ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN7110001
Exhibits: Nil
Dated: 1-11-22

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 8 June 2022.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1960, and my address is known to the Inquiry. I used to work as a caregiver, but I can no longer work as I am disabled.

2. I intend to speak about my sons GRO-B: S1 born on GRO-B 1981, and GRO-B: S2 born on GRO-B 1983. S1 and S2 were diagnosed with haemophilia A from a very early age.

3. I intend to speak about their infection with Hepatitis C ("HCV"). In particular, the nature of their illness, how it has affected them, the treatment they have received, and the impact it has had on our lives as a family.

4. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I wish to be anonymous.

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

Section 2. How Affected

6. My sons S1 and S2 have severe haemophilia A, so they began using Factor VIII very early on. They were diagnosed with haemophilia when they were still infants and teething. I noticed first with S1 and it was like a blood bath anytime he had new teeth coming in.

7. The children were under the care of Dr Frank Hill at Birmingham Children's Hospital. Whenever they had a bleeding episode, we would have to take them to the hospital so that they could receive treatment. I believe they received cryoprecipitate until they were about seven and five years old respectively.

8. When Factor VIII was first introduced, we used to have to go to the hospital for treatment whenever either of the children had a bleed. Our hospital visits were frequent. It seemed as though I was always going down with one or the other. Due to this, the introduction of home treatments was beneficial for us. The hospital staff taught us how to administer the treatment at home, and from a relatively young age, both boys could do their own injections.

9. As young lads, both boys suffered from spontaneous bleeds, particularly into their knees, and sometimes these occurred while they were asleep.

10. S1 had to have an operation for a hernia when he was about ten years old, and a few months after he was discharged, he had to go back to the hospital to have the surgery redone. S1 also suffered from an injury breaking two bones in his right arm, which required hospital treatment.

11. When S2 was about eight years old, he fractured his skull and had to remain in the hospital for some time.

12. As much as we tried to wrap the boys up in cotton wool to protect them, there were times they would sneak off as young boys generally do and would end up with some kind of injury that meant a bleed.

13. Aside from when we went to the hospital if the boys had an issue that required it, the boys also had regular six-monthly clinic appointments with Dr Hill.

14. Whenever we went to the hospital for the boy's regular appointments, we would sit around in a small waiting room, the place was not much bigger than a cupboard, in the unit while we waited for the doctor to arrive. A nurse or staff member would bring the boys' files around so that it was ready and waiting in the room before the doctor's arrival.

15. On one of our visits in 1988, I was looking at S2's file, and it said S2 had non-A, non-B hepatitis. There was also a yellow biohazard label on the file, but I thought this had to do with sharps and having to bin the needles used.

16. I asked the ward sister Marion Gregory; what does this mean, and she said "it does not really mean much, it's nothing to worry about." It seemed like no big deal with her reassurance, so I did not bother following this up further. S2 was only five years old at the time.

17. A few years later, when the news of HCV became more prevalent in the press, I asked Dr Hill what it could all mean for either of the boys. He responded that both of my sons had been HCV positive for about ten years.

18. I was shocked because no one had ever mentioned this before – not even the possibility. I queried why no one had informed me sooner, and he said he did not want to worry me as he understood I had a lot on my plate dealing with the boys' condition and family life. Both my husband and I liked Dr Hill but we found it hard to believe that no one thought we should be made aware of something so important.

19. By 1993, medical professionals seemed to have more knowledge about HCV, so I asked Dr Hill if there was any treatment that could help my sons. Dr Hill explained that their infection was still in the early stages and referred us to a liver specialist. At some stage I found out that S1 was Genotype 1 and S2 was Genotype 2.

20. The boys also had ultrasound scans of their livers. They could not have liver biopsies because of their haemophilia, as the risk of bleeding was high. The scans confirmed mild scarring on both S1 and S2 s livers.

21. Up until this stage, the only symptom the boys complained of was fatigue. I used to pick them up after school, and S2 was usually so tired I would find him fast asleep inside the school building while waiting to be picked up. The doctors told us to just let him sleep.

22. Sometimes they would wake up screaming and complaining of pain in their legs. Even now, S2 continues to experience pain in his legs. They also suffered from memory related problems, a sort of brain fog, which probably impacted their education.

23. When I found out that there was a treatment available for HCV in the mid 1990s if I remember rightly, I asked the doctors if S1 and S2 could be offered this treatment, but we were informed that they could not have it.

24. I insisted on speaking to the liver specialist at Birmingham Children's Hospital, Dr Diedre Kelly, and she explained that it was an expensive treatment and the response to it was not very good. I told her I was willing to try as they were young and deserved the chance but she said it cost £3000 each, and there was no funding available for it.

25. I was angry because I felt that the hospital had given my children an illness but did not want to have the responsibility of dealing with it. I contacted GRO-B one of the local news outlets, and they interviewed the children and I. I also began fundraising so that we could try to pay for the treatment privately.

26. A month after our interview with GRO-B the hospital contacted us to confirm that S1 and S2 could have the treatment. My interview with the news outlet and the publicity forced the hospital's hand into giving us the treatment.

27. The treatment consisted of a weekly injection of Interferon into the stomach and one Ribavirin tablet taken twice daily.

28. S1 and S2 both had a bad reaction to the treatment and had to be taken off after a few months, even though the treatment was supposed to last six months.

29. S1 experienced nausea, vomiting, itching and generally not feeling well. S2 experienced the same side effects but to a much more severe degree. Everything usually seemed to affect S2 more, but this could be because S1 is quite deep and usually keeps things to himself and, even if he was feeling poorly, would not complain as much.

30. While on the medication, the children were monitored regularly by Dr Kelly with monthly blood tests and ultrasound scans.

31. On one of our visits, I explained that the boys were suffering from these severe side effects, and I asked her if the treatment was working. She replied that it was not working, and this was when they decided to stop the medication. I was devastated as I had fought so hard for them to get the treatment but at the same time, I could see the effect it was having in them. The boys were disappointed too but luckily, they were still a bit too young to fully understand what it all meant.

32. After the failed treatment, the doctors continued to monitor their conditions via ultrasound scans, and we were informed that there was a sign of greater scarring on both S1 s and S2 s livers.

33. The next time the children were offered treatment was sometime in the late 1990s, about 18 months to two years after the failed treatment. I cannot recall if this was a mixture of tablets and injections but I know that the treatment again did not work for S1 and S2

34. By the time S1 completed the course of treatment he had not cleared the virus. S2 on the other hand, was informed that he had cleared the virus, and he remained clear for about 11 months when tests confirmed that his viral load had risen again, which meant he still had HCV. I dread to think how he felt about this, coming so close to clearing the infection after suffering the same side effects again. I was heartbroken for them both.

35. In the early 2000s, the boys were offered a third round of treatment which consisted of only tablets for 12 months. They both had the treatment at the same time. I cannot recall the name of the medicine now, and there might have been a difference in dosage due to height/ weight differences but aside from that, the treatment was the same.

36. This medication also had side effects, but it did not seem to be as bad as the first two rounds of treatment.

37. This time S1 and S2 cleared the virus and have remained clear since. However, the damage to their livers had already been done. The boys used to have regular monitoring and check-ups until the global pandemic in 2020.

38. S1 was diagnosed with liver cancer and has gone on to develop four tumours on his liver over the last six months. He is currently receiving chemotherapy treatment at the Queen Elizabeth Hospital, where the boys were moved to after they turned 16, for the cancer. He had to be referred to a liver specialist because, due to his haemophilia, some of the treatment options for cancer could affect his Factor VIII levels. He has had to have immunotherapy and needs to be closely monitored.

39. S2 s HCV genotype is said to not be as bad as S1 s, but he still has scarring on his liver. S1 apparently has the worst type to treat and S2 the one below that. I'm sorry but I don't know the actual type categories.

40. S1 and S2 have never received blood transfusions. S1 has a tattoo but this was done long after his HCV diagnosis at a professional establishment. Neither of my sons is or has been an intravenous drug user. As far as they and I are concerned their infection with HCV is a result of their use of blood products to combat their haemophilia.

Section 3. Other Infections

41. I do not believe either of the children received any infections other than HCV due to being given infected blood products.

42. Both of the boys have been tested for HIV and found to be negative. However, when S1 was around 10 or 12 years old, I was informed that he had received Factor VIII from a donor who had subsequently tested positive for HIV and that they would have to keep a close eye on it.

43. The doctors carried out an HIV test and a further test after 12 months which confirmed that he had not contracted HIV. It was a scary and extremely worrying time for all of us, S1 in particular, but we kept him in the loop so he was aware of what was happening as after all it was him who would be most affected. It was a horrible thing for him to contemplate at such a young age

44. There was also the occasion when Dr Frank Hill at the Birmingham Children's Hospital telephoned me to inform me that the boys may have been exposed to blood contaminated with vCJD. I think this was in the late 1990s but I can't be sure. He explained that they would have been exposed through Factor VII, but the doctors could not know if they had gone on to develop the illness.

45. Dr Hill seemed to be quite cagey about how S1 and S2 could have been exposed to vCJD. As a result, I no longer felt comfortable with him as my children's primary doctor and requested a change of doctor at the Birmingham Children's Hospital. Dr Mark Williams became their new doctor for a few years until the boys turned 16.

Section 4. Consent

46. I was never informed at any point that S1 and S2 were being tested for HCV. As far as I was aware, they were being tested regularly to monitor their Factor VIII levels, and the results normally would have been discussed at the children's next clinic session. If, however, there were any emergent issues, they would usually call me on my phone to

let me know and discuss a course of action. However, this was not the case when the boys were tested for Non-A, Non-B hepatitis.

47. No one ever informed us that the blood products, the Factor, could be contaminated or that there was a risk involved with using them and we were unaware that anything could be wrong until the news about HIV and then HCV became available to the public. Obviously, the factor product was a necessity for my sons but it would have been nice to know of the risks and be given the opportunity to make an informed decision.

Section 5. Impact

48. S1 and S2s haemophilia impacted their education and my ability to work when the boys were growing up.

49. From primary school onwards, it was difficult to find a regular school that would allow them to attend. Many of the local schools stated that there were not insured to cover if something happened to the boys, so they refused to take them on as students.

50. When we finally found a school that accepted them, they would only do so on the condition that I had to be available at all times, at home, so that if there were any issues, they could contact me via a pager. It was more than being a stay-at-home mum because it severely restricted me from leaving the house, which gradually had an impact on my mental health.

51. The school was also challenging for the children, particularly S2 because they experienced a lot of bullying. I believe this affected their education to a great extent.

52. I advised the school about what to do regarding bleeds and cuts due to the risk of HCV and HIV at the time.

53. When they began attending school, they were put on stage at assembly to announce to the rest of the school that the other children had to be careful not to hit them or bang them because of their bleeding disorder.

54. I believe this was meant to help and was well meant, but it may have also contributed to further bullying. Once, a boy told S2, "I would like to punch you to see how much you bleed".

55. They could not participate in any physical activities. There was no games or sports for them. These were banned and again showed the children up as being 'different'. I also recall S2 had to sit on the side-lines and do written work, which felt like a punishment, when the rest of the class was out playing at lunchtime, for example.

56. From time to time, the children had to be in a wheelchair if they had suffered bleeds into their knees, for example S2 had to have his arm in a sling on a couple of occasions. As a result, they were only allowed out with the other children when they were not in a wheelchair or were incapacitated in any other way. The other children also teased them because of the inconsistency in their use of the wheelchair. Consequently, it was difficult for the boys to make and keep friends.

57. At one point, I considered putting them in the GRO-B school for children with disabilities, but I was advised they would be better off in mainstream school.

58. S2 struggled at school and, at times, did not want to attend. He would lie about having a bleed to avoid attending school. I believe his fatigue also did not help because he was sleeping all the time. Right from when he was a baby, he slept through everything and in primary school, he used to fall asleep in class, and sometimes the school would send him home to sleep because he was too tired to learn.

59. By secondary school, he began attending only on a part-time basis due to fatigue, and in his final two years, he refused to attend school in person and instead received home tuition once a week for about two hours. This was arranged by the school and the local education authority. They informed me that it was a pity that S2 was studying via home education as he was naturally bright and had the potential to attend university – something he missed out on.

60. S1 and S2 attended different secondary schools. S1 like S2 had to use crutches and a wheelchair occasionally. It also had a massive impact on his education, and he was frequently truanting instead of attending classes. He completed his secondary education but did not do any exams.

61. S2 wanted to attend college, but his extreme fatigue and side effects from HCV treatments meant constant interruptions, and to a large extent, the schools did not help as they were reluctant to allow him to attend part-time in the first place and then he ended up with very limited home schooling.

62. He was an intelligent boy, but he was so frequently fatigued it dominated his life. He could sleep for up to 18 hours a day, and it got worse as he grew older.

63. The fatigue has also had a knock-on effect on S2s social life. He has never had a relationship because he believes it would not be fair to any girlfriend to spend half her time waiting for him to wake up or to deal with his ill health. He continues to have arthritis in his ankles and knees which will lead to long term mobility issues. He is very much aware of this. He has become a bit of a hermit, and I blame this on HCV.

64. S1 has a different personality from S2 He is the get up and go type and has a different outlook on life. He is outgoing and social, and

as a young man, he went out clubbing and dated. Although deeper about his feelings, he has not let the condition hold him back.

65. Now S1 is happily married and the father of two active children who were born after he cleared the virus.

66. We clashed when he was much younger and wanted to move in with his girlfriend at 16. She was a little older than him and was physically abusive towards him, which landed him in the hospital for about two or three weeks. She must have assaulted him in some way, and due to his haemophilia, his injuries were exacerbated.

67. S1 and S2 s illness has also had an impact on our family life. When they were 10 and 8, we wanted to take them to Disney world in the US, but our visa applications were rejected because S1 and S2 s HCV were considered a communicable disease.

68. I challenged this decision to deny us the visa. I thought it was ironic that we were being denied the visa because of an illness they had contracted through contaminated blood products which I had subsequently found out had been imported from the US.

69. My husband GRO-B used to work at a factory in various employments such as cabinet making, metal polishing, kitchen making and chrome plating. Around 1993/4, he had to give up work so he could look after the children when it became too much for me, and I had a mental health breakdown. This was around the time I was campaigning and pushing for the funding for treatment for our sons.

70. His salary was not a lot at the time, about £180 a week, but he also used to work a lot of overtime. However, suddenly he went from having full-time income to relying on income support to provide for a family of four. It wasn't an easy transition.

71. He was also concerned about continuing to work with heavy machinery, which may prove to be damaging to his long-term health, so the decision to quit working seemed the best.

72. He currently suffers from COPD and tinnitus, which are two of the long-term impacts of that kind of work. He is one of those people who just gets on with things, and he does not like going to the doctor and does not complain much. I do know it was a wrench for him to give up work as his view is it is the mans job to provide for his family but he had no choice in the circumstances.

73. GRO-B doesn't say much but I know that he worries deeply about the boys. He has witnessed their suffering first hand from the hospital runs for bleeds as babies through the angst of their school years to the struggle to live a normal life as an adult. It all takes a toll and he has had the additional burden of my troubles as well. I really don't know how he keeps going but he is my rock.

74. When I found out S1 and S2 had contracted HCV, my first thought was that my two children were going to die. I was worried about the potential damage to their livers and if they would need liver transplants and not be able to have surgery because of their haemophilia. It felt like both of my children were living with a ticking timebomb, and it drove me mad.

75. I have been on and off antidepressants since the age of 16, and shortly after the boys were diagnosed, I was prescribed antidepressants to cope with my low mood. During this period, I felt hopeless and an overwhelming sense of despair and took an overdose of sleeping pills and antidepressants.

76. I blamed myself fo S1 and S2 s haemophilia, which I knew was hereditary from my mother's side of the family. I was thinking about having to bury my two sons. My sister lost her son when he was four and a half years old because of haemophilia. I just felt that I could not cope any longer.

77. I ended up in the City Hospital on Dudley Road in Birmingham and was assigned to a regular psychiatrist. It was a dark episode in my life, and the doctors considered sectioning me or whether to try Electro Convulsive Shock Therapy (ECT).

78. Thankfully GRO-B stepped up and gave up his job to look after the children and I and I eventually recovered although I remained on anti-depressants.

79. Over the years, my dosage of antidepressants has gradually increased. I am currently on 100mg of Sertraline twice a day and have previously been on a high dose of Exor.

80. The medication has also had an impact on me, I have anxiety, and I rarely go out and socialise with people. They also make me lethargic, which contributes to me feeling a necessity to be left alone. I have trouble with anger and mood swings and am prone to lashing out.

81. I used to be more outgoing when the children were younger. The boys could not go to other people's houses because of the risk of bleeds, but their friends used to come to our house so we would have a house full of children so they could have company.

82. I could hardly recognise the version of myself that felt like an evil cow because I was taking out all my anger on GRO-B

83. From around 2002, I began drinking more because I could not cope with the reality of my children's health issues with the HCV and was formally

diagnosed as an alcoholic. I could cope with haemophilia because this had been in the family for a long time. My brother died from kidney failure in the 1970s, probably because of his condition and cousin I was very close to also passed away. He had haemophilia, but was a very private man. He got married and sometime later his wife succumbed to lymphoma, I believe and he himself later passed away in mysterious circumstances following a tracheotomy operation The family suspected that he had developed HIV but had kept it to himself. It has felt like a curse on the family.

84. I used to work as a home carer, and I would have liked to have continued working but it became too much for me.

85. When the children were growing up, I did not mix with the other mums or neighbours because I did not want to give them the opportunity to stigmatise us. Especially with the way HIV and later HCV were publicised in the media at that time. I knew there were many who equated HCV with AIDS and HIV and it made me wary of people. I felt it was best to keep ourselves to ourselves.

86. The dentists at the Queen Elizabeth Hospital used to wear spacesuits just to attend to S1 and S2 at regular check-ups. Eventually, we ended up getting a private dentist, and although they took precautions and left the boys to be treated last in the day, they were not as bad as the dentists at the Queen Elizabeth Hospital.

87. When S1 and S2 were younger, they took their diagnosis with a pinch of salt and just went about their lives being kids. They did not complain much, but this was also probably because they did not want to worry me.

88. I cannot recall if any of the doctors, such as Dr Hill, provided us with information regarding managing the risk of transmitting HCV infection to others. There were no leaflets about what to do handed out. I know that

I advised the children against sharing toothbrushes and being careful around cuts and anything to do with blood.

89. When I discovered that Dr Hill had waited years to inform me that S2 and S1 had contracted HCV, it was as though the world rocked under my feet, and you could have knocked me down with a feather. Even if no treatment was available at the time, we still had the right to know. What about any risk to us or more importantly other children that they were in contact with?

90. When the boys were young, and we were unaware of their diagnosis, I noticed that it took them longer to recover from chest infections and colds, and as mentioned they were constantly fatigued and often suffered a loss of appetite.

91. S2 lived on cereal for about two years and as I have stressed, used to sleep all the time but when I complained to Dr Frank Hill, he commented that S2 was probably just a lazy child. It makes me angry that he knew why all the time and chose not tell us, no matter what his motive.

92. My older sister GRO-B: died at the age of 50. As a child, she was diagnosed as having low-level Factor VIII deficiency. We used to tease her that she had a boy's disease. After she became pregnant and delivered her first child, her levels fluctuated from about a 5% deficiency to a 12% deficiency which the doctors said was unusual.

93. Towards the end of her life, S found out that she had contracted HCV through contaminated Factor VIII blood products. She was granted the stage one payment of £20,000 from the Skipton Fund.

94. She passed away in 2008/2009, and a post-mortem carried out showed that she had developed liver cancer. Due to this, her husband received a further £20,000 I believe from the Skipton Fund.

95. While she was alive, she suffered from headaches, brain fog and fatigue. However, she was diagnosed late in her life and by this time had also developed lung cancer from smoking, so our family will never know if it was truly the contaminated blood that killed her. I'm sure it played some part and HCV has had a cruel and devastating influence on my whole family.

96. I used to donate blood regularly, and from time to time would receive letters in the post asking me to come in to donate blood. On one occasion, when I turned up to donate, I mentioned having the haemophilia gene and was turned down because they said I could pass on the haemophilia. This was about 25 years ago, and I have not donated blood since.

Section 6. Treatment/Care/Support

97. The only time I believe there was ever a delay in receiving treatment was when the doctors refused to allow S1 and S2 to have the combined Interferon and Ribavirin treatment due to the cost and the generally unfavourable results of the treatment at the time.

98. However, this was not a long delay because I spoke to the media, which pressured the hospital into allowing them to have the treatment, which ultimately did not work and had extremely adverse side effects.

99. I was constantly pressuring the doctors about upcoming treatments. As a result, S1 and S2 were among the first people in their age group locally and nationally to receive the treatment that finally worked.

100. No one provided us with information regarding counselling or psychological support services when S1 and S2 were diagnosed with HCV. Nor was there ever anything of that nature offered during the various treatments they received.

101. The only time one of the children was offered support was when S2 struggled mentally long after their diagnosis. He said he hated everyone and that his illness was my fault. He also developed suicidal tendencies and threatened to jump out of the hospital window. He was referred to a psychologist initially and has been prescribed antidepressants for about five years now.

Section 7. Financial Assistance

102. In 2002, I found out about the Skipton Fund from Helen, one of the HCV nurses at the Queen Elizabeth Hospital.

103. We applied for support and received the stage one payment of £20,000 for each of the boys. We did not receive ongoing support from the Fund.

104. In 2017, after the English Infected Blood Support Scheme (EIBSS) replaced the Fund, S1 and S2 each received a further £20,000 and currently receive £2,400 monthly support.

105. When S1 was diagnosed with liver cancer earlier this year, he sent a letter to the EIBSS regarding this. The EIBSS responded that as far as they are concerned, both S1 and S2 have received full payment and have refused to pay out any further lump sums in light of S1's cancer diagnosis.

Section 8. Other Issues

106. I was an active member of the Haemophilia Society in the early 1990s, and I used to meet up with people and go on campaigning trips to discuss the issues of the time. I met up with the Minister for the Dept. of Health, Jeremy Hunt, down in London on several occasions. We were challenging the government to provide compensation to people affected by the contaminated blood scandal.

107. We wanted the government to tell us the truth about what had really happened. I remember travelling to Parliament about half a dozen times with GRO-B: F another campaigner who I think was infected with HCV too. None of our campaigning in those day seemed to make any difference. There were promises that always came to nothing

108. This has affected my trust and confidence in the NHS. I do not trust doctors, and I ask questions about every aspect. It is the NHS's fault and I want them to tell us the whole truth. I believe the doctors were aware of the risk but they kept this information from us. Maybe they were worried about the consequences if people refused fact products. After all, this would have had a big impact on the NHS themselves. I believe there has been a cover-up, and I no longer trust all doctors.

109. It has wrecked all of our lives. I know if my mum was alive, she would have continued to blame herself as she always did. She used to blame herself for my children inheriting the haemophilia gene and went to her grave thinking that, which in itself causes me all kind of emotional turmoil. I constantly worry for my sons. Will they have shortened lives due to the virus and its impact on their bodies? What lies in store for their children? It is all such a mess.

110. Neither of my sons has contacted the Inquiry. They are of the opinion that what happened, happened and you just get on with it despite the consequences that it has had for both of them. However, they are fully supportive of me telling their story and I felt it was something that I had to do. There is a need for everyone to be aware of how easily these things can happen and how organisations and Governments can brush over it at the time and it is the ordinary people who are left to pick up the pieces.

111. Update; As of 05 September S1 is in hospital having turned yellow about two weeks ago and after waiting for scans and tests was diagnosed as suffering from jaundice but more seriously with a blocked

duct in his gallbladder. This was initially treated with steroids which weren't working fast enough so he was admitted to the hospital. He is still on immunosuppressant treatment for his cancer and this is yet another worry for us as a family.

Statement of Truth

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

Signed GRO-B

Dated 1-11-22