A. We were told that he had mild Haemophilia A.

20. We don't know of anyone in our family who suffers with Haemophilia. We later found out that my wife was a carrier of Haemophilia but we did not know about this until S was diagnosed. I and my other children were tested for Haemophilia A at Great Ormond Street

Hospital and my eldest daughter was diagnosed as a Haemophilia carrier. We don't know of any family history of haemophilia. The doctors said that it can go back 7 generations.

21. After being diagnosed with Haemophilia at Great Ormond Street, I remember that S was under the care of a Docto GRO-B at Great Ormond Street from about 1981/82 onward. There was also a senior Haemophilia Nurse who we would see, but I cannot remember their name. Our regular visit would usually entail seeing the nurse first and then the doctor.

22. After being diagnosed with Haemophilia at Great Ormond Street, whenever he had a bleed, we would take S to Great Ormond Street and he would be treated with Factor VIII.

23. I recall them taking the substance from a plastic container. It was a yellowish colour from memory. Sometimes it was a small bottle they would put a needle into and withdraw the substance, which they would mix with water.

24. He may have been given cryoprecipitate, but as I am not a medical person, I cannot be sure. I have some recollection of a yellowish substance, but I do not remember the word cryoprecipitate being used.

25. S continued being treated at Great Ormond Street until he was 16 years old. His treatment was then moved to the Royal London Hospital.

26. S was diagnosed with HIV by Doctor GRO-B while he was still at Great Ormond Street Hospital. I do not recall the exact year that he was diagnosed, but I remember that it was a few years after he started treatment at the Great Ormond Street Hospital, so it would have been

around 1984/1985. Doctor GRO-B left Great Ormond Street right after she diagnosed S with HIV. She left to go to GRO-B for another job.

27. Up to the point where S was diagnosed with HIV, no mention was ever made by Dr GRO-B, or any other medical professional, of the risk associated with the Factor VIII products he was receiving, or him having any infection. Before this, no information was ever offered about the possibility of infection.

28. I recall Dr GRO-B saying that the blood products were imported from abroad. I think she mentioned the GRO-B and that the products were infected. This required them to heat the factor VIII prior to administering it to S but they didn't. This I recall she said was the reasons for S s HIV infection. Subsequently, they would heat the factor VIII before administering. But by this time serious damage was done to S s health with long term and terminal devastating consequences.

29. I feel that they knew that S was infected all along and that they (NHS/government) kept it from us. Everything imported into this country is checked for quality and safety. I can't believe that those responsible, who were receiving a batch of Factor VIII, did not check to see if it was ok. I blame the health department; they should have made sure the product was checked properly before being brought into or used in the UK.

30. I believe that doctors at Great Ormond Street kept the fact that S had received these contaminated products and was infected with HIV from us until they had no choice but to tell us. Public knowledge about HIV was then so rife amongst the haemophilia community and the general public. You could not avoid it, it was on the news, I read about it in the newspaper. It was a bit like COVID-19.

31. GRO-B

32. My daughter GRO-B has also commented that they must have known that the blood was contaminated. They had already discovered by 1977 that the blood was infected. She feels as though they took a risk on her brother's health as they must have had knowledge about the associated risks, but carried on treating him.

33. There was no mention made of treatment for HIV when Doctor GRO-B first diagnosed S and this was mentioned only much further down the line. There was also no mention made of S being infected with HCV.

34. As I mentioned previously, S moved from Great Ormond Street to Royal London when he was around 16 years old. He was mainly under the care of Doctor GRO-B at Royal London. I am not sure when the HCV was diagnosed, but I think that Doctor GRO-B probably diagnosed it. I remember that he was not immediately diagnosed when he moved over to Royal London, it may have been diagnosed a few years later.

Section 3. Other Infections

35. I do not believe that S was ever infected with any other infections besides HCV and HIV but I don't have access to his medical records I would like to know his full medical conditions – and will want his medical records at some point.

36. I did not recall S ever receiving any letters about vCJD. However, my eldest daughter has reminded me that letters were received about

this as in the early years she would support me, her mum and S with correspondence.

Section 4. Consent

37. We were never asked for our consent to treat S with Factor VIII. We would just take him to the hospital and they would tell us that the Factor VIII was what he should be given. We listened to this as we trusted their expertise and we just wanted the best treatment for our son. If the doctors knew about the risks associated with the product, they had a duty of care to inform us of them. It was their job to ensure we understood what the product was and what the risks were.

38. I do recall S saying that he felt like he was being experimented on. He felt as though treatments were being used on him without the doctors knowing exactly what the benefits of those treatments were.

Section 5. Impact

39. When S was diagnosed with HIV, it was very obvious how distressed he was. There were visible signs that he was distressed. I do remember that once S was tested and found positive for HIV, we were told that we should be extra careful and to make sure that we were washing our hands, a bit like we are being told now with COVID-19.

40. I recall that S became very obsessed with cleanliness. He was constantly washing his hands and face and wanted separate cutlery. He became extremely anxious and obsessed about cleanliness.

41. He didn't want anyone to use the same cups and plates as him. He even had his own mug which he would not let anyone else use. I'm not

sure how this became the main cause of concern for him but it occurred after he found out about the contaminated treatment.

42. If he had a nosebleed, we would see him disposing of his tissues so that no one else would have contact with them. He had an obsession about not passing on the infection. Perhaps more advice should have been given to him in relation to how to take care of himself and be able to ask for support and care. My wife and daughters saw him a lot more as they were at home with him. They would see the pain he was in and the poor quality of life he had.

43. Sometime later after his diagnosis with HIV, I believe S was put on Retrovir drugs for his HIV. While this drug may have prolonged his life a bit, the diagnosis, the side effects of the drugs and the stigma attached to being HIV positive had a huge impact on his life and outweighed any benefits. He was always very depressed, tired, short tempered and never had the full benefit of life. He was like a dead man living. We know that S went onto develop lots of other health problems – from eyesight to stomach issues.

44. I am not sure what treatment S was prescribed for the HCV. I know that he was on a lot of medication, and medication for HCV was possibly one of those medications. I know that he was taking something to treat the HIV, and that it depressed him, and there were other medications he was taking, but I am not entirely sure what he was taking for HCV.

45. I'm not sure exactly what he was taking as he went to the appointments by himself and made the decisions by himself. This is because when S turned 18 the doctors told him that from that point onwards, he must attend the appointments by himself. I was only allowed to attend appointments with him when he was seriously ill. I think that this was wrong as he was still only a teenager at the time

and he needed support. I think that he needed his father's presence as well as more professional support.

46. Presumably, he was given information on how to manage the infections, but he did not share this with us. As I have already mentioned, I was not in the medical appointments with him.

47. I do remember that S was told by Doctor GRO-B at some point after he was diagnosed with HCV that within 4 years something serious may happen, but he did not say what this would be. Within those 4 years he did fall seriously ill and was admitted to the Barts Hospital at one point.

48. He was close to his older sister GRO-B They grew up together and he confided in her and saw her a lot more. He used to say to her, "I'm going to die". Sometimes he would confide in my daughter GRO-B. They spoke a lot more for around the past 10 years. He commented to her that it was difficult for someone who is not ill to understand what he was going through.

49. His illness greatly affected his life. He could not live the life of a normal young man. He was a normal boy before the diagnosis, but after he became less social as he found it difficult to mix with others. He did not have any real friends and he could not form a relationship. He progressively became more and more depressed. He was very friendly and on his passing a lot of people came to see us to pay their respects. This just shows how personable he was.

50. The depression also affected his ability to concentrate, which also meant that he could not complete his law degree and he did not realise his full potential in becoming a solicitor.

51. When he was diagnosed, he said to me, "I'm not going to live long, so what's the point of studying?" I wanted him to study his favourite

subject but he lost the will to carry on and live his life. He progressively became more and more depressed.

52. Although he was depressed, he did try. Thank God he didn't commit suicide, with the burden that he had you can imagine one would feel suicidal.

53. He learned how to drive, he had ambitions and wanted to work, he wanted a family and children, but his illness took these opportunities away.

54. He had lots of acquaintances as we have been living in the area for 50 odd years. But they were just acquaintances, the kind of people who you say hello to in the street. Having a friend is different, a friend is someone you can sit and talk with. He didn't have anyone like this.

55. He felt didn't have anyone like this because he felt that he could not truly be himself, or share what had happened to him or what was going on for him, for fear of his trust and confidence being broken, stigma and discrimination.

56. He couldn't play football or any other contact sport because of haemophilia. Very early on the doctors at Great Ormond Street told him this. He liked boxing but he could only watch.

57. He wanted to get married and have children but he couldn't. He would say what he could say to a partner? What individual would marry him in that state? This was a very challenging part of his life as he grew up when others around him were settling down – sometimes younger than him.

58. In the last few years his eyesight deteriorated and he had all sorts of aches and pains. In his 20's, early 30's he became so distressed that over time he had pulled out all his eyelashes. It was like an anxiety

thing. He had the eyesight problems from when he was around 17/18 years old, but I am not sure if it was linked to HIV. He must have felt like it was another thing that he had to deal with.

59. He mentioned to my daughter GRO-B that he was having trouble seeing and she went with him to an appointment at the GRO-B Hospital. He had inquired about going privately to sort it out, and since he passed away my daughter has seen some of the correspondence with the hospital about his condition. It wasn't curable and the advice they gave him was to get glasses, but there was a possibility that he was going to go blind.

60. He avoided going out during the day. He went out in the evening. Even when he was invited to weddings, parties and family events, he would shy away because of the illness. Sometimes we would observe him at family events and he would sit by himself. Most of the time he would leave early and go home. He did not feel comfortable around people.

61. In his 20's early 30's he developed a rash on his arms. It seemed to have improved over the last 10 years, but there was a period where he had a really bad skin condition. It must have made him feel very uncomfortable. The condition made him very self-conscious and he didn't want to go out.

62. He lost lots of weight. He was very thin. S described himself as a 'dead man walking'. He was originally wearing a large size and he went down to medium. He never needed to wear a belt and he then needed to start wearing one. The weight loss was very noticeable to us

63. His skin colour became darker which was strange as he did not sunbathe and we never went on holidays. As I mentioned previously, he didn't want to go out. He did not to my knowledge ever go on holidays. He didn't even want to go to the shops to get milk as he was

afraid of running into someone as they would ask him questions about his life. He was scared that people would judge him for not working.

64. He couldn't work because of the illness and also because he would have needed to declare it to a potential employer. He did not want to do this because of the stigma associated with HIV. He was interested in law, estate agency work and conveyancing. He wanted to work but he couldn't.

65. He was afraid that others would think he was lazy as he didn't work, and this was another reason why he avoided going out and meeting people. It was upsetting for us as we saw how other young people were working and doing what they wanted, but our son wasn't able to.

66. We knew that S felt the one thing that stopped him was his contaminated blood health issue and so he got more frustrated, resentful and upset by this. He said to his oldest sister many times that he really wanted to feel like everyone else going out to work, having their own money and enjoying life.

67. S kept his infections a secret as he was concerned that other people would assume the worst as they did not know the circumstances of his infection. There was a stigma at the time with HIV being a gay disease. S was afraid that people would put things together and they would think that he was a homosexual.

68. Growing up, we wanted to contain information about the illnesses so we didn't really speak about it and because that is what S wanted. When S was younger and he was unwell, if his mum mentioned this to a relative or aunty, he would be angry and upset. He didn't like that at all. After the blood contaminated diagnosis, we respected his wishes for privacy, to be discreet and keep it confidential.

69. He really didn't like any information being shared about him, and we think that this had to do with the stigma associated with HIV and Hepatitis C.

70. I am not sure what drugs S was taking to treat the infections. I did see him taking some tablets and I know that he was on a lot of drugs (medication). He was good at taking the medication regularly, but it was difficult for him to maintain it, and we never fully knew what the impact was on him.

71. I assume that the medication had an impact, and that it may have contributed to some of the problems he was experiencing such as weight loss and eyesight problems, but I cannot be sure.

72. Today we know that HIV and Hepatitis C can be treated and cured. At the time of S's diagnosis, we were basically told that he would die. When I asked Doctor GRO-B whether he could get married, Doctor GRO-B responded with words to the effect of "I can't tell you only he knows what his responsibility is". The implication of this was that S knew that he would not be able to get married and have children.

73. S's illness affected us enormously. I wanted to see our son be successful in his preferred career, get married and go on holidays like other young people, and when I saw that he couldn't do this it had a profound impact on me and my family.

74. We didn't really go on holiday because of S's health conditions, but as the children got older my daughter tried to convince us and him to go, but he didn't want to. She thinks that inside he wanted to, but he was afraid as he thought that he needed to be near a hospital just in case he needed treatment.

75. He also had to think of getting insurance if he needed treatment abroad – all of which meant sharing and disclosing some very private

and painful health information. We know he was always worried about this and facing further mistreatment and stigma - this was the greatest barrier to him being able to travel.

76. When we went to GRO-B for my father's funeral when S was younger, he started getting pain in his shoulder and we couldn't get any help. We went to a local hospital and they didn't understand what haemophilia was.

77. Great Ormond Street hospital had prepared a package for him, but the hospital in GRO-B didn't know how to apply it. So, I know that this issue of how he would get treatment overseas if there was a problem would have been on his mind and therefore prevented him from travelling. In addition to this, the possible stigma associated with HIV abroad would have been worse and we know that he knew that.

78. The loss of my wife to a late cancer diagnosis and Crohn's disease in GRO-B 2017 impacted S a lot. It was very hard for him. She tried to help our son but she always thought that she could have helped him more even though she provided the best care 24/7 under most stressful circumstances. When visiting his mum in the last few days he would often be crying.

79. My wife was his carer so she couldn't work. She wasn't free to go out, on holidays etc. She had to be at home so that she could cook and clean for S He lacked the motivation to do these things. If she didn't have the commitment of looking after him (above normal parental care), she would have gone out to work.

80. I had suggested that S go out to work in a voluntary capacity, but he was afraid that people would ask him too many questions about his personal life. In my mind he was fearful that if he did, he would be asked questions and the fact that he had HIV would come out.

81. Given his skills, I thought that he would have been good on a management committee, but I think that his HIV status prevented him from pursuing any career. He had the potential to do a lot of other things career wise, but he just did not have a normal life.

Section 6. Treatment/Care/Support

82. We don't know whether there were other medications available that would have made his life better that he did not have access to or if they were made available to him.

83. S knew that HIV would have an impact on any treatment he went for. He had lots of dental problems. He knew that he would have to disclose this and he would have been reluctant to do so out of fear of stigma and mistreatment. He often told his older sister he found medical professionals treated him "worse" after his blood contamination diagnosis. We feel the medical profession were not trained enough in knowing about what happened and in caring for and supporting such patients.

84. S was not offered adequate psychological support to deal with his diagnosis. After he turned 18, we were not permitted to sit in doctor's appointments with him. I think that this was wrong as he was only a teenager at the time and he needed support from myself and the rest of his family.

85. I also feel that in addition to his father's presence, he also needed professional support. If you tell someone that they have a serious disease they will draw their own conclusions about it, so the NHS should have appointed a specialist counsellor to support him through such a difficult time. They did not put in place any psychological support package. I'm not sure why they did not do this. Was it because

of his ethnicity? Or because they had already "written him off"? I am not sure.

86. I think that there should have been support services that considered what the patient's specialist needs were. In my son's case, I think that a specialist support person who provided support which took into account his ethnicity should have been provided. I would often say to him, 'talk to me' or I would encourage him to talk to a specialist in the hospital, but there was no one to talk to.

87. As I have mentioned previously, S s health was deteriorating at the time and he wasn't the same young man anymore. He was depressed, didn't have a normal life, normal relationship, friends or a confidant to talk to. The medical profession should have identified that and offered a specialist counsellor to help him navigate through this difficult period.

Section 7. Financial Assistance

88. In around 1991/1992 a financial package was offered through the Macfarlane Trust and S started receiving payments through that. Prior to this time, he did not receive any kind of financial support as a result of being infected.

89. He did receive disability benefits and my wife received a carer's allowance. As he was living at home with us, he received the standard amount that was offered to claimants by Macfarlane.

90. To us, money was not a factor as money could not buy him comfort and a better quality of life. We were happy with the basic amount that he was receiving through Macfarlane and he didn't expect more. The money was adequate for his needs. S never placed any financial burden on me and I was happy to give him money for clothing etc.

91. It seems that Macfarlane was means tested. Initially it wasn't, but as time went on, I remember S having to fill in a financial assessment form. I recall him asking about how much I earned and my savings as he needed to provide this information to Macfarlane. He would have to declare how much money he made, who he was living with, what he needed the money for etc.

92. I remember that he had to repeat the information, which I think put him off and made it quite onerous in applying for financial support. He felt as though he had to prove he was deserving of the money, and I think that worried him a lot. It played on his mind, as he had to constantly repeat what was wrong with him.

93. I do not remember there being any preconditions attached to the payments and I do not remember S having to sign any waivers to receive payment.

Section 8. Other Issues

94. I feel that S did not get to live life, in a full sense, because of his infection with HIV and HCV. Because of his infections he led a very miserable, depressed life, and that in turn must have been very difficult for him. It also had a huge impact on my wife and other children.

95. No amount of money or financial compensation would have given him or us happiness. We just wanted a happy, healthy son.

96. The health department and those in the medical profession failed in their duty of care to recognise the risks associated with Factor VIII products. We were let down by this failure and so was our son.

97. I sometimes blame myself for not being more proactive and not asking the questions of the medical profession that we are asking today. We

put our whole trust and faith in the authorities and the doctors, as they have studied for so many years to be able to do what they do. My view is that when you are in that position of authority you should do your best and that is where I think they failed.

98. My daughters and I have found this process very painful as we have needed to relive S s life in telling his story, especially after his recent passing away.

99. We feel like the medical profession has let S and people like S down. We hope it is noted by the Inquiry that the impact of something like this cannot be underestimated as it has a ripple effect and sends shock waves through a person's life.

100. People without knowledge may think that S could have worked or got married, but they don't understand the seriousness of the illness he went through. I believe that a lot of his behaviour, and his general difficulty in life, was a direct cause of him being infected with HIV, HCV and other infections and consequential medical and personal problems, and no one has been prosecuted for that.

101. The medical profession should think about how to make medicine simple for ordinary men and women, especially the sufferers. When they gave patients Factor 8, they should have explained it adequately. We didn't know what it was, they didn't tell us how it works. They need to explain this in plain English. If we had known what it was, I might have understood it and asked more questions. We were putting our trust in them.

102. It seems that the UK imported lots of blood from GRO-B and because of this, the medical profession failed people like us as they did not adequately screen the blood. Anything that we import is checked for quality, so I don't understand why they didn't check the blood products.

103.There was always this feeling that you couldn't question the doctors. It existed then and it is still around today. Even these days, if you question their judgement, they will get defensive.

104.I want to add that since we found out S had received the contaminated blood products, the whole family was under tremendous stress and anxiety. We all wanted S to get better just as much as he wanted it himself and for this to go away. However S and we knew the reality of the situation–it was like a dark cloud hanging over us or a hard lump in the throat that cannot be swallowed.

105.We also feel very upset that S (his soul now he has passed) and people like S and their families and friends are being made to go through this inquiry in this way – causing further distress and upset. We hope justice will be done for the wrongdoing.

Statement of Truth

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

Signed GRO-B

Dated 9th December 21